

Stroke Survivors and Caregivers: How to Manage the NE Ohio Healthcare System

By Debbie Felt, Ph.D.

This is a working paper that provides stroke survivors and caregivers information about the Northeast Ohio Healthcare System. Comments and suggestions are welcome. Please send them to Debbie@gulbranson.com.

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About the Author: Deb Felt received her Ph.D. in Sociology (1991) specializing in health and social service evaluation research. Her husband had a severe stroke in 2007. Deb and her husband have learned much during the recovery process and they share that knowledge openly with others. This working paper is offered as a tool to help others navigate the health care system (pre-Affordable Care Act). Updates may be made from time to time and as health care services evolve with the implementation of the Affordable Health Care Act, additional information may be provided here or in a separate document.

Cleveland Hearing & Speech Center is pleased to make this information accessible to all of those who are surviving stroke or illness and managing health care services as they recover. This paper and additional resources are available at www.chsc.org/speakeasy and we welcome your inquiries.

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Introduction

The goal of this paper is to give the caregiver/stroke survivor information to make good decisions, to provide networking resources, and to suggest ways that can improve the medical system for all stroke survivors. The medical system is fragmented and unwieldy for stroke survivors, caregivers, insurance companies, and medical professionals. If we work together we can improve it.

Navigating the health care system, especially when your family is in crisis or dealing with a sudden illness/injury can be daunting. The largest common denominator in all areas typically relates to money and managing costs. In an effort to contain costs, Medicare, Medicaid, and private insurance companies have created many rules that essentially restrict patients from over-utilizing medical services. One-size-fits-all rules may be appropriate in most cases but they are not appropriate for stroke survivors or people with head injuries. People who have the ability to improve but do so more slowly because their brain has to develop new pathways progress differently and at a slower pace compared to the healing process from other injuries and surgeries. Additionally, when there are physical issues, such as paralysis or paresis (weakness) and care must be taken to not overstress weakened muscles and damage joints, progress is impacted. However, progress still is achieved and results in better functioning and greater independence. In many cases physicians may help patients get exemptions from the rules. Also, Medicare and Medicaid patients and caregivers can be their own advocates by calling a Medicare representative in Ohio:

(Ohio KePro <http://www.ohiokepro.com/aboutus/contactus.aspx> 800-589-7337).

There are three turning points where the rules imposed by insurance companies act as profound barriers to recovery: immediately after the stroke, within the first 3 months post-stroke, and after 6 months post-stroke. Medical rules and resources are different at each of the turning points. For the best health outcomes, it is important for the caregiver to know the rules and their options.

Doctors and therapists recognize that caregivers play a crucial role throughout the recovery process. Research shows that caregivers are crucial in determining where a stroke survivor will be discharged – home or inpatient rehab hospital, or nursing home -- and they are important in continuing exercise routines and supporting therapy regimens. Doctors and therapists also know that the healthcare system is fragmented, frustrating, and does not optimize outcomes for stroke survivors. Since there is very little good research on improvements made 6 months post-stroke, caregivers must be the ones to initiate therapy because the therapeutic community and insurance companies have created barriers to continued care. A good resource regarding this topic is “Comprehensive Overview of Nursing and Interdisciplinary Rehabilitation Care of the Stroke Patient: A Scientific Statement from the American Heart Association” *Stroke*.2010; 41: 2402-2448
<http://stroke.ahajournals.org/content/41/10/2402.full> .

The burden on caregivers has been well documented, especially when the stroke survivor suffers from aphasia (limitations of speaking, understanding, reading, and/or writing). When a stroke survivor comes home, caregivers feel like they are being asked to be a full-time nurse and therapist--without training--on top of managing their home, job, and family. Caregivers often feel they have no time to themselves and it is no wonder that caregivers are susceptible to depression and their own health problems--especially back, hip, and muscle strains from heavy lifting (<http://stroke.ahajournals.org/content/30/7/1478.full>). A strong social support network is the best predictor of caregiver happiness. (<http://psycnet.apa.org/journals/rep/46/1/44/>).

Turning Point 1: Release from an Inpatient Hospital

Typically after a severe stroke, a person enters the emergency room and then is sent to intensive care and sometimes to surgery. The stroke survivor is transferred from intensive care to a step-down unit for a few days. Then a crucial decision is made: discharge to an inpatient rehabilitation facility, a nursing home, or home. Your doctor and the hospital social worker will make a recommendation. Ultimately the caregiver and stroke survivor make the choice.

Transfer to a rehabilitation hospital will be typically recommended if the stroke survivor needs inpatient care, can initially withstand 3 hours of light therapy a day, and the hospital has an inpatient rehabilitation hospital/unit. Inpatient rehabilitation hospitals have the best recovery rates.

- (Stroke.2006; 37: 1477-1482 Published online before print April 20, 2006, doi: 10.1161/01.STR.0000221172.99375.5a
<http://stroke.ahajournals.org/content/37/6/1477.full?sid=52417080-66f2-4f19-bdaf-b2d05eb99e41>)
- (Stroke.2010; 41: 2402-2448
<http://stroke.ahajournals.org/content/41/10/2402.full#sec-1>)
- Also see the US Governments documentation on rehabilitation after stroke:
<http://www.ninds.nih.gov/disorders/stroke/poststrokerehab.htm>)

Transfer to a nursing home will be recommended if the survivor needs inpatient care and cannot withstand 3 hours of therapy per day, if the hospital system does not have an inpatient rehabilitation unit, or if the survivor does not have caregiver support and cannot live alone.

However, please note The Center for Medicare Advocacy, Inc. won the lawsuit saying that the three-hour rule was illegal. You can contact the Center and ask for a Medicare review. <http://www.medicareadvocacy.org/2012/02/10/february-2012-extender-bill-therapy-caps-and-health-reform-challenges/>

In *Hooper v. Sullivan* (1989 WL 107497 (D. Conn.)) the Center for Medicare Advocacy reached a settlement in a class action case challenging the application of a “three-hour rule” to deny Medicare coverage to patients in rehabilitation hospitals. A screening criterion in the Medicare Intermediary Manual required that patients receive at least three hours per day of physical and/or occupational therapy. This was being used by Medicare contractors to create an irrebuttable presumption of noncoverage for patients who did not require or could not tolerate three hours of therapy per day.

- The parties came to an agreement that denials based on the three-hour rule or other rules of thumb were not appropriate. As part of the settlement, the court entered an order calling for a revision of the Medicare Intermediary and Hospital Manuals. CMS also issued a bulletin to all rehabilitation facilities in Region I.
- However, recent changes in regulations governing inpatient rehabilitation coverage (42 C.F.R. §412.622(a)(3)(ii)) have been interpreted to support the use of a three-hour rule to deny coverage. The Center understands that Medicare contractors are again denying inpatient rehabilitation coverage on the basis that a patient does not require and receive three hours of therapy each day.
- The Center is considering action to enforce the *Hooper* court’s 1989 order. We are interested in hearing about any individual (particularly from New England) who has recently been affected by the three-hour rule, and whether advocates, organizations, or providers are also seeing application of this rule.

Transfer to home is recommended if the survivor does not require inpatient care, and has the needed support system to live at home. If a stroke survivor is receiving Medicare/Medicaid or some other insurance, a community social worker will be assigned to him to help him with equipment, home modifications, and support. <http://informahealthcare.com/doi/abs/10.1080/09638280210125814> If you do not receive a social worker you may request one by calling either your county’s Office on Aging or Western Reserve Agency on Aging (serving Cuyahoga, Geauga, Lake, Lorain, and Medina Counties) call: 216-621-8010 or go to <http://www.psa10a.org>.

The best predictor for place of discharge is the presence of a caregiver. <http://stroke.ahajournals.org/content/15/6/1039.full.pdf+html?sid=efc6df80-3a39-4739-b6fa-59e216e80108> . <http://www.neurology.org/content/47/2/388.abstract> . The final discharge decision is made by the caregiver and survivor.

Your Rights in Discharge Planning

Most of the time, discharge planning begins very early in the process of recovery while in the step down unit or medical floor. Your doctor may recommend that the survivor be discharged home, or to a rehabilitation hospital or to a nursing home. The ultimate goal is to be discharged home, so a rehabilitation hospital and/or a nursing home are intermediate steps. Stroke recovery can be like a roller coaster; some advances and some set-backs. You may be discharged to a nursing home, inpatient rehab, home, and then back to the hospital depending on complications. This is a difficult disease and healing process.

The caregiver and the survivor have the ultimate say in where and when the survivor will be discharged; any lawyer will tell you this. The hospital cannot force you to leave or force you to go to a nursing home. Asking for more time is especially helpful if you are concerned about safety and judgment issues and finding the best setting for the next step in the rehabilitation process. You have options other than nursing home care. Take the time to research them so you can make a well informed decision. In most cases, working with a social worker and talking with his/her therapist will be all you need. If there is a hang-up at the rehabilitation hospital, you can call them directly. If you need further help, you can call the hospital Ombudsman, Medical Director, or Quality Department. Typically, hospitals have a hierarchy or procedure to follow in which you first work with the medical director, then the quality department, and lastly, the Ombudsman if needed.

Hospital Recommends: Discharge to a Rehabilitation Hospital

If the recommendation is a rehabilitation hospital or unit, you can choose the one that meets your needs. You can start by visiting them or choosing the one closest to your home. Findings show that stroke survivors' recovery tends to be much better in a rehabilitation hospital than in a nursing home. (Stroke.2006; 37: 1477-1482 <http://stroke.ahajournals.org/content/37/6/1477.full?sid=52417080-66f2-4f19-bdaf-b2d05eb99e41>) (Stroke.2010; 41: 2402-2448 <http://stroke.ahajournals.org/content/41/10/2402.full#sec-1>)

What is an Acute Rehabilitation Hospital?

In a hospital patients wear hospital gowns, remain in bed or sit in a lounge chair, and rest when they are not in three hours of rehab. In a **rehabilitation hospital**, all procedures are redesigned to optimize patient strength, mobility, independence, and communication.

For example, in a rehabilitation hospital when a patient wakes up they go to specially designed bathrooms to re-learn bathroom habits, get dressed in exercise clothes, may eat in communal dining rooms, go to rehabilitation (therapy) for 3 hours a day, and are encouraged to spend their down-time in the halls walking or wheeling herself/himself around and talking. The staff and family work together to remove catheters and tubes, as quickly as possible, to encourage swallowing, continence, and mobility. Everyone (from doctors to janitors to family members) is trained by therapists to actively engage in conversation with the stroke survivor and empower them to be self-reliant. Notably, there are no lounge chairs in a rehabilitation hospital--back and neck strength is important! The experience is intensive, highly supportive, and produces results. Care is coordinated by the medical director who usually is a Doctor of Physical Medicine, a physician who specializes in rehabilitative medicine, called a physiatrist (completely different than a psychiatrist—a mental health physician).

If the stroke survivor needs additional medical care and can withstand 3 hours of therapy a day, s/he can be released to an inpatient rehabilitation hospital (aka acute care rehabilitation hospital). In Cleveland there are currently four acute inpatient hospitals associated with the Cleveland Clinic. University Hospitals Healthcare System (UHHS) has recently opened an inpatient rehabilitation facility near Richmond Road and Chagrin Blvd. Metro Health has a long-standing rehabilitation program which includes 3 floors of Metro Hospital. Lake Health West Medical Center also has a comprehensive rehabilitation program. Summa Health System opened a new rehabilitation hospital in Akron in 2012.

Cleveland Inpatient Rehabilitation Hospitals and Units

The Cleveland Clinic has four acute inpatient hospitals and ranks 19th in the country for inpatient rehabilitation. They are the following.

- Euclid Hospital (46 beds), which has a new medical director committed to continuing the delivery of superior-quality care that patients have come to expect for over 40 years. [Cleveland Clinic Rehabilitation Hospital at Euclid Hospital](#) 18901 Lake Shore Blvd. | Euclid, OH | 216.692.8668.
- Cleveland Clinic Rehabilitation Hospital at Lakewood Hospital (35 beds), which has undergone a \$5 million renovation and expansion to its private patient rooms and therapy gym. [Cleveland Clinic Rehabilitation Hospital at Lakewood Hospital](#) 14519 Detroit Ave. | Lakewood, OH | 216.529.7760.
- Cleveland Clinic Rehabilitation Hospital, main campus (17 beds), opened in January 2011. [Cleveland Clinic Rehabilitation Hospital, main campus](#) 9500 Euclid Ave. | Cleveland, OH | 216.445.0708.
- Cleveland Clinic Children's Hospital for Rehabilitation, Shaker Campus. <http://my.clevelandclinic.org/childrens-hospital/specialties-services/shaker-campus.aspx> Call: 800-223-2273.

UHHS opened a 50 bed freestanding inpatient rehabilitation hospital in Beachwood (one mile west of UH Ahuja Medical Center), on Thursday, March 27th, 2013. The hospital is for mainly neurologic patients, stroke, and traumatic brain injury. The decision whether to add pediatric rehabilitation services to the new hospital will be made at a later date. Click here for their Web page: [University Hospitals Rehabilitation Hospital](#) and to [Get Directions](#). Their address is: 23333 Harvard Road, Beachwood, Ohio 44122, and their phone is 216-593-2200.

Metro Health System opened a three floor, 60 bed rehabilitation hospital at its Old Brooklyn campus in October 2012. The Metro Health Rehabilitation Institute of Ohio at Metro Health Medical Center is the state's largest hospital-based rehabilitation program with 60 beds on three floors. <http://www.metrohealth.org/body.cfm?id=343> Metro Health Medical Center, 2500 Metro Health Drive, Cleveland, OH 44109-1998,

(216) 778-7800. It has a highly acclaimed spinal cord injury program. Metro Health also has a world-class stroke research program directed by Dr. Chae.

Lake Health West's Center for Comprehensive Rehabilitation (CCR) is located at Medical Center in Willoughby. The acute care center provides physical, occupational, speech therapy and rehab nursing to patients with a wide variety of disabilities to help them return to safe and independent living in their own homes. <http://www.lakehealth.org/the-center-for-comprehensive-rehabilitation> . For more information, call the CCR referral line at 440-953-6100 Lake Health West Medical Center, 36000 Euclid Avenue, Willoughby, Ohio 44094-4625.

Summa Rehab Hospital in Akron is a 60-bed hospital opened in January 2012. Their address is: 29 North Adams Street, Akron, OH 44304. Phone is (330) 572-7300 Visit: <http://www.summahealth.org/locations/Hospitals/summarehabhospital> .

Although the VA does not have a stroke inpatient rehab department as such, they do have world class researchers investigating new treatment methodologies for head trauma and stroke and neurological disorders.

How can I help my loved one in an Inpatient Rehabilitation Hospital?

While in the rehabilitation hospital, spend as much time as possible with the survivor. Caregiver involvement is the best predictor of recovery. Set goals with the staff every week and use your knowledge of the survivor's habits, hobbies, and routines to implement clinical goals. For example, eating solid foods is the first step to gaining continence. Knowledge of food preference and food allergies helps facilitate the process. Knowledge of regularity routines (morning, evening, etc.) and foods (juice) and habits (reading) that facilitate regularity are very helpful. Individual relaxation preferences (TV, reading, conversation) also help the survivor endure the rehab routine. Schedule visits with friends—the first visit with friends is often very difficult for the friend; it is somewhat easier if a small group of people are there for the first visit.

If there is a conflict with a physician or therapist, always take the survivor's side. The survivor's trust and ability to implement their will is pivotal to their success. If you want the survivor to say "yes" to the rigors of the rehab process and to striving to recover, relearn, and regain, then they must be able to say "no" occasionally.

Hospital Recommends: Discharge to a Nursing Home

If the recommendation is a nursing home, it is because the hospital system does not have an inpatient rehabilitation program or a bed is not available, the survivor cannot withstand 3 hours of therapy per day, or the survivor does not have the support needed to live alone.

Advocating for your loved one

If hospital system does not have an inpatient rehabilitation hospital or unit, you can ask the social worker to help you switch to another hospital system. It usually takes at least a couple of days to apply for a transfer and be approved—depending upon bed availability, intake and evaluation procedures. Medicare or Medicaid should cover the cost at the new hospital. You can call the Medicare/Medicaid hotline with any questions. If you have private insurance, you may not have to pay out-of-system charges. The acute rehabilitation hospital can work with your insurance company to negotiate an in-system rate. You may be able to help the negotiation process by calling your insurance company. You can also call the Medical Director of the rehabilitation facility directly. A concerned caregiver can make bureaucratic wheels turn faster.

If a survivor is recommended to be released to a nursing home because she does not have the needed support at home, ask the hospital social worker to give you information about alternative housing (assisted living facilities in your neighborhood) information and community resources (church nurses etc.). Contact an elder law specialist to help the survivor protect her property.

If the stroke survivor cannot quite withstand 3 hours of therapy a day, a few more days in a step-down unit will not only help you make decisions but will also help the stroke survivor grow stronger—which may be needed to be admitted into a rehabilitation hospital. It usually takes a few days to transfer to an inpatient rehab hospital. Starting the process of transfer can buy a few days, for which Medicare, Medicaid, and sometimes the insurance company will pay. **According to Medicare and Medicaid rules, hospitals cannot discharge the patient without the patient's consent. If you are on Medicare or Medicaid, call Ohio KePro (800-589-7337) to request an evaluation of your situation.** If you have private health insurance, talk to your insurance company or ask your doctor to contact your insurance company. If the private insurance company refuses your requests, you may want to also ask your employer, purchasing group, or lawyer to intercede with the insurance company. While you are negotiating, the insurance company may refuse payment and the hospital may ask you to become a private pay patient. You can continue to negotiate while the transfer process is ongoing. There is some chance you will have to pay for these extra days, but most of the time the insurance companies (including Medicare and Medicaid) will pick up the costs. If in the end you have to pay for the extra days, ask the hospital for a reduced rate. Hospitals and healthcare providers negotiate rates with individuals. They can even “forgive” the payment. Be nice but firm about your situation.

Finances

Unfortunately, at such a critical time, you may have to worry about finances. Nursing home care can cost between \$8,000 and \$10,000 per month. If the survivor has Medicare, Medicare will cover the first 100 days in the nursing home (some co-

pays might exist). If the survivor also has Medicaid, Medicaid will pick up the costs after 100 days. If the survivor has private health insurance, talk to your insurance case worker to understand your coverage. You may want to consult an Elder Law specialist – a lawyer that specializes in the state Medicaid law, legal trusts and estate planning, as well as power of attorney and living wills. A lawyer, with this specialty, will tell you your financial options and how to protect your family resources.

How do I help my loved one in a Nursing Home?

If the survivor needs inpatient care and cannot withstand 3 hours of mild therapy a day, and a few more days will not help; your only choice at this time may be a nursing home. However, you can request an evaluation by an inpatient rehab hospital every week. Stroke survivors can make big changes daily during the three months after a stroke. Make sure that the stroke survivor is getting high quality rehab while in the nursing home. If s/he is not getting the rehabilitation services they need, contact your Medicare, Medicaid, and/or your insurance office. After a call, a Medicare representative will contact the nursing home, on your behalf. For the local Medicare office, call: **Ohio KePro 800-589-7337**. They can also answer some Medicaid questions. As soon as the stroke survivor can withstand 3 hours of rehab a day, you can request an evaluation from or transfer to an inpatient rehab hospital.

Finally, while the stroke survivor is in the nursing home, try to spend as much time as possible with him/her. In the early stages after a stroke, the survivor sleeps a lot and their brain can seem foggy. This can be due to the healing process but also due to anti-seizure or other medication. If the survivor is not having seizures, ask the neurologist to try taking the survivor off the medication. A leading neurologist told us that about 20% of the survivors need the medication and the other 80% do not. The only way to know if it is needed is to be titrated (gradually taken) off the medication. The medication can make survivors feel groggy and interferes with thinking and speech and following instructions in physical rehabilitation.

When patients in a nursing home are quiet and passive, it is easy for nursing assistants to naturally spend more time with the responsive (both demanding and appreciative) patients. If a caregiver is present, the quality of care improves because the caregiver becomes the “appreciative and demanding customer.” The caregiver can also facilitate a more personal relationship between the survivor and the staff by personalizing the room, bringing treats, getting to know the other patients, etc. Leading psychiatrists say, “one of the most critical elements in a patient’s rehabilitation from stroke is the strength and commitment of their primary support system—usually their family.”

<http://www.aapmr.org/patients/conditions/neurologic/Pages/familystroke.aspx>

Hospital Recommends: Discharge to Home

If and when the recommendation is to go home, you can request a little more time to get the needed equipment and modifications in place. The social worker will work with the therapists to get the model numbers and specifications and then get a prescription from your physician in the hospital. The social worker will then coordinate delivery with you. Caregivers should talk to the therapist and survivor to make sure that the survivor will be comfortable with the equipment and that it will “fit” in your home. For example, wheel chairs have different backs, seat depth, seat height, cushions, break extensions, trays, and foot rests. If you are not involved in the process, you will get a standard generic wheel chair. If you and the survivor are involved in the process you will get a chair that will minimize fatigue, encourage self-mobility, and minimize skin outbreaks. Similarly, other equipment (shower benches, hospital beds, ramps, car modifications) should be selected with care so they will fit the survivor and his environment. You can ask the therapist to show you and the survivor how to use the equipment. Your hospital social worker should give you a list of medical supply stores where you can go visit to see your options.

You can request a home visit the week prior to discharge. Medicare, Medicaid, and insurance companies will pay for this. Therapists will bring your loved one home and help answer questions and make suggestions—where to put grab bars, how to do safe transfers, how to use medical equipment, etc. Also, the week before being released, request to do everything for the stroke survivor under the guidance of a nurse. Learn to work with any tubes. Ask about signs of skin and swelling problems. Understand swallowing and choking issues. Request tips on managing medication. Learn bathroom procedures. Ask the therapists to practice car transfers so you and the survivor are safe and comfortable doing them. Learn how to recognize and assist with muscle spasms. Make sure you get stretching exercises. Let the nurses and therapists teach you and your loved one your roles so when you get home you can “dance well” together.

Your first week home may be the week-from-heaven-and-hell, similar to the joys and stress of bringing your first baby home. The responsibility of care giving and managing family/home affairs on no sleep is overwhelming. Schedule a friend to be with you the first week so you can get groceries, solve household problems, pay bills, learn medication timing, and get through the first round of physician appointments safely.

You may be tempted to schedule home care services, but this is another one of the insane cost-cutting rules that work against stroke survivors. **Insurance companies (including Medicare and Medicaid) will not pay for outpatient rehabilitation and in-home care.** Patients recover much more quickly in intensive outpatient therapy (like the Euclid Hospital Neuro Day program) as compared to home care therapy. Choose to be an outpatient even though transfers in and out of the car are very difficult—especially in the winter. Therapists have told us that survivors who receive home care over an extended time do not improve as quickly as in structured group

programs like Euclid Hospital's Neuro Day program, or an intensive program sponsored by University Hospital at the VA, or the intensive programs at Metro Hospital. Caregivers and stroke survivors who receive home care have told us that they feel isolated and fight depression. Survivors who get used to getting out in a supportive community in a structured and challenging environment tend to respond well to social rewards and live up to the expectations of strangers and improve more quickly. They also compare themselves to others who have had a stroke, instead of comparing themselves to their pre-stroke self, which builds self-esteem. Most stroke survivors that we know love getting out, being in a car, and traveling.

If the stroke survivor is classified as an outpatient, you can still get additional support at home but the insurance will not pay for it. There are many organizations and people that provide respite care at no, low, or sliding fees, including churches and neighbors. (See our resource list at: www.chsc.org/speakeasy .)

Challenges in Caregiving at Home in the Early Stages after a Stroke

There are several common challenges for the caregiver after her loved one returns home from the hospital. These challenges are enormous in the first few months at home, but over time they lessen and can all but disappear.

Most important, ensure that the stroke survivor is given his old roles back; if you want your loved one to return to normal, you and everyone else must treat him just as before. Any decisions they would have made before the stroke they should make after the stroke: what TV stations to watch, who to visit, what food to eat, directions to travel, when to wake up and go to bed, etc.

Often, a stroke survivor cannot independently initiate and plan an activity. For example, if they are hungry, they do not think to go to the kitchen. If the survivor tries to cook, they may not remember to measure the ingredients before assembling. Start small, divide a task into steps and do one or two steps, then rest. Add steps over time. It is very important that the survivor gets as much practice as possible to initiate, plan, and implement everyday procedures. Every decision and completed task, no matter how minor, empowers, inspires self-confidence and promotes cognitive development. If the stroke survivor has aphasia, name every object, say every step aloud, and ask the survivor to repeat it. When you do exercises, count aloud...everything you repeat day-after-day (naming, steps, counting) will register with them. Repetition is the key to learning.

Many stroke survivors have difficulty with concentration. It can be difficult for them to remember what they want to do or say. Some times they will not be able to break concentration to concentrate on new stimuli. Sometimes they will not be able to focus their concentration for a period of time. Survivors often react emotionally when their concentration is interrupted. For example many survivors have to concentrate when they eat, swallow, transfer/walk, go to the bathroom, or wash. They get angry when they are interrupted and they cannot go to the next task until

the present task is completed. This is one of the most difficult aspects of caregiving. There is no negotiation when the stroke survivor is concentrating and “focused on a need.” The caregiver must comply with the wishes of the stroke survivor if a trusting relationship is to be maintained. After the task is completed and the survivor rests, the caregiver can discuss options for accomplishing tasks. Better yet, speech-language pathologists can give the stroke survivor exercises to help them improve their memory and increase their attention flexibility.

Finally, the stroke survivor’s energy is at a premium. No longer can you do things spontaneously. Everything must be planned and coordinated. The stroke survivor gets tired easily and must rest at least 4 or 5 hours between bouts of exhaustion. The stroke survivor’s brain is healing and needs rest to do so. Additionally, if the stroke survivor has paralysis, the paralyzed limbs are “dead weight” and strain the stroke survivor’s back and non-paralyzed side. Muscle spasms and pain on the paralyzed side are common and fatigue the survivor.

If the survivor stays active, exercises, and practices speech, all of these by-products of the stroke lessen over time.

Turning Point 2: Beginning Outpatient Therapy

When stroke survivors come home they are often referred to therapy but sometimes therapy is not discussed in the discharge process. In the first three months after a stroke, the more therapy a stroke survivor receives, the better they recover. The more intense and structured the therapy program, the better the recovery. Stroke survivors value from structured programs, social support, and well-defined roles.

There is strong evidence that organized, interdisciplinary stroke care will not only reduce mortality rates and the likelihood of institutional care and long-term disability but also may enhance recovery and increase ADL [activities of daily living] independence. Most stroke research, however, has focused on acute and post-acute care, with less attention given to the more chronic recovery phases. American Heart Association (Stroke.2010; 41: 2402-2448)
<http://stroke.ahajournals.org/content/41/10/2402.full#sec-1>

For a detailed literature review of the outcomes of structured programs see:
AHA/ASA-Endorsed Practice Guidelines Management of Adult Stroke
Rehabilitation Care A Clinical Practice Guideline* Stroke.2005; 36: e100-e143
<http://stroke.ahajournals.org/content/36/9/e100.full>

See also: AHA/ASA Guidelines for the Early Management of Adults With
Ischemic Stroke (Stroke.2007; 38: 1655-1711)
<http://stroke.ahajournals.org/content/38/5/1655.full>

Structured programs also facilitate stroke survivor self-esteem. Self-esteem is gained by selecting a realistic comparison group--others in the same situation.

Working in groups facilitates healthy and realistic comparisons for both the survivor and caregiver. Also, structured groups provide an opportunity for social networking. The best predictor of well-being for a caregiver is their social network.

Intensive Outpatient Therapy Options in Cleveland

The Cleveland area has a very fine intensive outpatient therapy program at Euclid Hospital called the Neuro-Day program. Ask the program administrator to work with your insurance company to fund the program. Many times, this will be accomplished.

The Veterans Administration (VA) and Metro Hospital offer free intensive therapy to stroke survivors if they are willing and eligible (each study has different requirements) to participate in a research study. You do not have to be a veteran to participate in the VA study. The major hospitals offer home therapy for home-bound survivors.

The major hospitals and non-profit organizations offer speech, occupational, and physical therapy on an hourly basis. If you are a veteran, the VA Hospital also offers excellent, nationally recognized outpatient therapy—the same therapists who work on the research study provide some therapy in the Outpatient Rehabilitation Department. Therapies also can be accessed through providers in private practice.

Investigate options and choose one that offers the most hours of rehab and the most supportive and challenging regimen. An intensive program typically includes two to five hours of therapy per day, three to five days per week over several months. See Northeast Ohio Stroke Survivor Programs and Services

Available on the Cleveland Hearing and Speech Center Website

www.chsc.org/speakeasy

Turning Point 3: After “Plateau”

Most survivors need or can benefit from therapy for many years after they are released from the hospital. If the survivor had a severe stroke, rehabilitation can take 10 years or more. Dr. Janis Daly, an acclaimed researcher at Case Western Reserve School of Medicine Neurology Department has just left to go to continue her research at the University of Florida. She is one of the premier doctors working on brain plasticity and stroke survivors. Her most recent working hypothesis is that to improve physically, stroke survivors will have to do about 7,000 repetitions to rebuild neuro pathways.

The research on neuroplasticity is very compelling. There is evidence that the brain does continue to generate and revise neural pathways with appropriate stimulation, falsifying previous beliefs that after a certain age, there is no way to change or

improve brain function. We now have data about neuro plasticity and the positive impact of repeated practice on developing and improving brain response and bodily function. One very readable resource is: [The Brain That Changes Itself: Stories of Personal Triumph from the Frontiers of Brain Science](#) by Norman Doidge which is available on www.amazon.com .

To regain communication skills, stroke survivors have to engage in at least 8 hours of active communication per week—as shown by the University of Michigan Aphasia Program. (One of the oldest aphasia research and therapy programs is sponsored by the University of Michigan Aphasia Program--UMAP. For cutting edge research results see their Website or contact them: <http://aphasiahelp.com/about/>). New research shows that survivors can continue to make improvements as long as they continue to use the body parts that were weakened by the stroke; the repetition in practice and carryover to daily use builds muscle and promotes the ongoing neurological improvements. The best results occur in intensive programs of two to five hours of therapy a day, five days a week, over months.

Barriers to Therapy

Patients need hundreds of hours of therapy to progress, especially within the first two years post-stroke. In Cleveland, intensive therapy programs could be available but Medicare, Medicaid, and insurance companies will not pay for them. Furthermore, Medicare, Medicaid, and insurance companies actively limit payment for all therapy by: capping payment and visits, refusing payment to those who do not significantly improve, and/or threatening legal fraud suits against the therapeutic organization.

Barrier 1. Medicare, Medicaid, and private insurance companies severely cap rehabilitation benefit dollars and visits.

Barrier 2. Medicare, Medicaid and private insurance companies require physicians to demonstrate the medical necessity of therapy. To monitor the current definition of “medical necessity”, insurance companies require therapists to evaluate patient progress every month.

Barrier 2a. Medicaid and private insurance companies can stop payment if the patient fails to improve or is not expected to improve. This is called the “improvement standard.” Medicare can not legally deny payment based on the patient’s ability to improve, but right now Ohio Medicaid and your insurance companies can deny payment based on the improvement standard—however they are still doing it—you may have to appeal the decision.

If sufficient progress has not been made within the month, the Medicaid can refuse payment, audit all rehabilitation records, require the hospital to repay the government for services already delivered, and sue the hospital for fraud—even though caps or limits have not been met. **To avoid the risk of an audit and**

penalties, medical organizations closely monitor therapeutic records and aggressively discharge patients. When a therapist does not think she can document significant progress over three months they discharge the patient by writing “plateau.” If the patient is improving slowly and the therapist wants to continue working with the patient the therapist can ask the patient to pay out-of-pocket, to avoid government and insurance sanctions.

Private Insurance

Insurance companies will only pay for 20-40 sessions. For example, Medical Mutual of Ohio SuperMed+ through COSE will pay for 40 visits (physical or occupational therapy) and 20 visits for speech therapy per year.

Private insurers can stop payment at any time based on their determination of medical necessity and the potential for improvement.

Medicare

The 2013 Medicare caps are \$1,900 for physical and speech therapies (combined) and \$1,900 for occupational therapy. <http://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNMattersArticles/Downloads/MM8129.pdf>

Congress did approve an exception process. If therapy is needed after the cap is reached, therapists can request an exception (continued therapy). Stroke is on the list of diseases that will be authorized for continued therapy. However, the exception process now requires an audit that providers will want to avoid. See below.

Before October of 2012, stroke patients could receive therapy from hospitals and that therapy would not count toward the cap. **As of October 2012, Medicare caps apply to all outpatient therapy regardless of point of care: hospital or non-hospital.** <http://www.cms.gov/Medicare/Billing/TherapyServices/index.html>

Deductible and coinsurance amounts applied to therapy services count toward the amount accrued before a cap is reached.

Section 3005 of the MCTRJCA also made several other changes affecting outpatient therapy services. The provisions that are effective on October 1, 2012, include: applying the therapy caps to outpatient hospitals, creating two new threshold amounts of \$3,700 (one for each therapy cap amount), and requiring a manual medical review process of claims over these new thresholds. All of the above, with the exception of the manual medical review requirement, were addressed through CR 7785. Please see the drop down on this webpage entitled Therapy Services Transmittals to view CR7785 and corresponding manual changes.

For information about the MCTR/JCA-required manual medical review process, please visit: (<http://www.cms.gov/Research-Statistics-Data-and-Systems/Monitoring-Programs/Medical-Review/index.html>)

For information about 2012-13 Medicare Limits on Therapy Services, please view the <http://www.medicare.gov/Pubs/pdf/10988.pdf>.

The medical necessity of rehabilitation has been difficult to defend, in general, and especially for persons with chronic diseases. Appendix 4 shows the entire text of the Medicare legal requirements. One definition used by Medicare is:

Description of Rehabilitative Therapy. The concept of rehabilitative therapy includes recovery or improvement in function and, when possible, restoration to a previous level of health and well-being. Therefore, evaluation, re-evaluation and assessment documented in the Progress Report should describe objective measurements which, when compared, show improvements in function, or decrease in severity, or rationalization for an optimistic outlook to justify continued treatment. (Page, 169 ff)
<http://www.cms.gov/Medicare/Billing/TherapyServices/Downloads/bp102c15.pdf>

As of January 15th, 2013 Medicare does not require patients to improve to reimburse for rehab services. If you were denied skilled nursing facility care, home health care, or outpatient therapy services (occupational therapy, physical therapy, or speech therapy), CMS has a time-sensitive process of "re-review" for Medicare beneficiaries. For more information, go to <http://www.medicareadvocacy.org/> However, Medicare caps and demonstration of medical necessity (without the improvement standard) and monthly assessments are still mandated for Medicare payments.

Note, Medicare's response to the law suit: <http://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/SNFPPS/Downloads/Jimmo-FactSheet.pdf>. To get required coverage, the patient and caregiver may have to file an appeal. Here is the process: <http://www.medicareadvocacy.org/take-action/self-help-packets-for-medicare-appeals/>. To monitor rule changing go to: <http://www.cms.gov/Regulations-and-Guidance/Guidance/Transmittals/2013-Transmittals.html>

Ohio Medicaid

Ohio Medicaid does not cap outpatient therapies provided by hospitals. However, after 48 outpatient visits they will audit the all of the patient's claim and ensure that the patient meets the improvement standard. <http://codes.ohio.gov/oac/5101%3A3-2>

(C) Coverage conditions and limitations applicable to outpatient services only.

(1) When recipients use greater than forty-eight outpatient visits per year, information from paid claims will be reviewed by the department to determine whether the recipient should be referred to a managed care program. As a result of this review, the department or its contractual designee may also review hospital medical records in accordance with rule 5101:3-2-07.13 of the Administrative Code to determine whether services were medically necessary and appropriate to the recipient's illness or injury as described in rule 5101:3-2-02 of the Administrative Code.

Ohio Medicaid will reimburse non-hospital providers for 30 visits of physical or occupational therapy and 30 visits of speech or auditory therapy per year but the patient must be expected to make significant improvement. Below is an excerpt from the Medicaid code last reviewed on 1/1/2013.

<http://ifs.ohio.gov/ohp/consumers/benefits.stm#occupational>.

<http://codes.ohio.gov/oac/5101:3-34> (<http://codes.ohio.gov/oac/5101%3A3-34-01.2>)

5101:3-34-01 Physical therapy, occupational therapy and speech-language pathology/audiology services: general provisions.

(1) Skilled therapy services are allowable for Medicaid reimbursement only if all the following criteria are met:

(a) A Medicaid authorized prescriber prescribes therapies for a reasonable amount, frequency, and maximum duration of sixty-day period of treatment or less for rehabilitative services or a maximum duration of six-month period of treatment or less for developmental services, with the period of treatment beginning with the evaluation and concluding with a re-evaluation. In accordance with paragraph (C)(1)(e) of this rule, the re-evaluation includes development of either a new/revised plan of care and treatment or a maintenance plan. The prescribed therapy services:

(i) Non-institutional settings, per twelve month period:

(a) Thirty dates of service per twelve month period for any combination of physical and occupational therapy services; and

(b) Thirty dates of service per twelve month period for any combination of speech-language pathology and audiology services; although

(c) Additional therapy services can be requested through prior authorization in accordance with Chapter 5101:3-1 of the Administrative Code.

Ohio Medicaid requires that the patient is expected to improve. Ohio Medicaid's definition of medical necessity is based largely on the physician's recommendation. Legal challenges have largely sided with the physician. Here is the legal code.

<http://codes.ohio.gov/oac/5101:3-34>

(1) Skilled therapy services are allowable for Medicaid reimbursement only if all the following criteria are met:

(a) A Medicaid authorized prescriber prescribes therapies for a reasonable amount, frequency, and maximum duration of sixty-day period of treatment or less for rehabilitative services or a maximum duration of six-month period of treatment or less for developmental

services, with the period of treatment beginning with the evaluation and concluding with a re-evaluation. In accordance with paragraph (C)(1)(e) of this rule, the re-evaluation includes development of either a new/revised plan of care and treatment or a maintenance plan. The prescribed therapy services:

(i) Are medically necessary, in accordance with rule 5101:3-34-01.1 of the Administrative Code;

(ii) Are of such level of complexity and sophistication, or the condition of the patient is such that the service can be safely and effectively performed only by or under the direct supervision of a licensed therapist; and

(b) A physician or licensed therapist conducts and documents a clinical evaluation and assessment that indicates that the patient has a deficit in physical, occupational and/or speech-language/audiology functionality, and:

(i) Potential exists for the patient's condition to improve within a sixty-day period of treatment for rehabilitative services or six-month period of treatment for developmental services and for the patient to attain or make significant progress toward expected milestones (developmental) or restore functionality (rehabilitative) within twelve months of treatment, beginning with the evaluation; or

(ii) Potential does not exist for the patient to attain or make significant progress toward expected milestones or restore the individual's functionality within twelve months, but a safe and effective maintenance program may be established in accordance with paragraph (C)(1)(e) of this rule;

When the patient is not expected to improve, they may receive a maintenance plan (an exercise program) but Medicaid will not pay for any on-going therapy.

<http://codes.ohio.gov/oac/5101:3-34>

(W) "Maintenance," describes physical therapy, occupational therapy, and/or speech-language pathology/audiology services provided to individuals for the purpose of maintaining a level of functionality, not improvement of functionality. Although the development of a maintenance plan is considered part of developmental and rehabilitation services, the services furnished under a maintenance plan are not skilled therapy.

To summarize, Ohio Medicaid does not cap therapy at hospitals, however they do severely limit therapy by the requirements of medical necessity and the improvement standard. Medicaid **does** cap outpatient therapy at non-hospital facilities and also severely limits therapy based on the improvement standard.

Due to Medicaid's strict adherence to the "improvement standard", many Medicaid beneficiaries do not ever reach the caps. People with severe strokes are forced to live with paralyzed limbs and with impaired speech, simply because they can not improve at an arbitrary rate. Many who are currently living in nursing homes and bedridden could be living in the community and walking.

For those who qualify for both Medicare and Medicaid ("dual eligibles"), Medicare pays the bills according to their rules and then sends the remainder to Medicaid. Medicaid pays or denies according to their rules. This means that Medicare will pay

for therapy, even if the stroke survivor is not improving, before the bill ever gets to Medicaid—until the Medicare cap or extension limit is reached.

Similarly, for those who have Medicare and private insurance coverage, Medicare should pay for therapy, even if the stroke survivor is not improving, before the bill ever gets to the insurance company—until the Medicare cap or extension limit is reached. But you may have to file appeals to get needed therapy.

Barrier 3. The IRS has increased the testing of claims data to find and prosecute medical providers for fraud and abuse. In this economic environment providers do not want an audit or economic penalties. They would rather release a patient than risk an audit. Although I do not have proof of this, caregivers are faced with this explanation each and every day.

Barrier 4. Brain Studies are in their infancy. Very little is known about how therapy is impacting brain reorganization. Currently neurologists can describe the regions of the brain and know a little about how the regions function together and a little about the chemicals that help us think. However, the brain is a highly integrated system that is ever changing -- regions can share functions and grow new pathways. What we know about the brain could fit into a thimble compared to what we want to know. Every day there are new discoveries. Obama wants this to be the next frontier because we know close to nothing about how to help persons with neurological injuries and diseases.

Right now brain studies show that immediately after a stroke the brain produces chemicals to heal itself in the three to six months after a stroke. It is similar to the chemical process that babies experience in the first year of life to accelerate learning. It was believed that after these chemicals stop being produced, learning stops.

New evidence shows that after three to six month “acute” phase, the brain does not stop learning but rather continues closer normal rate of learning. Similar to children, after the first year of life, the rate of learning slows a little but the child continues to learn. New evidence also shows that stroke survivors often do not show improvement in language skills until several months after their stroke.

Barrier 5. Current evidence based research is not showing strong results for any specific therapeutic techniques. This may be because brain research is in it’s infancy stage and often uses small sample sizes, of dissimilar persons, with dissimilar brain damage, and imprecise measurement—all of which would mask real results. Since we know almost nothing about the brain works, we don’t know how to fix it. Different therapeutic techniques work on different people at different times. For the most recent results, see: <http://www.ebrsr.com/>

Medicare, Medicaid, and insurance companies use the lack of consistent outcome results to justify severe rehabilitation limits. But anyone working in the field of stroke

rehabilitation will tell you that improvements can be hard to measure in month to month increments but at the end of a year you can see significant improvements. It may be that current rehabilitation research uses the wrong set of assumptions—the wrong way of thinking about the problem. Instead of a medical model focused on a time-bound medical cure (using pills or surgery for quick results), maybe a long-term educational model (re-learning and re-education) would be far more predictive.

Barrier 6. Few researchers are using developmental psychology and educational models. One example is Cleveland's Dr. Janis Daly (a physical therapist with a Ph.D. in developmental psychology) are showing significant results <http://casemed.case.edu/dept/neurology/daly.html> . For one example of her research results see: Janis J Daly, Roger Cheng, Kenneth Hrovat, Jean M Rogers, Krisanne Litinas, Mark E Dohring. [Cognitive and Motor Learning Research Program, and Development and Testing of Non-Invasive BCI + FES/Robot System For Use in Motor Re-Learning After Stroke](#). IFESS 2008 Case Series, Sept 2008. (Note, Dr. Daly has recently moved her research to the University of Florida.)

Therapists using a developmental psychology model (a model that began with Piaget) have demonstrated for 40 years that the brain does not develop a little bit every day on a straight line going upward. Instead, the brain develops in steps. Through practice, study, and repetition, we achieve a certain level of skill, and then we take the next step up, and begin the studious climb again. Developmental psychologists call the landing of the step “latency” and see it as the most important stage of development. Clinical neurologists call the same stage “plateau” and see it as therapeutic failure and therapists stop providing services.

Developmental researchers used to think that the brain relaxes during the plateau stage of development, kind of the lull before the storm. In child development, a famous plateau happens when a child is around 3rd grade or 9 years old. Children at that age seem to intellectually tread water. But researchers discovered that during latency, the brain is reintegrating itself (condensing information into new concepts) so that the person can take the next big step. For example, until about the age of 9 children mostly think about their own needs and wants; they are the center of the universe. Beginning in latency, 9 year olds begin to reorganize their thoughts and begin to perceive groups and become concerned with social standing. This latency period prepares children for the teenage years and prepares them to learn the social skills necessary to negotiate groups. Similarly, when an individual is in their late teens, they go through another latency period when their brain reorganizes so they can recognize larger groups (society) and comprehend the idea of the “common good.” Actually, developmental psychologists believe that the most important work of the brain happens during the latency period. They believe that during latency the brain is reorganizing the network of neurons to process information more efficiently, so neurons can be freed-up to be dedicated to learn more information.

Ironically, clinical neurologists see latency as a failure and therapists stop treating during latency (“plateau”) -- when the brain is working it's hardest—

because signs of improvement are slow or not detected! Be aware of this period and recognize that reorganization may be taking place to allow for the next step in learning. Support, exercise, and therapy are needed during this period.

We do not withdraw educational support of youth in latency stages (9 year olds and seniors in high school), even though learning is slower at these stages. Youth in latency continue in school to prepare them for the next step. Why then does the medical profession deny the stroke survivors the opportunity to walk, use their hands, and communicate? If the brain processes at work during recovery from stroke are similar to that during these developmental periods, then ongoing stimulation and practice would be warranted.

The problem with withdrawing therapy in latency periods is that we do not know when a growth spurt has begun again. Looking again at adolescence: what outward signs are there that a new phase has begun for 10 year olds or for college students? There are no flairs in the sky when a student has mastered an important step, just quiet problem solving. As the American Heart Association has noted, most research projects end at the first latency period and we do not conduct research again. We do not know how long latency lasts because we are no longer observing. Have we created a self-fulfilling prophecy because we refuse to observe?

Additionally, there is a growing body of research that supports the plasticity of the brain. The brain is capable of growing new pathways but it takes time and repetition to complete the process. For a good readable review of the baseline research see [The Brain That Changes Itself: Stories of Personal Triumph from the Frontiers of Brain Science](#) by Norman Doidge.

Barrier 7. Because general practitioners and therapists have out-dated ideas, they often do not refer stroke survivors to therapy or cut-off therapy at exactly the wrong time. When the insurance company stops paying, the therapists stop providing services and discharge the patient, writing “plateau” in the chart. Family physicians do not know enough to challenge the therapists so they tell the survivor, “You’re lucky to be here, you’ve reached your potential, you have to learn to live with what you have.” Survivors and their families react with tears and very often start a sharp descent into depression and hopelessness.

Consequently, due to these barriers, therapists write the word “plateau” in the patient’s chart when their therapy has not produced measureable improvements within a month. **“Plateau” does not mean that the survivor can not improve. “Plateau” simply means that the therapist’s program is not showing measurable results in the arbitrary monthly timeline set by Medicare, Medicaid, and insurance companies, which focuses on cost containment more so than the nature of progress.**

When a student fails a math class, is it the student's fault or the teacher's fault? Students can fail one quarter and then take a break, change teachers, join a study group, and then excel the next year. Was it time? Was it the social environment? Was it the teacher? Who knows? It works out because the student kept trying.

Similarly, when a therapist's program is not showing measurable results is it the patient's fault or that of the therapy program or therapist? No one knows. One thing is for sure, something needs to change... preferably a fun change (a rest, a vacation, over-night visitors)... and then try a new therapist, a research project, a social group, a new kind of therapy. In Cleveland, we have a very strong stroke survivor and caregiver community. We can help.

Stroke survivors can continue to improve, and with support, will be able to take the next step *but at their own pace*. The brain needs a lot of time to heal and make new pathways, and weakened limbs need time to be stretched and strengthened. Stroke survivors who make the most timely improvements seem to do so with a combination of therapy and a group exercise routine. But to continue therapy, survivors and caregivers must know their options, the insurance rules, and how to advocate for what is needed from an uncooperative medical and insurance system.

Physiatrists (Doctors of Physical Medicine and Rehabilitation) and therapists have told us that in severe cases you will have to see many different therapists at many different facilities because of the limitations of therapist training (no reliable or valid measurement tools; no special training in brain plasticity or stroke recovery; and high rates of therapist burnout, injury, and turnover).

If a therapist no longer believes they can help you, it is time to replace them. Henry Ford said, "If you think you can do a thing or think you can't do a thing, you're right." If the therapist believes they can't help further they are probably right. It is best to thank them for their honesty and find a clinician who knows how to accompany the survivor and caregiver on the next part of the journey. It is kind of like getting different guides along the way... the stroke survivor is taking a journey from early childhood through adulthood in terms of speech or physical development. Would you want the same teacher for that entire process? One therapist told us, "When I see a patient right after a stroke in a medically unstable condition, I cannot imagine them ever walking. Yet if I see that patient a year later, I can easily see them walking." Similarly, most teachers and parents cannot imagine their babies being truck drivers, athletes, parents, and grandparents. We are all caught in the moment and with time our vision of the future improves.

How to Challenge the Rules

The rules are called objective-based payment rules. Below are the typical rules of operation and how to challenge them. To read more about the insurance rules that impact speech therapy see the American Speech Language and Hearing

Association Website at: <http://www.asha.org/public/coverage/> with separate links to commercial, Medicaid, and Medicare coverage.

Rule 1. Medicaid caps the amount they will pay to non-hospital providers. Medicare and commercial insurance companies cap the number of visits or dollar amount of rehab that they will reimburse in one year. However, if a physician—particularly a physiatrist (Doctor of Physical Rehabilitation Medicine) or a neurologist write a letter and improvement has been made, Medicare, Medicaid, and insurance companies will override their own caps, especially in the first two years post stroke because there are exception clauses. For example, if the cap is 40 outpatient visits per year, you can actually get more than 120 hours, if you continue to make good improvement and the physiatrist and neurologist are advocating for you. You can get therapy to reach the cap, take a three month break (but remember to exercise), and then request a new evaluation. If you have Medicaid you can get as much therapy as you need, if you work hard, receive it from a hospital, and your therapist does not write “plateau.” If the therapist writes “plateau” on the medical record, you must wait for 3 months to ask for a new evaluation or pay out-of-pocket.

Inpatient therapy is not limited by Medicare, Medicaid, or insurance companies. Therapy in nursing homes is limited by a special set of rules. See the Medicare Website or call the local Medicare number.

The caps are legal contracts. The insurance companies must pay up to the cap if the patient is making progress. In addition, there is an exception clause and insurance companies can increase the cap if they believe it will help the patient return to work or improve their health status. One insurance company increased the limit several times during the first two years post-stroke.

The Center for Medicare Advocacy, Inc. says, “You should request an exception to the therapy cap. Have your doctor order the continued therapy and state in writing that a skilled therapist continues to be required for you to maintain your condition or slow deterioration. This should be a basis for continued care above the cap, as it is to begin therapy. For more information, see this [issue brief on the therapy cap exceptions process](http://www.medicareadvocacy.org/medicare-info/improvement-standard-2/).” (<http://www.medicareadvocacy.org/medicare-info/improvement-standard-2/> , point 10). Also see: <http://www.medicareadvocacy.org/take-action/self-help-packets-for-medicare-appeals/>

Rule 2. Medicaid and insurance companies will not pay for a stroke survivor to maintain their health and abilities. They will only pay if a therapist evaluates the patient and demonstrates that there is improvement or loss of abilities. Like many things, there are ebbs and flows in survivor progress. When you notice regression, perhaps after a period of illness when less involved in therapy/home practice, you may be able to ask your physician for a re-evaluation and possibly a new prescription for therapy. The physician can only write a prescription for a

therapy evaluation. The physician can not tell the therapist how often to see the patient or for how long.

If the physician does not want to be exposed to an insurance investigation but wants to advocate for the patient, they will write in the medical record: "Recommend therapy evaluation at the request of the patient." An evaluation is just a baseline assessment and a month of therapy is usually recommended by the therapist. If progress is made, therapy can continue. If progress is not made, the therapist must end therapy and you can choose to take a break or pay out-of-pocket.

Rule 3. Medicaid and insurance companies require the therapist to document that significant improvement will be made. Monthly assessments must be completed to demonstrate that goals will be met within 3 months. Insurance companies can stop funding after one month's time. Medicare still requires monthly assessments and visits to the primary care physician. New reporting rules that measure improvement are scheduled to be effective July 1, 2013.

<http://www.asha.org/members/research/noms/> .

Experienced therapists who know the progression of recovery can document small improvements and improvements in functional skills outside the therapy environment. This is very helpful to getting additional/ongoing therapy covered. It is so important for caregiver and survivor to report things they can do now that they couldn't do before.

As mentioned above, if the patient is improving Medicare and Medicaid have exception rules, so caps theoretically can be extended. More often than not the medical organization does not want to risk an audit and penalties and will refuse to file—it is easier to require out-of-pocket payment or discharge. If the cap will not be extended and you have Medicaid, you can transfer to a hospital outpatient care, as long as they can document significant improvement. If you have Medicare and have reached the cap, you will have to pay out-of-pocket or ask for an extension.

If you have Medicaid, you could just seek therapy at a hospital, so you do not have to worry about caps. However, hospitals are often not the best place to receive therapy. Hospitals sometimes have too many patients and discharge therapy patients prematurely to make way for new patients. Additionally, hospital therapy departments experience large turnover and try to optimize staffing; so you may receive therapy from several therapists who have less than optimal knowledge of and commitment to their patients.

No matter how hard the therapist and caregiver work, progress for stroke survivors is slow (it takes time to build neuro-pathways and build muscles and there are often complicating health factors that inhibit physical progress). Eventually, despite the best efforts of the therapist, (s)he will not be able to document significant improvement for Medicaid and insurance companies. (Similarly, teachers cannot

document significant improvement in a student's learning every single month. Learning isn't a straight-line ever improving process; learning occurs in steps, with periods of slow progress (ups and downs) at the rise of each step. At the top of the step, learning pauses to allow the brain to integrate and generalize learning.)

You have the choice to pay for therapy yourself or take a break and try again in 3 months.

Rule 4. Medicaid and insurance companies require a patient to wait at least 3 months after a therapist has discharged a patient (“plateau”). Note: this does not apply to Medicare. Once you are on disability, you will not have to worry about this. After 3 months, a patient can ask their physician to write a prescription for an evaluation. Once a therapist has written “plateau,” most therapists will not accept the patient again. You will have to ask your physician for a referral to a new facility and a new therapist. We suggest that you join a Stroke Club to learn about your community's resources—to get a referral to a good therapist and good local exercise programs. Getting to the next level can be as simple as doing repetitions everyday with someone you like. Have faith in your body and your loved ones and open your life to new people.

Rule 5. The government requires hospitals and therapists to charge Medicare, Medicaid, insurance companies, foreign citizens, and private citizens the same amount. However, the government allows each of these entities to negotiate payment. Hospitals and therapy companies will negotiate price with you if you ask for a discount, though they are reticent to do so. After you have been a self-pay patient for a while, ask again for a reduced rate. If they say “no”, begin to look for a new therapist.

Recommendations for Continued Recovery

Recommendation 1. Select a primary care physician (an Internist) and at least two specialists (a Doctor of Physical Medicine and a Neurologist) to help you. You will need all three because stroke is a complex disease and each of these specialties complements each other. (If you have blood clots, you will also need a highly recommended Pulmonologist to closely monitor your medication—new research is showing that the medications have limited effects over time. You need an expert on your side.) You will also need all of these physicians to effectively push back the insurance companies and get approval for rehabilitation and new technologies. Together these doctors are very strong and can intervene with the insurance companies, Medicare, Medicaid, hospitals, and rehabilitation facilities throughout the area.

Recommendation 2. Use your physician team to be your advocate with your therapists and insurance companies.

If you want changes in care, you will have to initiate it. Your first line of appeal should be your physician. Physicians in general are the gatekeepers of the outpatient medical system. Hospitals, insurance companies (including Medicare and Medicaid), and therapists want good relationships with physicians. If you have a good team of physicians who believe in your recovery, they can be very effective in implementing change (new evaluation, more therapy, new goals, better timing, etc.). Hospitals and insurance companies pay particular attention to physiatrists (doctors of physical rehabilitation medicine) and neurologists. This is true especially of the Cleveland Clinic which is owned and managed by physicians.

Medicare and insurance companies typically put a limit on the number of therapy visits allowable per year. **MEDICARE, MEDICAID, AND PRIVATE INSURANCE COMPANIES MAY PAY FOR MORE THERAPY AT A PHYSICIAN'S REQUEST.** Furthermore, physical and occupational therapy departments are completely dependent on referrals from physicians, especially physiatrists. A team of physicians is necessary because Medicare and insurance companies use the threat of audits to control individual physician referrals. Physicians are much more powerful in teams and provide much better care in teams.

Even with supportive physicians, you will have to do your homework and be polite and assertive to make the system work for you. Caregivers and survivors can be very effective in moving the process along. One call to a quality manager or an insurance representative can work wonders to move things along. You will have to learn the rules and the appeal process of your insurance company, Medicare, and Medicaid. You will have to make all the first steps and monitor the situation. In the end, everyone in healthcare knows that the rules are arbitrary and meant to curb abuse. Insurance companies (in consultation with physicians and therapists made the one-size fits all rules) and can suspend them on an individual basis with enough assertive pressure. Look at caps as contractual obligations. Insurance companies have to approve benefits up to the cap, if significant progress has been made, but if they believe that additional services now will save them money over the long run, they will approve the added benefits now.

Recommendation 3. Choose your therapists carefully. Choose only those who have been recommended by another stroke survivor, physician, or therapist. The good therapists have over ten years experience working with stroke survivors, spend time building rapport, and use a home exercise program to get results. If the stroke survivor does not like the therapist, change the therapist. The survivor will not give their best effort if they do not like or respect the therapist. The American Speech-Language-Hearing Association has a checklist of how to select a therapist on their Website: <http://www.asha.org/public/speech/consumerqa.htm> . They suggest patients and caregivers ask number of years experience, success rate, comfort with patients with this disease, approach to working with family, etc.

Options after Discharge from Therapy (Plateau)

Option 1. Take a break for 3 months, get a new prescription, and call for a new evaluation. You may have to go to another facility (hospital, clinic, or stand alone therapeutic organization). You may try to go back to a former facility if there has been a change, either improvement or regression. Otherwise, you will have to start therapy at another place. You do not have to transfer records. Just call a different hospital or clinic and give them a prescription. If you are on Medicaid, there are no limits to the number of visits you can receive if you go to a hospital outpatient rehab center. There are limits at the stand alone clinics. For Medicare, you can call any rehabilitation provider who accepts Medicare payments; ***however Medicare may not pay for your rehab if you have reached the cap, unless your therapist files for an extension.***

Many survivors need a break from therapy. It is great to re-establish your life, but remember, you must continue to exercise or risk going backwards. Many stroke survivors and caregivers enjoy working out at local gyms (YMCA or Curves) or Break-Out Fitness. Break-Out Fitness is program for persons with disabilities at Euclid Hospital. For further information, call Mike at 216-548-5383. If you exercise regularly, you are much more likely to improve during this three month break. You are also much more likely to stick with the program, make new friends, and enjoy yourself.

Option 2. Join a stroke group or club. The stroke survivor is training for the greatest marathon of his/her life. No one can tackle a long-term goal without social support. Some club members are 30 years or more post-stroke and they are still improving. Club members can help guide you around the pitfalls and suggest therapists and programs that have helped them. Here are two great groups:

Cleveland Stroke Club meets on the near East Side, 1st and 3rd Wednesday of the month, 6:30-8:30. Contact Dottie Norton at 440-338-1136.

<http://clevelandstrokeclub.wordpress.com/>.

Speak Easy is a speech practice group sponsored by The Cleveland Hearing and Speech Center, Mondays 1-3. Activities include current events conversation, poker, and word games. Contact Jean Neisenbaum at 216-368-3351 or visit

<http://www.chsc.org/speakeasy> .

For many other resources, including other stroke clubs, see the Stroke Resource list available at www.chsc.org/speakeasy .

Option 3. Take advantage of free intensive therapy research studies. Some of the best therapy in the country is available locally at Metro Health, the VA Hospital (you don't have to be a veteran to participate in research studies but you have to be a veteran to get routine therapy at the VA), Cleveland State, and at the Cincinnati

Research Lab. These research studies are paid for by government grants for cutting edge research and are free. Metro even provides travel and Cincinnati will provide dorm housing. More studies are approved every quarter. Call once or twice a year to keep current.

VA		216-791-3800
Metro	Peggy Maloney	216-778-8563
Cleveland State	Dr. Ann Karas Reinthal	216-687-3576
Cincinnati Res. Lab	Dr. Stephen Page	513-558-2754

Research programs have a slow time table (there are often delays in scheduling and call-backs) and sometimes waiting lists. Keep trying. Also, call back every few months and check the National Institutes of Health Website for new studies:

Cleveland at Veterans Administration and Metro Hospitals: <http://fescenter.org>
National Clinical Trials: www.clinicaltrials.gov <http://www.clinicaltrials.com/>
National Institute of Health: www.nih.gov
Cincinnati Rehab Lab: www.rehablab.org

The only drawback to these studies is once the study is finished, therapy is finished regardless of your progress. You will have to find a new therapist because they will not make a referral or continue therapy. However, you can participate in more than one study.

Reminder: Cleveland's VA Hospital has some of the country's leading rehabilitation researchers working on new ways to help stroke survivors. If you are a veteran you are eligible to receive rehabilitation, support (home care), and medical supplies (including wheel chairs, trailers, and ramps).

Option 4. Consider paying for therapy. If you are willing to pay out-of-pocket for therapy, you can get as much therapy as you want with a doctor's recommendation. You will need to pay-as-you-go or provide a credit card to guarantee payment. Again, you can negotiate price with the business manager. (The usual discount is 50% of charges or they may offer a sliding fee.) Once you are a patient, they may be willing to reduce payment even further.

If you cannot afford to pay for therapy, consider asking former employers, unions, churches, non-profit groups to help you until you are able to get back on your feet.

Hospital-based outpatient therapy is the most expensive therapy and can be the least user-friendly due to overhead and bureaucracy (high staff turnover, unrelenting business offices, paid parking, long winding halls, long wait-times etc.). True stand-alone non-profit organizations are often staffed with committed long-term therapists, moderately priced with the availability of sliding fees. Similarly, good recommended for-profit therapy companies can be moderately priced, customer-oriented, and have highly qualified therapists.

Option 5. Consider paying for intensive programs. Ann Arbor (UMAP: <http://www.aphasiahelp.com>) and St. Petersburg (The Aphasia Center at Steps Forward <http://www.theaphasiacenter.com/>) offer world famous speech therapy clinics showing remarkable outcomes (6 hours of therapy per day, 5 days per week, for 6 weeks). There is a world renowned occupational therapy program at the University of Mississippi <http://www.taubtherapy.com>. Insurance companies and Medicare will pay only a small portion for these programs.

The costs are considerable in the short-term (over \$15,000) but they can produce more results in 6 weeks than conventional therapy produces in years. It's like the choice to go full-time for college and have a great career or taking one course a year and graduating when it is time to retire. Quality of life and long-term costs and benefits are part of the decision making. Often, churches, work groups, and other community organizations will help with funding.

Option 6. Join together with other stroke survivors and caregivers to contract with therapists and ask non-profit organizations to help build programs for you. Medicare, Medicaid, and insurance companies may pay for some small group therapy sessions (currently speech group therapy is limited to 4 members in the group. But a larger group of survivors can approach a therapist and agree to share the costs of therapy. An \$80/hour one-on-one session can become \$10/per hour per participant in a group of 8. Stroke survivors gain a lot from structured group settings and a routine schedule.

Option 7. Use combinations of options 1-6 to meet your needs. Depending on your health and your goals, use all the options: take a break, contact a therapist, join a group, put your name on the list for a study, participate in community programs, exercise, etc. You are in charge of your own progress. If your current therapist does not believe in your ability to progress or is not meeting your needs, change therapists. If you are bored with therapy, try another activity or sport that improves your body and spirit. When you do not see improvement after 3 months, check back in with a therapist. Use your physicians to help you secure the right help at the right time.

Remember that with each health set-back (hospitalizations, falls, surgeries, long bouts of pneumonia, negative reactions to medicines that upset your balance, additional weakness, repeated seizures, arthritis, stiffness, etc.) you are entitled to a re-evaluation and continued therapy. Don't let health or social/psychological setbacks trigger a downward physical spiral. While you are in the midst of a setback, ask your physician to recommend a home care therapist or do home exercises. When it is over, ask your physician to recommend an outpatient therapist to help you regain your strength. Your physician can also recommend a social worker to work with Medicare, Medicaid, your insurance company, or the VA to help you get ramps, bars, wheel chairs or other equipment to help keep you mobile and safe.

For a list of resources and caregiver tips, go to the Cleveland Hearing and Speech Center website www.chsc.org/speakeasy.

Advocacy for Better Therapy and Better Policy

The system is broken. Stroke survivor and caregivers should not have to fight this hard for services during the worst period of their life. They worked hard and paid their taxes. They pay top dollar for good health insurance. They are entitled to a good recovery process. Let's start with a quick review of what we know about stroke treatment and then discuss necessary changes, current policy initiatives, and other ideas.

What We Know

1. You just can't stay in your bedroom and exercise paralysis away. Similarly, stroke survivors cannot just practice swallowing and then have throat muscles strong enough to swallow. One set of instructions doesn't produce change in anyone. Muscles and nerves are regenerated doing the right exercise repetitively in the right way at the right time. Using an athletic analogy, great athletes require a coach and a medical team who knows the interplay of stretching and strengthening and endurance. Athletes put in time doing repetitions but not the same repetitions. The tasks are made harder and more complex as the athlete improves. If one exercise does not work, they try another. Athletes are able bodied people who need a coach, a team, equipment, and access to medical professionals. After injuries, athletes sometimes train for years to regain their abilities. **Why would we expect stroke survivors, some of whom have lost functioning in half their body, to be significantly better in 3 months?**

2. Nobody in the medical field denies that stroke survivors could benefit from therapy. Nobody in the medical field says a stroke survivor cannot improve. Nobody in the medical field pretends to know a persons capability or capacity to learn. Nobody in the medical field thinks there is a magic pill or surgery that will give a stroke survivor back their abilities. **Why limit access to therapy?**

3. Some would say we should limit all therapy because it is not cost effective. By not receiving proper therapy—by not spending time building strength in arms and legs, stroke survivors are confined to very sedentary lifestyles which leads to obesity, lung disease, heart disease, diabetes, and problems with bowels, bladders, and kidneys. Most of all, paralyzed limbs hurt and the body responds to stress and pain in very negative ways. Medicare and Medicaid are long-term payers. **What are the long-term costs of these diseases compared with the cost of therapy? What are the long-term costs of surgery and medication compared to non-invasive therapy and physical fitness? This point was made very effectively recently by The Center for Medicare Advocacy, Inc.**

(<http://www.medicareadvocacy.org/medicare-info/improvement-standard-2/>, point 13).

“In an October 24, 2012 editorial, "[A Humane Medicare Rule Change](#),"[3] the *New York Times* recognized the proposed *Jimmo* settlement as reversing an "irrational and unfair approach to medical services." *The Times* also noted that significant cost savings could result from covering necessary services to maintain an individual's condition. As *The Times* recognized, when people receive medically necessary nursing and therapy services that enable them to maintain their functioning or slow their decline, many are able to stay home and avoid expensive hospitalization and nursing home care.

A recent study regarding a Veteran Administration (VA) care model makes this point. In the VA program primary care teams are provided to assist the highest cost patients with multiple chronic diseases in their homes. The program operates in more than 250 locations, has an average daily census of more than 27,000 patients and has shown savings where costs are the highest of 24%. It has reduced hospitalizations by over 60% and has reduced nursing home use by over 80%. Many similar programs show savings on the highest cost patients of 50% or more, while showing very high patient/caregiver satisfaction.”

4. The current rules that require significant improvement every 3 months and measurement every month are completely and utterly inadequate. We are willing to give our children twenty-plus years to master of their bodies but we are only willing to give our stroke survivors 3 months! The newest research shows that significant gains can be made in intensive 6-week intervals. But significant progress to a therapist (trace wrist movement which depends on the ability to move and coordinate many muscle groups that haven't worked in years) is not what doctors and politicians want to see. They want to see full functionality. How can you rebuild one-half of an adult body (muscles and nerves) in six weeks or six months or six years without injury? It cannot be done without skilled therapy and hard work.

To conclude, I believe that with the guidance of therapists and regular exercise, recovery is the 10 year process that neurologist Jill Bolte Taylor describes. ([My Stroke of Insight: A Brain Scientist's Personal Journey](#), by Jill Bolte Taylor, July 2009. See her video: http://www.ted.com/talks/jill_bolte_taylor_s_powerful_stroke_of_insight.html).

We have, therefore, failed stroke survivors by not giving them the time and resources they need to rebuild themselves. If we decided arbitrarily not to care for moms after their first trimester, we would pay a high price. If we were to demand that children carry full adult workloads, we damage their bodies and their spirit—a high price. **The time-frame for meeting goals is our choice.** If we limit access to therapy, we pay the high price of watching stroke survivors spend 10 bedridden years in a revolving door of nursing home and hospital visits and subject them to a downward spiral of depression and anger. On the other hand, if we provide stroke survivors with the necessary therapy and training (similar to what we provide for athletes); we can watch them progress, become independent, improve self-esteem, and make a contribution. We can watch their families fulfill their promise also.

State of Current Therapeutic Testing and Research

Most current methods for evaluating patient improvement are woefully lacking **statistical reliability** (consistency between two observers or consistency of results over time), **statistical control** (most tests have not been standardized for stroke survivors and we know very little about the impact of gender, age, type of injury, co-morbid conditions, environmental conditions, and rehab treatments), **statistical validity** (the tests can only measure big changes, they are not sensitive enough to measure small progressive changes). So we are left with measuring idiosyncratic guesstimates at time 1 and time 2 and we pretend that it is valid. In other words, we are using tests that have very little accuracy to justify denying services to people who desperately need it, in the name of cost-effectiveness. Unfortunately, stroke survivors come to think it is their fault that they are not improving and start the downward spiral.

The current physical therapeutic research methodologies use much more sophisticated measurement tools (robotic arms, computer calculations, brain stimulators, and MRI's). The studies utilize stronger methodologies: match randomized samples. They have extensive history and environmental data on each patient. These studies are showing strong results but they have been completed on relatively small samples of select stroke survivors (healthy survivors that can withstand weeks of intensive treatment). To demonstrate validity and generalizability, these studies need to be replicated and expanded to include different types of stroke survivors. Replication requires multi-year studies, performed on vulnerable subjects (large drop-out rate due to health issues). If these studies continue to demonstrate that stroke survivors can make significant improvements, two questions remain. Who will pay for the therapy? The therapeutic techniques used in the current studies are intensive techniques (requires up to 15 hours of therapy per week for 6 weeks) and would not be funded by Medicare, Medicaid, or insurance companies if proven effective. See the work of Cleveland's own Dr. Janis Daly and Dr. Chae for great examples.

Care should be used in interpreting statistics. Statistics describe the odds of success in populations; statistics do not predict the future of individual success. No statistic can validly quantify dedication, ability, resourcefulness, etc. Statistics can simply be used to say the odds of success of the current study and the current participants. We are very far from generalizing results to the population of stroke survivors and understanding the human brain. The only thing that is gained by trying to predict the future for individuals is a self-fulfilling prophecy--practitioner's deny access, survivors don't try, funders don't fund, and outcomes are negative.

The Medicare/Medicaid databases are the largest treatment databases in the world. We analyze and trend the treatment of many diseases from the national data. But Medicare researchers cannot come to valid conclusions about stroke, when therapists and institutions preemptively discharge patients before they get the appropriate care. From what I have seen, nearly every single stroke survivor is

underserved. Even if Medicare did not deny one charge/payment, this population would still be nearly 100% underserved because the hospitals and providers lock the door before service can be delivered. Medicare cannot find and correct its mistake because it does not have the data to do so. (This is statistical bias due to missing data.) At this time, the disease codes for stroke are not reliably used.

For a summary of current therapeutic results see: <http://www.ebrsr.com/>

Economic Critique of Social Policy: Long vs. Long Term Costs

To say that therapy is not necessary or critical for stroke survivors is also a false claim. Without proper therapy many stroke survivors are confined to beds and wheel chairs and are therefore susceptible to pneumonia, heart disease, bowel, and bladder diseases—all of which would be helped by appropriate exercise and mobility. Without appropriate speech therapy, stroke survivors cannot swallow and they are susceptible to lung disease. Without appropriate speech, occupational, and physical therapy stroke survivors spend their lives dependent and in pain. Most often, the families of stroke survivors are also dependent upon Medicare/Medicaid because the spouse cannot be a full-time caregiver and a full-time worker. Many families have to choose between paying for therapy and sending their children to college. What a terrible choice.

National Institutes of Health Funding for Research Studies

The government (National Institutes of Health, NIH) is funding national studies to evaluate treatment protocols and encourage new techniques. This funding started due to the great efforts of the Kennedy and Shriver families in the 1970's because their patriarch, Joe, suffered a stroke. Stroke survivors are encouraged to participate in these studies. These studies are great opportunities to receive the best therapy, free of charge. The NIH should consider the following recommendations. Please note that NIH funding is currently threatened if Congress does not resolve the budgetary issues. For more information see:

<http://yourethecure.org/aha/advocacy/default.aspx>

1. Disseminate findings to neurologists, professors, practitioners and stroke survivors. Research results are simply not reaching their audience. Practitioners continue to say, "No improvement is possible past ___ months (the number varies depending on the dated-source used)."
2. Open the studies to more "typical" stroke survivors.
3. Fund more stroke speech therapy studies. Stroke survivors with aphasia (survivors with difficulty speaking, reading, writing, and/or understanding) and their families live very difficult lives.

4. Fund studies that can be implemented in community wide programs. All over the country community aphasia programs are being implemented that includes reading, writing, speaking, understanding, and physical/occupational therapy and exercise.

http://www.aphasia.org/aphasia_community/programs_and_centers.html#tx

Stroke survivors can work and learn easily in groups particularly if a speech-language pathologist is involved in the leadership. Caregivers are more than happy to participate and provide assistance.

5. NIH and Medicare and Medicaid should work together. It does not help for NIH to demonstrate great findings without Medicare and Medicaid funding. When the FDA approves medications or medical devices, there is a process whereby Medicare will fund it. There is no process in place to fund therapeutic programs that are showing great results. Medicare does not have any payment methodologies in place to pay for “coached fitness programs,” intensive therapy programs, community programs.

To conclude, so who’s to blame for stroke survivors attenuated recovery? Well everyone in the system. The government makes one-size-fits-all reimbursement rules. Practitioners are not advocating for their patients. Hospitals are dependent on Medicare and Medicaid dollars and do not want audits. Therapists act as gatekeepers. They triage their patients in a very busy hospital setting and give therapy to those they know they can help in the short-term—ortho patients. They tell stroke patients “You have plateaued” and stroke patients and caregivers don’t have the knowledge or self-esteem to fight back. The data is never collected so the government can’t monitor stroke survivor rehab and self-correct. Everyone is to blame.

New Policy Initiatives by National Groups

1. Do not deny access to care just to cut the healthcare budget. Adopt the definitions of medical necessity published and agreed to by major professional medical associations. <http://www.carf.org/DevicesStatement/> The following are important.

- Medically necessary services in habilitation and rehabilitation services and devices (1) promote medical recovery, (2) enhance and maintain function, (3) promote participation in life roles and activities, (4) avert medical complications, and (5) assist in learning, improving and acquiring skills. Enhancing and maintaining function is essential to maintaining health and averting medical complications.
- There should be no arbitrary limits or caps on medically necessary services.

- Services may be delivered across a variety of care settings based on the individual needs and may include inpatient, outpatient, post-acute, day program, and residential settings. These services may also include the use of durable medical equipment, prosthetics, orthotics, supplies and assistive and adaptive devices that improve or maintain function.

2. Additionally, the Obama Administration just conceded that chronically ill patients did not have to demonstrate improvement to receive Medicare benefits for rehabilitative services. See the Settlement Agreement and Questions and Answers. <http://www.medicareadvocacy.org/medicare-info/improvement-standard-2/> See the American Speech and Hearing Association comments. <http://www.asha.org/News/Advocacy/2013/Medicare-Settlement-Clarifies-Coverage-of-Services-That-Maintain-Function.htm>

3. The American Heart Association is proposing new models of care for stroke survivors (Stroke.2010; 41: 2402-2448 <http://stroke.ahajournals.org/content/41/10/2402.full#sec-1>). The American Speech-Language-Hearing Association is actively working to reform speech therapy funding <http://www.asha.org/advocacy/federal/cap/>. Caregivers and concerned organizations are coming together to put together new programs and options. The National Stroke Association (<http://www.stroke.org/site/PageNavigator/HOME>) is actively lobbying to change rehabilitation and treatment rules. The American Stroke Association is lobbying to improve stroke research regulations (<http://yourethecure.org/aha/advocacy/default.aspx>).

Proposed Changes: Immediate

1. Occupational therapy visits and speech therapy visits should NOT have a combined cap. This cap makes stroke survivors chose between improving their speech or their hand. See the reasoning behind the combined cap: http://www.medpac.gov/documents/Dec05_Medicare_Basics_OPT.pdf

2. Moreover, the Medicaid cap on non-hospital entities is not needed anymore. Medicare used to pay a percent of costs. Now Medicaid pays all healthcare providers a specific payment. In other words, Medicare determines what it will pay for a service. In 2003 when caps did not exist, medical costs went up especially for non-hospital providers. This can be for many reasons. 1) People were getting the services that they desperately needed, for once. 2) Non-hospital providers can provide better outpatient services than a hospital (it is easier to schedule, park, register for an appointment, closer to home, and can specialize). If the long-term costs were calculated, therapy is very cost-effective and should not be restricted.

As a matter of fact, if the Medicaid cap was removed, it would save money. In Cleveland, small non-profits and for-profits provide excellent therapy for \$50-\$75/hour. As you can see in Appendix 2 below, Cleveland hospitals charge almost 10 times that amount. In Cleveland the smaller outpatient facilities, especially good non-profits and for-profits, are much higher quality and customer oriented than the hospitals. The senior level therapists as well as the stroke survivors end up leaving the big bureaucratic hospitals for smaller settings to give and receive more personal services. Outpatient services in hospitals are more expensive due to overhead and cost shifting. There is really nothing justifying this other than Medicare and Medicaid want to save dollars in the short-term by denying access to rehabilitation services.

3. Use new definitions of medical necessity that support the treatment of the chronically ill.
4. Medicaid and insurance companies must drop the requirement that improvement must be shown within a three month window. Denying payment and access serves no good social purpose.
5. NIH should to disseminate information to universities, practitioners, and survivors. They should change funding policies to include more representative groups of survivors and community-ready techniques.
6. Medicare and Medicaid should devise and implement payment methodologies for rehab using new methodologies. Instead of hourly rates develop program rates. Devise payment rates for group therapy and fitness programs.
7. Medicare and Medicaid should calculate long-term costs and short-term costs, when evaluating programs.

Proposed Changes: Long term--New Ideas

1. I believe much more can be done in a group setting combined with individual consultation. Stroke survivors are like athletes, they have a very long and hard road ahead and value greatly from being on a team. Much of what they need to do is repetitions. But they also need a coach who knows when to say, "OK, let's add reps," or "Make that a little more complex." They need a coach to say, "Slow it down a little. This is a marathon not a sprint." Survivors can learn in class room settings. They can learn in competing teams along with individual coaching on the side.
2. Most states have community aphasia centers where stroke survivors receive support in communicating and mobility. These centers should be expanded and supported. New models can be explored.

2a. Speech-language pathologists can experiment with adult community educational models transforming clinicians into a teacher role in traditional English as a Second Language classes.

2b. Physical and occupational therapists can experiment with fitness and athletic models transforming therapist into a coach role in spring training.

3. We need to continue to develop and experiment with computerized software, Web communication, electrical stimulation, robots, and home devices to reinforce body building and communication building exercise.

It's time for the government, non-profits, and community organizations to come together to create new programs to help those with neuro-muscular diseases improve and stay healthy.

Wishing you the best recovery,
Deb Felt

Send comments and suggestions to: Debbie@gulbranson.com

Appendix 1: Key Source Document Links

Medicare Payment Analysis That Limits Rehabilitation Benefits:

http://www.medpac.gov/documents/Dec05_Medicare_Basics_OPT.pdf

http://www.medpac.gov/documents/MedPAC_Payment_Basics_11_OPT.pdf

<http://www.medpac.gov/documents/Jun11DataBookEntireReport.pdf>

Medicare Rehabilitation Payment Policy

<http://www.cms.gov/Medicare/Billing/TherapyServices/Downloads/bp102c15.pdf>

Ohio Medicaid Rules for Reimbursement of Therapy Services

<http://codes.ohio.gov/oac/5101%3A3-34-01.2> (Reviewed 1/1/2013)

American Speech-Language-Hearing Payment Advocacy

<http://www.asha.org/advocacy/> Speech Therapy Advocacy

New Definitions of Medical Necessity Supported by Major Professional Assn.

<http://www.carf.org/DevicesStatement/>

New Legal Change Deleting the Improvement Clause from Medical Necessity

<http://www.medicareadvocacy.org/hidden/highlight-improvement-standard/>

Also see the Settlement Agreement:

<http://www.medicareadvocacy.org/wp-content/uploads/2012/10/Settlement-Agreement-for-Web-00011098.pdf>

Comprehensive Treatment Model for Stroke (Stroke.2010; 41: 2402-2448

<http://stroke.ahajournals.org/content/41/10/2402.full#sec-1>)

Evidence Based Review of Stroke Research (EBRSR) is the most comprehensive and up-to-date review available examining both therapy-based and pharmacological interventions associated with stroke rehabilitation. <http://www.ebrsr.com/>

Other Stroke Resources:

Stroke Caregiver booklet <http://www.strokeboard.net/index.php?showtopic=5111>

Appendix 2: Cleveland Hospital PT & OT Charges, Cost, Payments

Table 1. Calendar Year 2013 Physical Therapy Charges			
Hospitals	PT Charge Eval	PT Charge Ther. Ex. per 15 min	PT Charge Ther. Ex. per hour
Parma Community General Hospital		\$ 136	\$ 544
University Hospitals Case Medical Ctr	\$ 374	\$ 120	\$ 480
MetroHealth Medical Center	\$ 345	\$ 110	\$ 440
Lake Health	\$ 200	\$ 140	\$ 560
The Cleveland Clinic	\$ 466	\$ 193	\$ 772
Euclid Hospital	\$ 341	\$ 191	\$ 764
Fairview Hospital	\$ 295	\$ 165	\$ 660
Hillcrest Hospital	\$ 341	\$ 191	\$ 764

Table 2. Calendar Year 2013 Occupational Therapy Charges			
Hospital Name	OT Charge Eval	OT Charge Ther. Ex. per 15 min	OT Charge Ther. Ex. per hour
Parma Community General Hospital		\$ 136	\$ 544
University Hospitals Case Medical Ctr	\$ 374	\$ 120	\$ 480
MetroHealth Medical Center	\$ 345	\$ 110	\$ 440
Lake Health	\$ 200	\$ 100	\$ 400
The Cleveland Clinic	\$ 518	\$ 193	\$ 772
Euclid Hospital	\$ 443	\$ 191	\$ 764
Fairview Hospital	\$ 383	\$ 165	\$ 660
Hillcrest Hospital	\$ 443	\$ 191	\$ 764

Source
http://www.parmahospital.org/PatientAndVisitorInfo/HospitalCharges/ http://www.uhhospitals.org/case/patients-and-visitors/billing-insurance-and-medical-records/patient-pricing-information http://www.metrohealth.org/body.cfm?id=2246 http://www.lakehealth.org/procedure-pricing http://my.clevelandclinic.org/patients-visitors/billing-insurance/default.aspx http://my.clevelandclinic.org/patients-visitors/billing-insurance/default.aspx http://my.clevelandclinic.org/patients-visitors/billing-insurance/default.aspx http://my.clevelandclinic.org/patients-visitors/billing-insurance/default.aspx

Note 1: MD's, Ph.D.'s, and lawyers do not charge \$700/hour to individuals!
Note 2: Non-profit and for-profit therapy organizations in Cleveland are charging between \$80/hour and \$125/hour for excellent therapy.

Appendix 3: Medicare Charges, Costs, and Payments for Greater Cleveland Hospitals

The following tables were obtained from the Medicare Outpatient PPS Limited Data Set for Calendar Year 2011. There is a two year delay in publishing Medicare data due to checking, cost analysis, and inserting safeguards for confidentiality.

See table below and note discrepancies between payments, costs, and charges. Uninsured persons, those who have reached the Medicare and Medicaid therapy caps, and those who have “plateaued” must pay **charges**. The hospitals say they will provide discounts but none is offering 80% discounts—as they should to match Medicare payments! Hospitals do not offer referrals and patients do not know their options. This feels like a bait and switch scheme: great introductory offer and they you get bills of over \$700 per hour.

The tables below do not tell the whole story. An evaluation can take 15 minutes or less and then therapists can provide therapy for the other 45 minutes. (Evaluations are required every month by Medicare, talk about wasted money in the system....) If you add up the charges from an evaluation plus one or two types of therapy, charges can be well over \$800 per hour (bills I have received). Not even doctors, lawyers, or financial consultants in Cleveland charge \$800/hour!

Looking at the cost column you will see the huge mark-up. Therapists typically receive less than \$40 per hour salary, including benefits. Most facilities are old and do not contain special equipment (often a bench, or table, and chair.)

J.B. Silvers Ph.D., Professor of Healthcare Finance at CASE, contends that charges make no difference because no one pays charges. This is largely correct, Medicare and Medicaid negotiate cut rates—while insurance companies often pay a percent of charges. **Devastatingly, when hospital outpatient therapy departments discharge stroke survivors and/or insurance stops paying, many stroke survivors stop seeking therapy and begin to regress due to lost hope. That is, one single arbitrary political “business decision” becomes a long-term self-fulfilling prophecy. Survivors and their families are left to live out their lives with undue physical limitation, dependency, and despair. Due to charges, no self-pay individual can afford hospital-based therapy.**

However, high quality therapy from small not-for-profit and for-profit organizations in the Cleveland area can be as low as \$125 per hour for new patients and \$80 per hour for those receiving extended services. **There is no reason, at all, that anyone (individuals, Medicare, or Medicaid) should be paying more than \$125/hour for therapy, especially not for an evaluation.** Clearly from the tables below, Medicare is not and neither should you. See Table 3 for more information.

Table 3. From Medicare's Outpatient PPS Limited Data Set for Calendar Year 2011

<u>Provider Number</u>	<u>Hospital</u>	<u>CPT Number</u>	<u>Short Descriptor</u>	<u>Patient Claims</u>	<u>Number of Units</u>	<u>Total Charge</u>	<u>Total Cost</u>	<u>Total Payment</u>	<u>Charge Per Eval</u>	<u>Cost Per Eval</u>
360041	Parma Community General Hospital	97001	Pt evaluation	146	147	\$34,398	\$13,083	\$6,663	\$234	\$89
360059	MetroHealth MedicalCenter	97001	Pt evaluation	144	144	\$34,848	\$23,040	\$8,226	\$242	\$160
360077	Fairview Hospital	97001	Pt evaluation	174	174	\$49,068	\$11,484	\$10,352	\$282	\$66
360082	Euclid Hospital	97001	Pt evaluation	114	114	\$29,426	\$10,925	\$7,074	\$258	\$96
360098	TriPoint Medical Center	97001	Pt evaluation	229	230	\$43,470	\$14,950	\$14,375	\$189	\$65
360137	University Hospitals Case Medical Center	97001	Pt evaluation	133	134	\$40,785	\$18,429	\$8,425	\$304	\$138
360143	Marymounth Hospital	97001	Pt evaluation	253	255	\$71,910	\$21,675	\$16,299	\$282	\$85
360180	The Cleveland Clinic	97001	Pt evaluation	514	519	\$210,195	\$55,014	\$32,317	\$405	\$106
360230	Hillcrest Hospital	97001	Pt evaluation	354	357	\$100,674	\$42,840	\$21,402	\$282	\$120
Sum		97001	Pt evaluation	2,061	2,074	\$614,774	\$211,440	\$125,133		
Average per Eval		97001	Pt evaluation			\$296	\$102	\$60		

Table 3. From Medicare's Outpatient PPS Limited Data Set for Calendar Year 2011

<u>Provider Number</u>	<u>Hospital</u>	<u>CPT Number</u>	<u>Short Descriptor</u>	<u>Patient Claims</u>	<u>Number of Units</u>	<u>Total Charge</u>	<u>Total Cost</u>	<u>Total Payment</u>	<u>Charge Per Eval</u>	<u>Cost Per Eval</u>
360041	Parma Community General Hospital	97003	OT evaluation	102	103	\$24,102	\$6,489	\$7,425	\$234	\$63
360059	MetroHealth MedicalCenter	97003	OT evaluation	64	65	\$15,730	\$4,290	\$4,350	\$242	\$66
360077	Fairview Hospital	97003	OT evaluation	134	134	\$49,044	\$10,452	\$9,720	\$366	\$78
360082	Euclid Hospital	97003	OT evaluation	53	53	\$17,715	\$5,214	\$3,735	\$334	\$98
360098	TriPoint Medical Center	97003	OT evaluation	95	95	\$17,955	\$4,370	\$6,639	\$189	\$46
360137	University Hospitals Case Medical Center	97003	OT evaluation	62	62	\$19,245	\$4,577	\$4,524	\$310	\$74
360143	Marymounth Hospital	97003	OT evaluation	152	152	\$55,632	\$10,336	\$11,013	\$366	\$68
360180	The Cleveland Clinic	97003	OT evaluation	387	388	\$166,064	\$19,012	\$26,887	\$428	\$49
360230	Hillcrest Hospital	97003	OT evaluation	155	155	\$53,067	\$12,132	\$10,268	\$342	\$78
Sum		97003	OT evaluation		1,207	\$418,554	\$76,872	\$84,561		
Average per Eval.		97003	OT evaluation			\$347	\$64	\$70		

Table 4. From Medicare's Outpatient PPS Limited Data Set for Calendar Year 2011

<u>Provider Number</u>	<u>Hospital</u>	<u>CPT Number</u>	<u>Short Descriptor</u>	<u>Patient Claims</u>	<u>Number of Units</u>	<u>Total Charge</u>	<u>Total Cost</u>	<u>Total Payment</u>	<u>Charge Per 15 min</u>	<u>Cost Per 15 min</u>
360041	Parma Community General Hospital	97110	Therapeutic exercises	43	168	\$20,496	\$6,908	\$4,248	\$122	\$41
360059	MetroHealth MedicalCenter	97110	Therapeutic exercises	29	183	\$14,457	\$8,215	\$4,740	\$79	\$45
360077	Fairview Hospital	97110	Therapeutic exercises	126	185	\$29,230	\$6,618	\$4,412	\$158	\$36
360082	Euclid Hospital	97110	Therapeutic exercises	44	302	\$43,572	\$15,146	\$7,640	\$144	\$50
360098	TriPoint Medical Center	97110	Therapeutic exercises	124	494	\$51,975	\$17,547	\$12,813	\$105	\$36
360137	University Hospitals Case Medical Center	97110	Therapeutic exercises	28	87	\$9,570	\$4,302	\$2,273	\$110	\$49
360143	Marymounth Hospital	97110	Therapeutic exercises	173	249	\$39,342	\$10,795	\$5,742	\$158	\$43
360180	The Cleveland Clinic	97110	Therapeutic exercises	845	2,234	\$376,542	\$86,479	\$56,915	\$169	\$39
360230	Hillcrest Hospital	97110	Therapeutic exercises	58	110	\$17,380	\$7,224	\$2,701	\$158	\$66
Sum Total		97110	Therapeutic exercises		4,012	\$602,564	\$163,234	\$101,484		
Average per 15 min.		97110	Therapeutic exercises			\$150	\$41	\$25		
Average per hour		97110	Therapeutic exercises			\$601	\$163	\$101		

Table 4. From Medicare's Outpatient PPS Limited Data Set for Calendar Year 2011

<u>Provider Number</u>	<u>Hospital</u>	<u>CPT Number</u>	<u>Short Descriptor</u>	<u>Patient Claims</u>	<u>Number of Units</u>	<u>Total Charge</u>	<u>Total Cost</u>	<u>Total Payment</u>	<u>Charge Per 15 min</u>	<u>Cost Per 15 min</u>
360098	TriPoint Medical Center	97112	Neuromuscular reeducation	20	89	\$9,879	\$3,044	\$2,486	\$111	\$34
360137	University Hospitals Case Medical Center	97112	Neuromuscular reeducation	25	70	\$7,700	\$3,500	\$1,862	\$110	\$50
360180	The Cleveland Clinic	97112	Neuromuscular reeducation	165	329	\$55,272	\$14,352	\$9,133	\$168	\$44
Sum Total		97112	Neuromuscular reeducation		488	\$72,851	\$20,896	\$13,481		
Average per 15 min.		97112	Neuromuscular reeducation			\$149	\$43	\$28		
Average per hour		97112	Neuromuscular reeducation			\$597	\$171	\$111		

Table 4. From Medicare's Outpatient PPS Limited Data Set for Calendar Year 2011

<u>Provider Number</u>	<u>Hospital</u>	<u>CPT Number</u>	<u>Short Descriptor</u>	<u>Patient Claims</u>	<u>Number of Units</u>	<u>Total Charge</u>	<u>Total Cost</u>	<u>Total Payment</u>	<u>Charge Per 15 min</u>	<u>Cost Per 15 min</u>
360041	Parma Community General Hospital	97116	Gait training therapy	39	98	\$9,506	\$3,626	\$1,978	\$97	\$37
360059	MetroHealth MedicalCenter	97116	Gait training therapy	27	60	\$4,514	\$2,989	\$1,348	\$75	\$50
360077	Fairview Hospital	97116	Gait training therapy	66	98	\$11,074	\$2,550	\$1,733	\$113	\$26
360082	Euclid Hospital	97116	Gait training therapy	34	131	\$13,503	\$5,026	\$888	\$103	\$38
360098	TriPoint Medical Center	97116	Gait training therapy	155	221	\$19,890	\$6,851	\$4,562	\$90	\$31
360137	University Hospitals Case Medical Center	97116	Gait training therapy	24	45	\$4,950	\$2,250	\$960	\$110	\$50
360143	Marymounth Hospital	97116	Gait training therapy	158	227	\$25,651	\$7,718	\$2,628	\$113	\$34
360180	The Cleveland Clinic	97116	Gait training therapy	240	499	\$71,856	\$18,595	\$10,311	\$144	\$37
360230	Hillcrest Hospital	97116	Gait training therapy	172	237	\$26,781	\$11,376	\$3,047	\$113	\$48
Sum Total		97116	Gait training therapy		1,616	\$187,725	\$60,981	\$27,455		
Average per 15 min.		97116	Gait training therapy			\$116	\$38	\$17		
Average per hour		97116	Gait training therapy			\$465	\$151	\$68		

Table 4. From Medicare's Outpatient PPS Limited Data Set for Calendar Year 2011

<u>Provider Number</u>	<u>Hospital</u>	<u>CPT Number</u>	<u>Short Descriptor</u>	<u>Patient Claims</u>	<u>Number of Units</u>	<u>Total Charge</u>	<u>Total Cost</u>	<u>Total Payment</u>	<u>Charge Per 15 min</u>	<u>Cost Per 15 min</u>
360077	Fairview Hospital	97140	Manual therapy 1/> regions	67	1,061	\$141,113	\$30,155	\$25,656	\$133	\$28
360098	TriPoint Medical Center	97140	Manual therapy 1/> regions	20	65	\$6,825	\$2,340	\$1,620	\$105	\$36
360137	University Hospitals Case Medical Center	97140	Manual therapy 1/> regions	27	63	\$6,930	\$3,150	\$1,555	\$110	\$50
360180	The Cleveland Clinic	97140	Manual therapy 1/> regions	117	218	\$32,700	\$8,328	\$5,291	\$150	\$38
Sum Total		97140	Manual therapy 1/> regions		1,407	\$187,568	\$43,973	\$34,122		
Average per 15 min.		97140	Manual therapy 1/> regions			\$133	\$31	\$24		
Average per hour		97140	Manual therapy 1/> regions			\$533	\$125	\$97		

Table 4. From Medicare's Outpatient PPS Limited Data Set for Calendar Year 2011

<u>Provider Number</u>	<u>Hospital</u>	<u>CPT Number</u>	<u>Short Descriptor</u>	<u>Patient Claims</u>	<u>Number of Units</u>	<u>Total Charge</u>	<u>Total Cost</u>	<u>Total Payment</u>	<u>Charge Per 15 min</u>	<u>Cost Per 15 min</u>
360041	Parma Community General Hospital	97530	Therapeutic activities	26	88	\$10,208	\$3,472	\$2,432	\$116	\$39
360059	MetroHealth MedicalCenter	97530	Therapeutic activities	145	251	\$18,680	\$11,115	\$7,429	\$74	\$44
360077	Fairview Hospital	97530	Therapeutic activities	59	93	\$11,253	\$2,509	\$1,849	\$121	\$27
360082	Euclid Hospital	97530	Therapeutic activities	141	802	\$88,682	\$29,484	\$20,975	\$111	\$37
360098	TriPoint Medical Center	97530	Therapeutic activities	110	166	\$17,430	\$5,587	\$4,307	\$105	\$34
360137	University Hospitals Case Medical Center	97530	Therapeutic activities	17	30	\$3,300	\$1,476	\$902	\$110	\$49
360143	Marymouth Hospital	97530	Therapeutic activities	228	350	\$42,350	\$10,883	\$7,382	\$121	\$31
360180	The Cleveland Clinic	97530	Therapeutic activities	365	854	\$145,180	\$26,391	\$23,022	\$170	\$31
360230	Hillcrest Hospital	97530	Therapeutic activities	315	721	\$87,362	\$30,152	\$15,741	\$121	\$42
Sum Total		97530	Therapeutic activities		3,355	\$424,445	\$121,069	\$84,039		
Average per 15 min.		97530	Therapeutic activities			\$127	\$36	\$25		
Average per 60 min.		97530	Therapeutic activities			\$506	\$144	\$100		

Table 4. From Medicare's Outpatient PPS Limited Data Set for Calendar Year 2011

<u>Provider Number</u>	<u>Hospital</u>	<u>CPT Number</u>	<u>Short Descriptor</u>	<u>Patient Claims</u>	<u>Number of Units</u>	<u>Total Charge</u>	<u>Total Cost</u>	<u>Total Payment</u>	<u>Charge Per 15 min</u>	<u>Cost Per 15 min</u>
360059	MetroHealth MedicalCenter	97535	Self care mngmt training	13	66	\$5,214	\$1,511	\$1,855	\$79	\$23
360077	Fairview Hospital	97535	Self care mngmt training	127	687	\$74,883	\$15,852	\$19,580	\$109	\$23
360098	TriPoint Medical Center	97535	Self care mngmt training	73	148	\$13,764	\$3,310	\$3,937	\$93	\$22
360143	Marymouth Hospital	97535	Self care mngmt training	98	147	\$16,023	\$3,254	\$2,245	\$109	\$22
360180	The Cleveland Clinic	97535	Self care mngmt training	157	278	\$47,260	\$6,953	\$6,811	\$170	\$25
360230	Hillcrest Hospital	97535	Self care mngmt training	65	81	\$8,249	\$2,131	\$846	\$102	\$26
Sum Total		97536	Self care mngmt training		1,407	\$165,393	\$33,011	\$35,274		
Average per 15 min.		97537	Self care mngmt training			\$118	\$23	\$25		
Average per hour		97538	Self care mngmt training			\$470	\$94	\$100		
Other Services										
360180	The Cleveland Clinic	97532	Cognitive skills development	32	48	\$6,864	\$769	\$1,160	\$143	\$16
360180	The Cleveland Clinic	97002	Pt re-evaluation	24	24	\$5,424	\$1,416	\$815	\$226	\$59
360077	Fairview Hospital	97016	Vasopneumatic device therapy	25	63	\$10,962	\$2,331	\$882	\$174	\$37
360180	The Cleveland Clinic	97022	Whirlpool therapy	52	55	\$5,445	\$1,310	\$1,039	\$99	\$24
360059	MetroHealth MedicalCenter	97032	Electrical stimulation	108	108	\$6,048	\$3,974	\$1,606	\$56	\$37

Table 4. From Medicare's Outpatient PPS Limited Data Set for Calendar Year 2011

<u>Provider Number</u>	<u>Hospital</u>	<u>CPT Number</u>	<u>Short Descriptor</u>	<u>Patient Claims</u>	<u>Number of Units</u>	<u>Total Charge</u>	<u>Total Cost</u>	<u>Total Payment</u>	<u>Charge Per 15 min</u>	<u>Cost Per 15 min</u>
360137	University Hospitals Case Medical Center	97032	Electrical stimulation	27	52	\$6,916	\$3,120	\$770	\$133	\$60
360098	TriPoint Medical Center	97035	Ultrasound therapy	18	48	\$5,040	\$1,728	\$480	\$105	\$36
360180	The Cleveland Clinic	97113	Aquatic therapy/exercises	25	92	\$18,032	\$4,728	\$3,219	\$196	\$51
360180	The Cleveland Clinic	97150	Group therapeutic procedures	55	287	\$30,135	\$5,859	\$4,633	\$105	\$20
360180	The Cleveland Clinic	97542	Wheelchair mngmt training	13	46	\$7,176	\$1,792	\$1,003	\$156	\$39

Appendix 4: Current Medicare Therapy Benefit Policy
Chapter 15 – Covered Medical and Other Health
Services
(Rev. 151, 11-18-11)

<http://www.cms.gov/Medicare/Billing/TherapyServices/Downloads/bp102c15.pdf>

See Page 167 ff

Therapy Services

References: Pub. 100-08, chapter 13, §13.5.1,
42CFR410.59,
42CFR410.60

A. General

To be covered, services must be skilled therapy services as described in this chapter and be rendered under the conditions specified. Services provided by professionals or personnel who do not meet the qualification standards, and services by qualified people that are not appropriate to the setting or conditions are unskilled services. Unskilled services are palliative procedures that are repetitive or reinforce previously learned skills, or maintain function after a maintenance program has been developed.

Services which do not meet the requirements for covered therapy services in Medicare manuals are not payable using codes and descriptions for therapy services. For example, services related to activities for the general good and welfare of patients, e.g., general exercises to promote overall fitness and flexibility and activities to provide diversion or general motivation, do not constitute therapy services for Medicare purposes. Also, services not provided under a therapy plan of care, or are provided by staff who are not qualified or appropriately supervised, are not covered or payable therapy services.

Examples of coverage policies that apply to all outpatient therapy claims are in this chapter, in Pub. 100-04, chapter 5, and Pub. 100-08, chapter 13. Some policies in other manuals are repeated here for emphasis and clarification. Further details on documenting reasonable and necessary services are found in section 220.3 of this chapter.

B. Reasonable and Necessary

To be considered reasonable and necessary the following conditions must each be met. (This is a representative list of required conditions and does not fully describe reasonable and necessary services. See the remainder of this section and associated information in section 230.):

- The services shall be considered under accepted standards of medical practice to be a specific and effective treatment for the patient's condition. Acceptable practices for therapy services are found in: Medicare manuals (such as this manual and Publications 100-03 and 100-04),
 - Contractors Local Coverage Determinations (LCDs and NCDs are available on the Medicare Coverage Database: <http://www.cms.hhs.gov/mcd>, and
 - Guidelines and literature of the professions of physical therapy, occupational therapy and speech-language pathology.
- The services shall be of such a level of complexity and sophistication or the condition of the patient shall be such that the services required can be safely and effectively performed only by a therapist, or in the case of physical therapy and occupational therapy by or under the supervision of a therapist. Services that do not require the performance or supervision of a therapist are not skilled and are not considered reasonable or necessary therapy services, even if they are performed or supervised by a qualified professional.
- If the contractor determines the services furnished were of a type that could have been safely and effectively performed only by or under the supervision of such a qualified professional, it shall presume that such services were properly supervised when required. However, this presumption is rebuttable, and, if in the course of processing claims it finds that services are not being furnished under proper supervision, it shall deny the claim and bring this matter to the attention of the Division of Survey and Certification of the Regional Office.
- While a beneficiary's particular medical condition is a valid factor in deciding if skilled therapy services are needed, a beneficiary's diagnosis or prognosis should never be the sole factor in deciding that a service is or is not skilled. The key issue is whether the skills of a therapist are needed to treat the illness or injury, or whether the services can be carried out by nonskilled personnel. See item C for descriptions of skilled (rehabilitative) services.
- There must be an expectation that the patient's condition will improve significantly in a reasonable (and generally predictable) period of time, or the services must be necessary for the establishment of a safe and effective maintenance program required in connection with a specific disease state. In the case of a progressive degenerative disease, service may be intermittently necessary to determine the need for assistive equipment and/or establish a program to maximize function (see item D for descriptions of maintenance services); and
- The amount, frequency, and duration of the services must be reasonable under accepted standards of practice. The contractor shall consult local professionals or the state or national therapy associations in the development of any utilization guidelines.

NOTE: Claims for therapy services denied because they are not considered reasonable and necessary are excluded by §1862(a)(1) of the Act and are thus subject to consideration under the waiver of liability provision in §1879 of the Act.

C. Rehabilitative Therapy

Description of Rehabilitative Therapy. The concept of rehabilitative therapy includes recovery or improvement in function and, when possible, restoration to a previous level of health and well-being. Therefore, evaluation, re-evaluation and assessment documented in the Progress Report should describe objective measurements which, when compared, show improvements in function, or decrease in severity, or rationalization for an optimistic outlook to justify continued treatment.

Covered therapy services shall be rehabilitative therapy services unless they meet the criteria for maintenance therapy requiring the skills of a therapist described below.

Rehabilitative therapy services are skilled procedures that may include but are not limited to:

Evaluations; reevaluations

Establishment of treatment goals specific to the patient's disability or dysfunction and designed to specifically address each problem identified in the evaluation;

Design of a plan of care addressing the patient's disorder, including establishment of procedures to obtain goals, determining the frequency and intensity of treatment;

Continued assessment and analysis during implementation of the services at regular intervals;

Instruction leading to establishment of compensatory skills;

Selection of devices to replace or augment a function (e.g., for use as an alternative communication system and short-term training on use of the device or system); and

Patient and family training to augment rehabilitative treatment or establish a maintenance program. Education of staff and family should be ongoing through treatment and instructions may have to be modified intermittently if the patient's status changes.

Skilled Therapy. Rehabilitative therapy occurs when the skills of a therapist, (See definition of therapist in section 220 of this chapter) are necessary to safely and effectively furnish a recognized therapy service whose goal is improvement of an impairment or functional limitation. (See also section 220.3 of this chapter for documenting skilled therapy.)

The passages that were recently struck down by the courts are crossed out below. They are no longer applicable as of January 2013. My understanding is that Medicaid and insurance companies are still enforcing these clauses.

~~Skilled therapy may be needed, and improvement in a patient's condition may occur, even where a chronic or terminal condition exists. For example, a terminally ill patient may begin to exhibit self-care, mobility, and/or safety dependence requiring skilled therapy services. The fact that full or partial recovery is not possible does not necessarily mean that skilled therapy is not needed to improve the patient's condition. In the case of a progressive degenerative disease, for example, service may be intermittently necessary to determine the need for assistive equipment and establish a program to maximize function. The deciding factors are always whether the services are considered reasonable, effective treatments for the patient's condition and require the skills of a therapist, or whether they can be safely and effectively carried out by nonskilled personnel without the supervision of qualified professionals.~~

Services that can be safely and effectively furnished by nonskilled personnel or by PTAs or OTAs without the supervision of therapists are not rehabilitative therapy services. If at any point in the treatment of an illness it is determined that the treatment is not rehabilitative, or does not legitimately require the services of a qualified professional for management of a maintenance program as described below, the services will no longer be considered reasonable and necessary. Services that are not reasonable or necessary should be excluded from coverage under §1862(a)(1) of the Act.

Potential for Improvement Due to Treatment. ~~If an individual's expected rehabilitation potential would be insignificant in relation to the extent and duration of physical therapy services required to achieve such potential, therapy would not be covered because it is not considered rehabilitative or reasonable and necessary.~~

~~Improvement is evidenced by successive objective measurements whenever possible (see objective measurement instruments for evaluation in the §220.3.C of this chapter).~~

~~Therapy is not required to effect improvement or restoration of function where a patient suffers a transient and easily reversible loss or reduction of function (e.g., temporary weakness which may follow a brief period of bed rest following abdominal surgery) which could reasonably be expected to improve spontaneously as the patient gradually resumes normal activities. Therapy furnished in such situations is not considered reasonable and necessary for the treatment of the individual's illness or injury and the services are not covered. (See exceptions for maintenance in §220.2D of this manual).~~

D. Maintenance Programs

During the last visits for rehabilitative treatment, the clinician may develop a maintenance program. The goals of a maintenance program would be, for example, to maintain functional status or to prevent decline in function. The specialized skill, knowledge and judgment of a therapist would be required, and services are covered, to design or establish the plan, assure patient safety, train the patient, family members and/or unskilled personnel and make infrequent but periodic reevaluations of the plan.

The services of a qualified professional are not necessary to carry out a maintenance program, and are not covered under ordinary circumstances. The patient may perform such a program independently or with the assistance of unskilled personnel or family members.

Where a maintenance program is not established until after the rehabilitative therapy program has been completed (and the skills of a therapist are not necessary) development of a maintenance program would not be considered reasonable and necessary for the treatment of the patient's condition. It would be excluded from coverage under §1862(a)(1) of the Act unless the patient's safety was at risk (see below).

EXAMPLE: A Parkinson patient who has been under a rehabilitative physical therapy program may require the services of a therapist during the last week or two of treatment to determine what type of exercises will contribute the most to maintain the patient's present functional level following cessation of treatment. In such situations, the design of a maintenance program appropriate to the capacity and tolerance of the patient by the qualified therapist, the instruction of the patient or family members in carrying out the program, and such infrequent reevaluations as may be required would constitute covered therapy because of the need for the skills of a qualified professional.

Evaluation and Maintenance Plan without Rehabilitative Treatment.

After the initial evaluation of the extent of the disorder, illness, or injury, if the treating qualified professional determines the potential for rehabilitation is insignificant, an appropriate maintenance program may be established prior to discharge. Since the skills of a therapist are required for the development of the maintenance program and training the patient or caregivers, this service is covered.