

Stroke and the Family

A NEW GUIDE

Joel Stein, M.D.

HARVARD UNIVERSITY PRESS
Cambridge, Massachusetts
London, England
2004

Recovery and Rehabilitation

Louise and Mary are both women in their mid-seventies who find themselves hospital roommates after experiencing strokes within a few hours of each other. Louise suddenly developed right-hand weakness and slurred speech. Her physician tells her that she has had a “small” stroke affecting mostly the motor functions to her right hand and speech articulation. Mary, by contrast, has severe weakness of her entire left side. She is told by her physician that she has had a large stroke affecting the right hemisphere of the brain.

Over the next few days, Louise finds that her hand is gradually recovering and her speech is steadily improving. Mary, however, finds little change over the same time period. Louise is discharged directly home from the hospital and ultimately has a near complete recovery. Mary, on the other hand, is transferred to a rehabilitation hospital. She never regains useful movement in her arm and only limited movement in her leg.

The cases of Louise and Mary raise a number of important questions: Can the brain heal itself? How much recovery will a person experience after a stroke? What can someone do to maximize the amount of recovery?

Despite the importance of these questions, the answers are still only partially known. Substantial recovery frequently occurs after stroke but is often incomplete. Although physicians have worked to develop tools to help them predict recovery, it is still difficult to foresee how much someone will recover. What we do know is that recovery is not a “passive” pro-

cess but one that, if it is to be successful, requires the active participation of the patient and, ideally, his loved ones as well.

The terms “rehabilitation” and “recovery” are often used together. Although the two processes are closely connected, there are important distinctions between them. “Recovery” is best defined as the actual return of neurological function after stroke. Regaining normal use of a weak arm after stroke is an example of recovery. Everyone (patients, family, and healthcare providers) would like to see as much recovery occur as possible, and hence a return to the state of health the stroke survivor enjoyed before her illness. Recovery is often incomplete, however, despite our efforts to stimulate this process. Future research on stimulating recovery should continue to identify new and more effective approaches to restoring neurological function.

Since recovery is often incomplete, stroke survivors need to learn skills to manage in spite of altered neurological function. These skills are often termed “compensation.” Compensation takes a variety of forms, some more obvious than others. For someone who has lost the use of an arm, a compensatory strategy might include learning how to button his clothing using one-handed techniques. Another example of compensation would be learning exercises to strengthen the unaffected leg for someone who sustains leg weakness after a stroke. This increased strength may help walking ability, despite the fact that the original weakness has not changed.

“Rehabilitation” encompasses both recovery and compensation. Rehabilitation is the process of helping someone who has had a stroke regain her ability to function in daily life and society. This includes taking advantage of spontaneous recovery, stimulating further recovery to the extent possible, and teaching compensatory strategies to fill in the gaps. Rehabilitation is a very important part of the process of resuming a satisfying and full life after a stroke.

Neurological Recovery

Neurological recovery usually begins within the first few days after a stroke and may be quite rapid in some cases. Recovery appears to occur

through a number of mechanisms. In some cases, there is substantial swelling (edema) of the brain surrounding the area of the stroke, and it gradually returns to normal over a period of days to weeks. This edema is particularly prominent in cerebral hemorrhages. Often an area around the perimeter of the stroke has experienced a partial loss of blood flow. Once blood flow is restored, portions of this area, known as the ischemic penumbra, may recover from the injury and regain normal functioning.

The brain has many interconnections between different functional areas. The sudden loss of activity and “input” from an area of the brain affected by stroke can cause loss of function in an area physically remote from the damage site. This phenomenon is known as diaschisis. It is somewhat analogous to an automobile factory in which shutting down the section that fabricates the transmissions may lead to temporarily shutting down the areas where the drive train is assembled. Diaschisis often improves as the remote areas of the brain learn to compensate for the lost activity and input that formerly came from the area damaged by the stroke.

Unfortunately, the brain cannot regenerate or “grow back” areas that have been lost as a result of stroke. Nonetheless, the brain has mechanisms for restructuring itself to recover somewhat from the aftereffects of a stroke. Older views of the brain as a static organ incapable of change once a person reaches adulthood have been turned upside down in recent years. The brain’s ability to adapt is known as “plasticity.” We know that the brain undergoes adaptive changes after a stroke even without specific treatments. Increasingly, however, we are learning that this process can be enhanced by specific activities, with the result of improved function.

In plasticity, new connections form between brain cells. Through this process of “rewiring,” areas that were not damaged by the stroke take over the responsibilities of the areas that have been lost. This is most marked in small strokes, where this ability may be sufficient, over time, to completely overcome the effects of the stroke. In larger strokes, however, the adjacent areas of the brain may also be severely affected by the stroke. More distant areas may lack the connections needed to assume the lost functions, and may already be specialized in other key brain

functions. In some cases, a different mechanism is used by the brain to adapt to the damage it has sustained. In these cases, some of the lost functions are taken over by the “matching” or equivalent area on the opposite side of the brain from the stroke. While the general principle is that the right side of the brain controls the left side of the body and vice versa, the reality is a bit more complex. Even in people without any history of stroke or other neurological disorder, there are connections between each side of the brain and the same side of the body, though fewer than those between each side of the brain and the opposite side of the body. It seems that these “same-side” connections may be able to take over some of the functions of the damaged side of the brain. Thus after a stroke affecting the left side of the brain, the right side may assume some of the control of movement of the right side of the body.

The relative importance of each of these mechanisms of recovery varies on the basis of the nature of the stroke and perhaps other, as yet unknown, factors.

How long after a stroke can recovery take place? Surprisingly, we don't know the answer to this question. In the past, it was assumed that the possibility of neurological recovery ended within a few months after stroke. More recently, however, scientists are questioning this assumption. Research showing improvements with exercise training even years after a stroke has opened the possibility that some recovery may be long-lasting. Despite this encouraging news, the fact remains that most recovery takes place within the first few months after a stroke.

Neurogenesis

In an important new discovery, scientists have recently found that the human brain can produce new brain cells (neurons). We don't yet know the extent to which this is possible, but it is clear that at least some areas of the brain are capable of producing new brain cells (neurogenesis) throughout adulthood and even into old age. At the same time, this ability appears to be limited and does not include the regrowth of damaged brain tissue. Some scientists have proposed stimulating this capability in some fashion to improve recovery after stroke. Although this is not yet feasible, it is an extremely important and exciting area of research.

Growth Factors

Other techniques to help the brain recover after stroke have been proposed and studied to varying degrees. One approach is to use chemicals that stimulate the cells within the brain to form more connections to other brain cells. The idea behind this treatment strategy is that forming more connections after a stroke may allow the brain to “rewire” itself more effectively to recover lost functions. These chemicals, known as “growth factors,” are normally produced in the brain in small quantities. By identifying them and producing larger amounts in the laboratory, neuroscientists hope to discover growth factors helpful in stimulating recovery after stroke.

Stem Cells

Stem cells are cells within the body that retain the ability to produce a variety of different specialized cell types needed by the body. Stem cells have received considerable attention in the media in recent months owing to controversy over the use of fetal tissue for research purposes. The ethical debate concerns stem cells that are obtained from aborted fetuses or from embryos produced in the laboratory using in vitro fertilization techniques. But these are not the only sources of stem cells; research has increasingly identified stem cells in adults as well. It is conceivable that by placing a person’s own stem cells in the area of the brain damaged by stroke, we might further enhance recovery. Despite the obvious appeal of this approach, it has not yet been shown to be workable or effective. A variety of theoretical and technical problems must be solved before this treatment becomes standard after stroke.

Medications

Medications have also been used to improve brain recovery after stroke. The most promising of these are stimulant medications known as amphetamines and related compounds. Dexedrine (dextroamphetamine) has been shown in some preliminary studies to stimulate recovery of motor abilities when combined with physical therapy. Other studies have looked at similar medications, such as Ritalin (methylphenidate). Cur-

rently these medications are used after stroke for other purposes—most typically for problems focusing and maintaining attention (see Chapter 13). Larger, more definitive research studies are under way to determine if these medications are truly helpful in promoting recovery after stroke.

Exercise for Recovery

Recovery of movement after stroke is clearly a key goal for many stroke survivors and their families. Animal studies have provided important insights into the influence of activity on the recovery process for weakness after stroke. In one experiment, strokes were induced in animals, who were then placed in one of two groups. In one group, the animals had their weak forelimbs placed in a restrictive splint so they couldn't use the limbs during the first few weeks after their stroke. In the other group, the animals were allowed to move about freely and use the limbs as much as they were able. The animals that weren't allowed to use their limbs did not recover as much movement as the animals that had free use of their weak limbs. This study demonstrated that activity is important to recovering function after a stroke.

A similar experiment looked at stroke in rats. Half of the rats were allowed to move around normally in their cages, whereas the other half were given a special cage with increased activities available (for example, a wheel and mazes to run in). The enriched environment provided to these rats can be thought of as a sort of “rat rehabilitation” program. These animals recovered more movement than those that did not have access to extra activities.

On the basis of these and other animal studies, most physicians and scientists agree that exercise and activity enhance recovery. Research examining the use of exercise to promote stroke recovery in humans is discussed in Chapter 11.

The Process of Rehabilitation

For many stroke survivors, rehabilitation is a long and multistaged process. Navigating this complex and often unfamiliar part of the healthcare system is challenging and requires some understanding of the components of rehabilitation and the settings in which they are provided.

In an ideal world, all decisions regarding medical care would be based solely on the needs of the patient, and all stroke survivors would receive the best possible rehabilitation care. In reality, many factors affect the provision of rehabilitation care after stroke, including insurance coverage, controversies regarding the efficacy of various interventions, geographic and cultural considerations, physician preference, patient and family preference, and many others. While there is no clear definition of what constitutes the ideal rehabilitation program, some general guidelines are provided here that should aid stroke survivors and their families in their decision-making. Family advocacy can play a critical role in obtaining the optimal rehabilitation program for a stroke survivor, as will be further described below.

Rehabilitation in the Acute Care Hospital

Rehabilitation activities should begin as soon as possible after a stroke. At first, these may be focused on assessment and prevention of complications rather than on restoration of function. For example, a speech therapist may be called upon to assess swallowing function and the safety of resuming eating. If there is ankle weakness, a physical therapist may provide a splint to keep the ankle in a favorable position. If the patient has experienced mild loss of balance after a stroke, a physical therapist may practice walking with him so he can return directly home from the hospital.

Because of the short duration of most acute care hospitalizations after stroke, rehabilitation efforts in this phase of care are usually limited in scope and duration. The next phase of rehabilitation is determined during the acute care hospitalization, however, so that's the time for the patient and family members to ensure that optimal rehabilitation care is arranged. Unfortunately, loved ones often have little time to investigate rehabilitation options owing to the pressure to move stroke patients out of the acute care hospital as soon as they are medically stabilized. Family members should begin investigating rehabilitation options in their area as soon as possible after the patient is admitted to the hospital, and engage both the physician and the case manager assigned by the hospital in a discussion of options after discharge. Physical, occupational, and speech therapists, as well as nurses on the stroke/neurology floor, may

also be a helpful source of information regarding rehabilitation facilities in the area. Planning post-hospitalization rehabilitation as early in the hospital stay as possible will help avoid a hasty choice of the first available facility rather than selection of the best one available.

Inpatient (Hospital-Level) Rehabilitation

A freestanding rehabilitation hospital or a rehabilitation hospital unit located within an acute care hospital generally provides the most comprehensive and intensive rehabilitation services post-stroke. These programs are designed to provide at least three hours of rehabilitation therapies each day, in addition to making available nurses and physicians specializing in stroke rehabilitation. Physicians are usually trained in physical medicine and rehabilitation (a medical specialty devoted to rehabilitation), neurology, or occasionally other rehabilitation-related specialties. They are typically highly involved in the rehabilitation process, visiting patients at least three to five times per week. The physical, occupational, and speech therapists on these units are usually employed full-time at the rehabilitation hospital/unit, and they all meet regularly with nurses and the physician to review each patient's progress and rehabilitation program.

The average stay at inpatient rehabilitation units is about three weeks for stroke survivors, though there is significant variability from facility to facility and from patient to patient. Since this level of care is relatively expensive, some insurance companies provide limited benefits or may not provide coverage at all. This type of care remains the "gold standard" for moderate to severe strokes, however, and family members may need to advocate for this level of care when it is needed.

A variant of this type of care is the "long-term acute care" or "LTAC" hospital or hospital unit. These hospital-level programs typically are capable of providing a high degree of medical management. There is considerable variation among these hospitals, with some providing the same scope of rehabilitation services as a rehabilitation hospital, and others more focused on specialized medical care, such as treatment of patients requiring mechanical ventilators.

Obtaining reliable and meaningful information to help guide the selection of a hospital-level rehabilitation program can be challenging.

Some programs (particularly freestanding rehabilitation hospitals) may have web sites that provide some information about the program. Families should inquire about the staffing of the program, including professional background of physicians and whether or not they are devoted to the program full-time. Most high-quality programs are accredited as rehabilitation programs through a voluntary organization known as CARF (the Committee on Accreditation of Rehabilitation Facilities). Most high-quality programs collect data on their outcomes, which may be available on request. Comparing data from different facilities can be difficult, however, because patient populations sometimes vary. Often decisions regarding rehabilitation programs are based on local reputation—this is not a perfect measure of a good program, but often it is the best available.

Skilled Nursing Facilities

Skilled nursing facilities, sometimes known as SNFs, provide a highly variable level of rehabilitation services. Some skilled nursing facilities have relatively robust and well-organized short-term rehabilitation programs, whereas others may provide limited rehabilitation therapy services with little coordinated management of the rehabilitation program. Physician involvement is usually substantially less than in a rehabilitation hospital, and physician care may not be provided by a physician specializing in stroke rehabilitation.

In addition to short-term rehabilitative care, skilled nursing facilities usually (though not always) provide long-term residential care for individuals who are unable to return to the community. In some cases the short-term rehabilitation-oriented program and long-term care program are intermingled; in others they are housed on separate units.

Skilled nursing facilities may be appropriate choices for individuals with relatively mild strokes who are anticipating a short stay and have fairly modest rehabilitation needs, or for individuals who are so severely affected that they are not expected to benefit much from rehabilitation. For patients with intermediate levels of impairment from stroke, I believe rehabilitation hospitals generally offer a more comprehensive approach. Some skilled nursing facilities provide excellent rehabilitative care, however, and are deserving of consideration as an alternative.

Skilled nursing facilities are also appropriate in some cases as an inter-

mediate step between a rehabilitation hospital stay and return home. A short stay in an SNF may allow further time for recovery and rehabilitation in some individuals and facilitate return to the community. In other cases, long-term nursing home care may be required owing to the severity of the stroke and the inability of a family to provide the extensive supportive care needed at home.

Before selecting a skilled nursing facility for short-term rehabilitative care, family members should investigate how much therapy is provided, how the rehabilitation process is managed, and whether physicians with expertise in stroke rehabilitation are available to help manage the rehabilitation process. These resources may be particularly important if a person is having difficulty achieving her rehabilitation potential. A visit to the skilled nursing facility may be helpful in assessing the stroke rehabilitation care provided there.

In cases where long-term nursing home care is required, families should be sure to visit the specific unit where their family member is likely to reside. Cleanliness, staffing levels, staff attitudes, medical coverage, amenities for residents, and physical surroundings are all important factors to assess. The U.S. government now provides detailed information regarding nursing home performance and outcomes on a publicly available web site: <http://www.medicare.gov/nhcompare/home.asp>. This site provides a wealth of information about past performance. A major caveat when using this data is that the nursing home industry is very unstable, with frequent changes in management. It is important to inquire about recent changes in management and staffing since the most recent data were posted.

Transitional Care Units

Transitional care units (sometimes abbreviated TCUs) are skilled nursing facilities located within an acute care hospital. These units are generally oriented toward short stays only and do not have a long-term residential component. Because they are located in a hospital setting, these units generally have frequent physician availability and structured rehabilitation programs. They often function as intermediate levels of rehabilitation, with less intensity than a rehabilitation hospital but more intensive rehabilitation services than a skilled nursing facility located in the com-

munity. As a result of changes in the reimbursement system, TCUs are less widely available now than in the past.

Home Care

Some stroke survivors are fortunate enough to be able to return directly home. Others, as discussed above, may require another stop (for example, a rehabilitation hospital) before returning home. Many stroke survivors from both of these groups, however, will require home care services to help them adjust to living back at home. Home care agencies (also known as visiting nurse agencies) are organizations devoted to providing this type of care. Many are affiliated with hospitals or hospital systems, whereas others are independent organizations. The keystone of home care is the visiting nurse. Even for individuals with minimal nursing needs, the nurse serves an important role in coordinating care at home and trouble-shooting any problems. The nurse can provide education and assistance with a variety of tasks that may seem daunting to stroke survivors and their families after return home. Educating patients and family members on the administration of injectable medications (such as insulin), instructing them how to use tube feedings for individuals with swallowing difficulties, and monitoring the use and effects of medications such as Coumadin (warfarin) are just some of the things visiting nurses do.

One of the peculiarities of home care is the requirement by Medicare (and often other health insurers as well) that someone be “homebound” in order to receive these services. This generally means that all rehabilitation therapy and nursing services must be provided either at home *or* in the outpatient setting. “Mixing and matching” outpatient and home care services is generally not allowed by insurers. The logic appears to be that if you are able to leave the home for some services, you are no longer homebound, and so no longer qualify for home care services. This can cause difficulties for individuals who would prefer outpatient rehabilitative services but have nursing needs that can only be managed at home. Some private insurance companies have more flexible rules and may allow mixing home and outpatient services.

Home care services may also include assistance with daily tasks from a home health aide. Assistance with bathing, for example, may be pro-