

## Body and Mind

BY MELVIN KONNER, M.D.

## The Long Haul

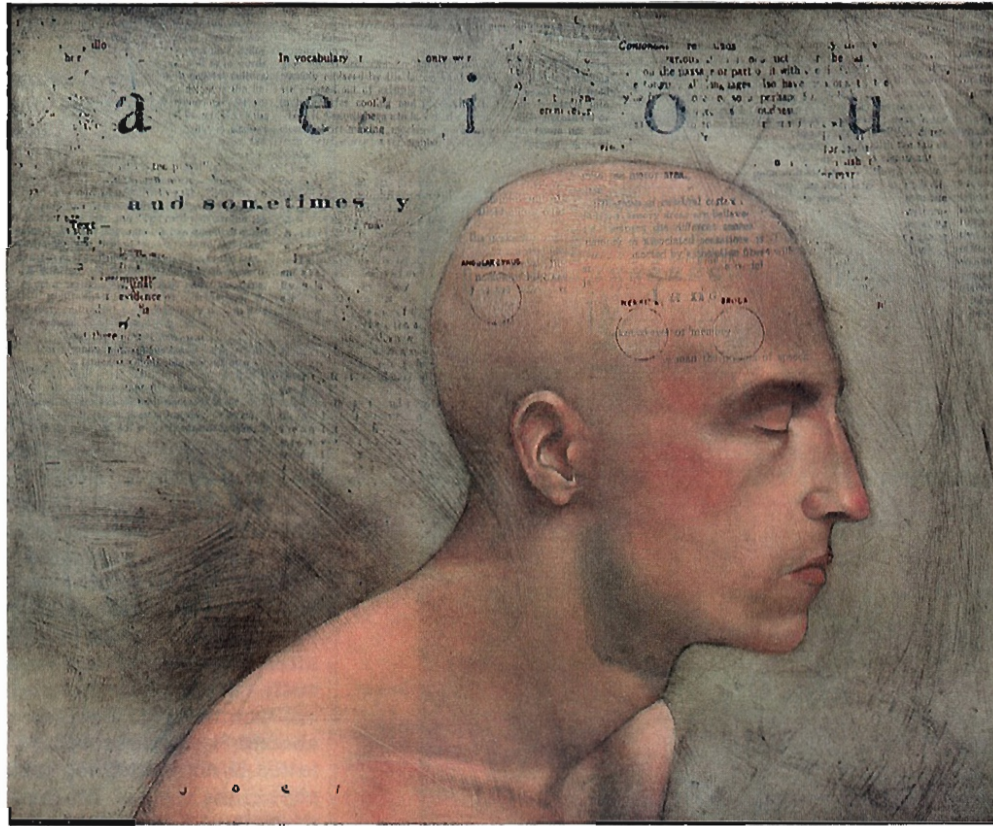
**M**Y SISTER-IN-LAW, Ronnie, is a 44-year-old screenwriter and mother of two who suffered a major stroke 18 months ago. A tiny blood vessel in the brain had ruptured; she became slightly unsteady at first, and her tongue felt a bit thick. But she worsened so fast that within a week she had been hospitalized, and rapidly became paralyzed and comatose. Her son, Jeremy, then 7, had come to see her as though it might be the last time. Even more unusual than her type of stroke was the form of treatment selected for her — brain surgery. Two weeks after the operation, she could only open and close her eyes and weakly squeeze a hand. She was aware of our presence — she would blink once for yes and twice for no — but just how far this awareness went, we don't know — even now. She stayed in that condition for weeks.

Nobody really had much hope. One neurologist, who had been dubious about the surgery in the first place, thought the not-unlikely outcome for her would be essentially worse than death — a lifetime in bed, eating and breathing through tubes. But at that time her husband fixed on a vision: Ronnie in a wheelchair at home, not doing much of anything for herself, but able to follow the growth of her children, accept their hugs and kisses after school, sit with the family at dinner. "That's all I'm hoping for," he said.

That hope has been far exceeded. Ronnie is at home, writing again, and the pages of a screenplay, commissioned by Jessica Lange before the stroke, are piling up almost miraculously. A computer with a large screen and a large-type printer has become the focus of much of her daily life. "This is not make-work therapy," her husband, also a screenwriter, says. "This is real."

Not day by day, maybe not week by week, but month by month she has learned to focus her eyes, to talk again, to control her hands, to walk. Donna, an attendant who recently left nursing school to prepare for medical school, helps her out of her chair, and they make the circuit through the den, sunlit kitchen and down the hall to the computer. This event with four-pointed cane somehow reminds me of the world's Olympic candidates dashing, leaping, twisting in practice for what they will try in 1992. For Ronnie, the effort is every bit as intense, and will take as long. And in her way she, like them, is pushing against the frontiers of human motivation and achievement.

As such, she is part of an important new concept of rehabilitation medicine: greater and more carefully researched attention to long-term stroke therapy. Traditionally, the treatment of brain, nerve and spinal-cord damage has been



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Stroke sufferers are benefiting from new techniques in rehabilitation therapies.

divided into "acute" and "post-acute" phases — the first dealing with the immediate medical consequences of the damage and the need to stabilize the patient; the second, some weeks later, consisting of a few months of physical, occupational and speech therapy.

Generally, studies on the effects of long-term stroke therapy have not been conclusive, and some neurologists remain skeptical about the need for it. After hearing, for the 100th time, the story of actress Patricia Neal's struggle back to health after her major stroke, one commented, "For all we know, Patricia Neal could have been hanging in a closet for two years and had the same recovery." In other words, long-term therapy can be expensive and difficult and painful; so, if we haven't proved it does any good, why bother? Well, there is now increasing evidence that long-term stroke therapy should be more aggressively pursued than it has been. Half a million people suffer strokes in the

United States each year — and about 300,000 of them survive. It is becoming apparent that hundreds of thousands of stroke victims might improve their quality of life with proper long-term therapy.

Indeed, attempts to improve on the understanding and administration of that therapy are now being made. In the forefront of these efforts is the Neuromuscular Retraining Clinic, at the University of Wisconsin-Madison Medical School, run by Richard Balliet and Paul Bach-y-Rita, whose interest deepened after his own father, a 65-year-old college professor, suffered a stroke in the brain stem. Recovery was apparently full, but it took at least five years and a five-hour-a-day exercise program designed by his son George, then a medical student.

Several months after the stroke, Bach-y-Rita says, his father "could lift his arm over the typewriter, visually position his arm so that the middle finger was above the desired key, and then drop his arm, striking the key. Thus, using very gross movements, and with many errors, he was able to begin to type." Three years after the stroke, he returned to work. Four years after that, at the age of 72, he died of an unrelated cause, a heart attack, while mountain hiking. But perhaps the most remarkable fact, one that heightens science's interest in the case, was that the brain was examined at autopsy and extensive damage was still very much in evidence. The man was hiking in full vigor with a half-cubic-centimeter hole in a key portion of his brain known as the pons — enormous for that region — and with extensive degeneration leading out from it. How could he possibly have recovered?

As Bach-y-Rita realized, his father's case illustrates how little we understand about brain healing. Nerve cells, as far as we know, do not replace themselves once they are killed off. Extensions of the surviving cells — the "wiring" by which they send messages — can regenerate to some extent. But getting those old connections right again — crucial

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circuitry initially formed in the tiny machinery of the embryo — can prove impossible. Damage in adulthood can leave them dangling.

In addition, at least two other processes may help account for long-term healing. Other undamaged portions and functions of the brain, quiescent or even redundant before the stroke, may now come into their own. They may be strengthened over the long haul and accomplish feats once performed by circuits now injured. Thus left-handed stroke victims recover better from language loss than right-handed ones because they tend to have language functions distributed more widely in the brain. And finally, the rest of the body may help out. Circumventing brain repair, it can enable the stroke sufferer to compensate for lost functions, by using different muscles, even different senses. The increase in sensitivity of vision and smell in some people with hearing loss is an example.

These and other mechanisms can be aided by practice over time. Lots of time.

Balliet says that people who are still suffering from the effects of stroke a year after it occurred are seriously neglected by the medical community. Prejudices abound. Long-term rehabilitation is not something most physicians view as dramatic medicine. And because research remains inconclusive, insurers and other third-party payers feel justified in pulling the therapeutic floor from under the patient after a few months have elapsed. Further, because many stroke patients are elderly, and have other serious illnesses, caretakers can become too easily convinced of the futility of extended treatment. Even the pace of recovery can deceive: a plateau in improvement, needed for consolidation of gains before a further advance, is often misinterpreted as the final attainable outcome. This misjudgment can confirm itself tragically, leaving the patient needlessly stranded on the plateau.

Fortunately, those prejudices are under active attack.

In the February issue of the *Archives of Physical Medicine and Rehabilitation*, John V. Basmajian talks of "breaking intolerable time locks for stroke survivors"; time locks that have kept us in "the winter of our discontent." New studies in England have shown that more than 45 percent of stroke survivors are functionally independent at

six months. This is hardly a hopeless condition. Authorities like Bach-y-Rita and Balliet, who start an average of nine years after the initial injury, are reversing the trend and believe in the importance for stroke victims to keep plugging, working and exercising over the long term. They are not indulging in the overoptimism of those who preach "positive thinking" for treatment of advanced cancer, for example; exercise has been clearly shown to stimulate nerve function and growth, and attitude is known to make a difference for brain rehabilitation. But the rehabilitation experts now concede that it is high time for better research to show precisely what kind and how much therapy produces precisely what measure of results.

**W**ITH THIS NEED in mind, Balliet, Bach-y-Rita and their colleagues are pioneering new techniques of rehabilitation — they emphasize slow movement and exacting home programs — and are carefully studying the results with up-to-date measures of muscle, nerve and brain activity. In addition to intensive physical and occupational therapies, they specialize in problems of balance and in special retraining of facial muscles. And new techniques are being employed to teach stroke victims to walk again. Few will be as lucky as Bach-y-Rita's father, but many will show significant improvement after years on a plateau.

It has now been more than a year since Ronnie was discharged from the hospital, and she has made an astounding recovery. Yet, in an important sense, it is only the beginning. No one can say just how much more recovery is in store for her; the answer lies in unsolved mysteries of the brain. But relative youth, exceptional motivation, good doctors and therapists and a supportive family are on her side — along with the new outlook in rehabilitation: long-term improvements should be expected.

And this is a field in which expectations can become self-fulfilling prophecies.

Balancing herself between her better leg and her cane, leaning only occasionally on Donna for support, Ronnie comes down the stretch of the long smooth wooden hallway, heading for her computer. Donna — intelligent, caring, firm, not without humor — says brightly: "Just three more steps, Ronnie. That's it. That's beautiful. Just three ... more ... steps." ■