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Living With Spinal Cord Injury

Questions and Answers for Patients, Family and Friends

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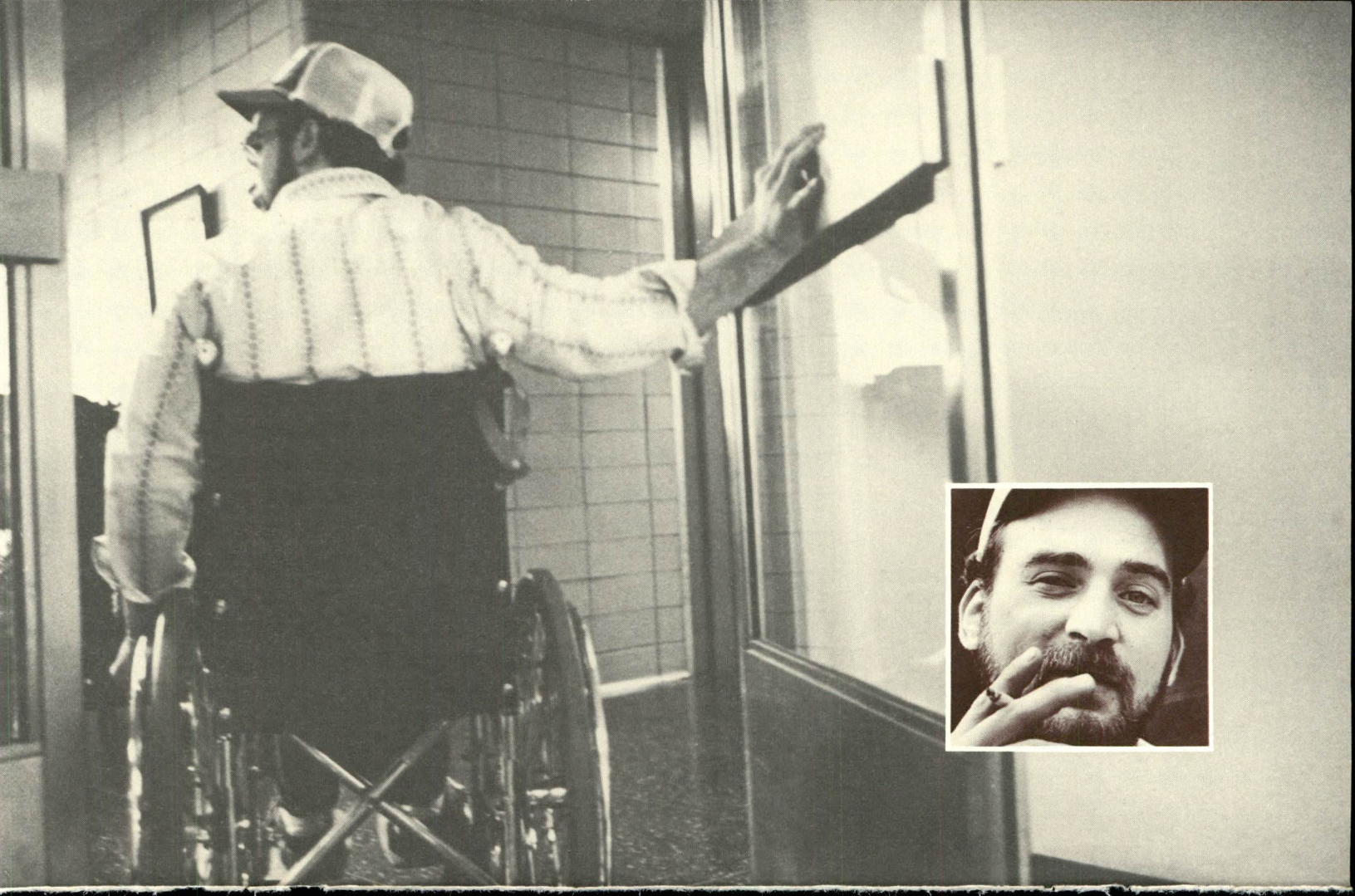
The impact of spinal cord injury can be overwhelming. Most such injuries happen to people who are just beginning their adult life; over 80% occur between the ages of sixteen and twenty-four.

This sudden thrust into a state of dependence is always difficult. The young person who is just beginning to experience independence and a sense of identity may find it hard to have to rely on others. For older persons who incur spinal cord injury, changes in the role as a parent or spouse may be particularly challenging.

In addition to physical changes such as paralysis and loss of sensation, dealing with spinal cord injury demands many psychological adjustments—not only by the injured person, but by family and friends as well. Their support can encourage efforts to resume a full and active life.

This booklet provides basic information on spinal cord injury for the injured person, as well as for family and friends. It answers some of the most common questions about this disability, and emphasizes the necessity for communication between the injured person and those who care for his or her well-being. It is important to discuss problems as they arise, even though the words may not come easily.



What is spinal cord injury? What does it mean to say that I have "broken my back" or "broken my neck"?

The spinal cord has a consistency like firm gelatin, and is surrounded protectively by a bony spinal column, made of 33 vertebrae. This bony structure protects the spinal cord in everyday activities. However, the spinal cord can be damaged when it is injured by impacts of great force such as occur in highway or sports accidents, or in falls.

The spinal cord is composed of bundles of nerve fibers which are the communication lines between the brain and all parts of the body. The messages it relays control such functions as voluntary motion, reflex responses, and sensation. The spinal cord has such a critical role that when it is damaged, major changes in function such as paralysis and loss of bladder and bowel control, may result.

Each level of the spinal cord controls the functioning of different parts of the body. The higher in the spinal cord the injury occurs (as in a "neck injury" vs. a "back injury") the more functions may be disrupted. Those areas above the injury site or lesion will remain unaffected, and function as they did before the accident.

The level at which the injury to the cord occurs is an important factor in determining how much function the individual will retain. Persons with injuries at or below the thoracic or chest region may be "paraplegic" (paralyzed in both legs). Those with injuries in the cervical or neck region may be "quadriplegic" (completely or partially paralyzed in arms and legs). Sometimes spinal cord injuries cause weakness, not total paralysis, which is known as "paraparesis" or "quadriparesis."

Spinal cord injuries are classified as "incomplete" or "complete". In an incomplete injury, the cord has been bruised or hemorrhaged, but not totally disrupted. In such cases, it is still possible for some messages from the brain to travel past the spinal cord injury site, although probably with some difficulty. In the case of a "complete" injury, the cord has been so extensively damaged that no messages can go below the injury site.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Is spinal cord injury fatal?

No. Once the injured person has become medically stable, one may anticipate a normal or close to normal life expectancy. This is due to the major advances made in the field of medicine over the past forty years. For example, someone injured today at the age of seventeen can expect to live another 40-60 years, even though confined to a wheelchair. This is why functional retraining to achieve maximum independence is so critically important.

Will the spinal cord injury get worse through the years?

No. After the person has passed through the "spinal shock" of the first few weeks after the injury, and when the bony spinal column has been properly stabilized, the injury itself will not worsen. However, the spinal cord injured person has different health needs than before the injury, and complications can occur if proper routines are not followed. Special nutritional needs, exercise, bladder and bowel routines, and skin care to prevent pressure sores, must be followed for a lifetime to avoid complicating problems that can be serious or even life-threatening.

Will the spinal cord injured person get better?

Possibly. It depends on the type of lesion, since the effect of spinal cord injury is slightly different in each instance. In cases of "complete" injury there is rarely a return of physical function below the injury site. In "incomplete" lesions, where there is still some movement or feeling below the injury site, there may be a progressive return of varying degrees of function within months and sometimes years after injury. There is, however, no way to predict how much improvement, if any, will occur in such "incomplete" lesions. Physical therapy is vital to develop maximum function of the remaining muscles.

Is there a medical cure for spinal cord injury?

Not yet. Destroyed nerve fibers of the spinal cord do not heal or grow back (regenerate). International

research is being conducted to seek a better understanding of how the spinal cord functions, and to find means to promote healing of the damaged nerve fibers. The Federal Government has also recently increased funding for spinal cord injury research.

Two non-profit organizations—The National Spinal Cord Injury Foundation and the Paralyzed Veterans Association—can provide information on the kinds of spinal cord research currently in progress.

How can family and friends help?

Family members and friends can actively contribute to and participate in the rehabilitation process in many positive ways. They can help most by not being over-protective, yet still providing the help which is truly needed.

Allowing the injured person to express feelings, when ready to do so, can be important even though it may be painful to hear. Feelings such as anger, depression, and anxiety, are some of the normal responses to the trauma of spinal cord injury.

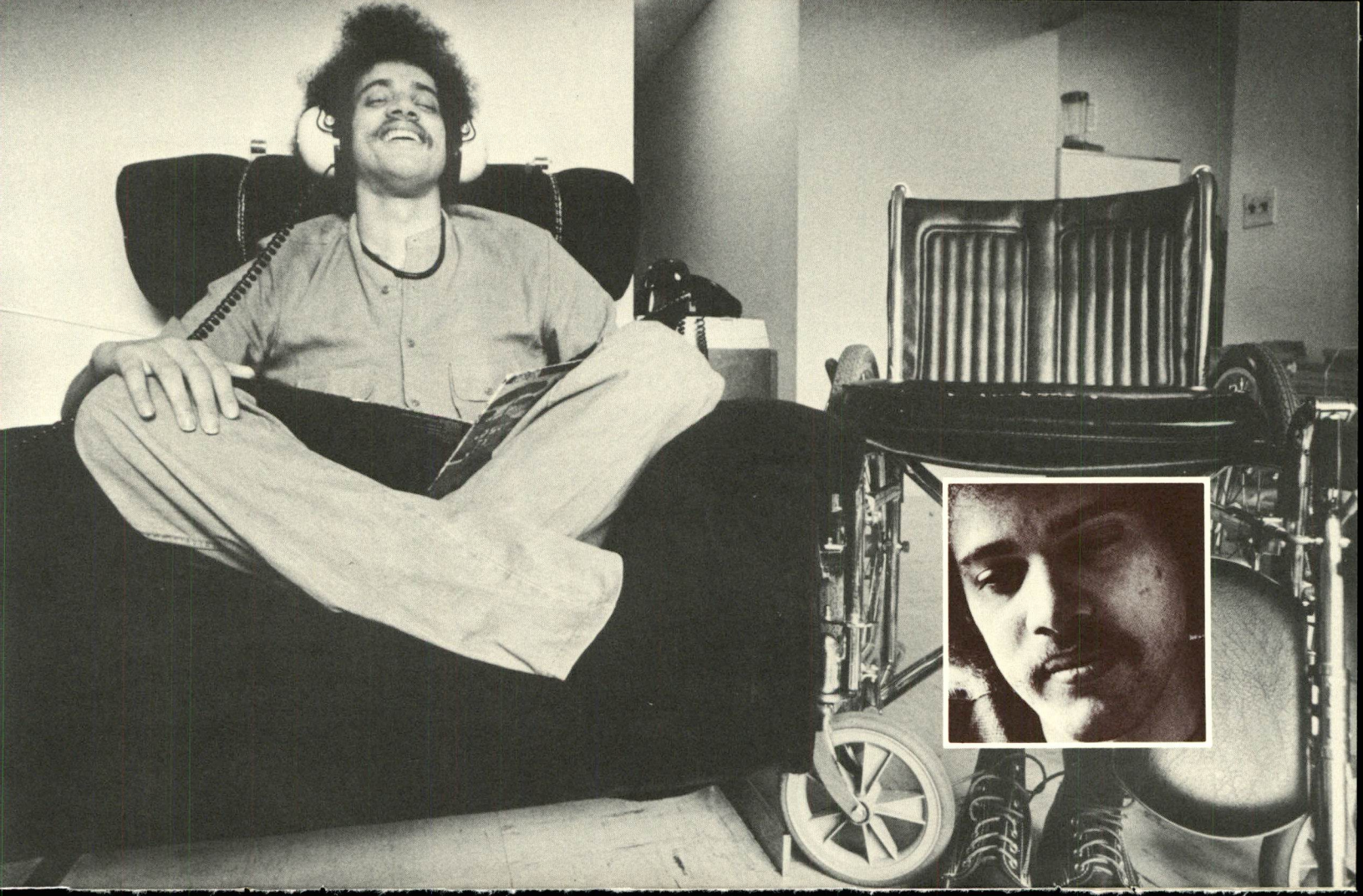
It is important to find out what the injured person is still physically capable of doing so that appropriate assistance may be given, if necessary. Family and friends can encourage the injured person to be as independent as possible.

What is rehabilitation? Why is it so important?

Rehabilitation is the re-training of the body to make maximum use of the capabilities each person has retained; it is a process of adjustment to a traumatic occurrence.

Its primary goal is to help the disabled person return to as full a life as possible by re-learning functional activities, and readjusting his or her psychological, social, and vocational life. Often professional counseling or psychotherapy, as well as physical therapy, is needed to achieve this goal.

In a formal rehabilitation setting, such as a Spinal Cord Injury System, the delivery of rehabilitation services is the responsibility of a team of professionals including physical, occupational and recreational therapists,



nurses, psychologists, vocational counselors, social workers, and rehabilitation physicians. The patient is the most important member of this team—which works together to provide emotional support while helping the patient achieve maximum independence.

Rehabilitation does not end with discharge from the hospital, but continues in the community and home environment. The passage of time and the experience of living with the disability can reveal both limitations and strengths, and enhance the process of adapting to spinal cord injury. It remains possible to have a full and satisfying life. Spinal cord injured persons work, go to school, marry, travel, raise children, drive cars, and enjoy most of the things able-bodied people do.

Why do many spinal cord injured people lose control of their bladder and bowel?

When normal bladder and bowel functions are disrupted by spinal cord injury, they are termed "neurogenic". This term means that the nerve passageways that communicate the need to empty the bladder or to evacuate the bowel are interrupted. The injured person is unaware of these needs and is therefore unable to control them voluntarily.

These problems can be managed by various methods, and by retraining the body to function on a schedule. The physicians, nurses and the urology department will assist in establishing a workable routine for each individual. While accomplishing this requires much time and patience, it can be helped by prescribed medications and other aids.

What is spasticity in the spinal cord injured?

Spasticity can be described as involuntary movements or muscle rigidity. It commonly occurs following spinal cord injury, and typically involves the arms and legs but sometimes may affect the trunk. Its development does not signal the return of voluntary motion, and it is a largely unexplained phenomenon. Spasticity may progress for a few years after the injury but usually tends to stabilize thereafter.

Spasticity is not dangerous, except in instances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where the spasms are so severe that they interfere with activities of daily life, or cause falls or loss of balance. In some cases of severe spasticity, surgical treatment may be recommended, but generally medications used in moderation will satisfactorily control it.

At times, a moderate degree of spasticity may be functional to the individual if the stimulus needed to produce the spasms can be identified and depended on to work reliably. In such instances it can be positively used as an aid in dressing, transferring and emptying the bladder.

Why do some spinal cord injured people have pain even though they are not sensitive to touch below the injury site?

About ten percent of all spinal cord injured people report pain at one time or another. Nerve damage at the site of the injury is sometimes the source of pain, but more often it is difficult to identify the precise cause.

Management of pain can be a complex problem and may require professional treatment for relief. It is important to determine when and where the pain occurs and what activity restrictions modify it. There are many approaches for dealing with the problem, including prescribed medication, steroid injections, hypnotherapy, psychotherapy, behavior modification, biofeedback therapy, electrical neurostimulation, and ice or heat treatments.

Individual consultation with a physician must be sought if the problem is severe. Your physician may refer you to one of several pain centers throughout the United States that specialize in the management of this problem.

Will people react differently to a spinal cord-injured person in a wheelchair?

In many cases, yes. Although attitudes are improving, misconceptions concerning physical disabilities still abound. A person in a wheelchair may be regarded by others as "ill" or someone to be pitied. Neither of these attitudes is an appropriate social response, and should be tolerated only as a display of ignorance. The wheelchair serves as a means of transportation and inde-

pendence; it does not define the person who uses it.

People are sometimes uncomfortable around a person in a wheelchair, because they don't know why the wheelchair is needed and are too embarrassed to start a conversation. In these instances the injured person may wish to educate others about the disability, letting them know that spinal cord injury is not a taboo topic. Often people will display curiosity, but frequent exposure to people in wheelchairs will usually soften this reaction. Sometimes even close friends avoid contact with a person after an injury, perhaps because they are afraid of saying the "wrong thing". This is unfortunate, since friends are always needed and important.

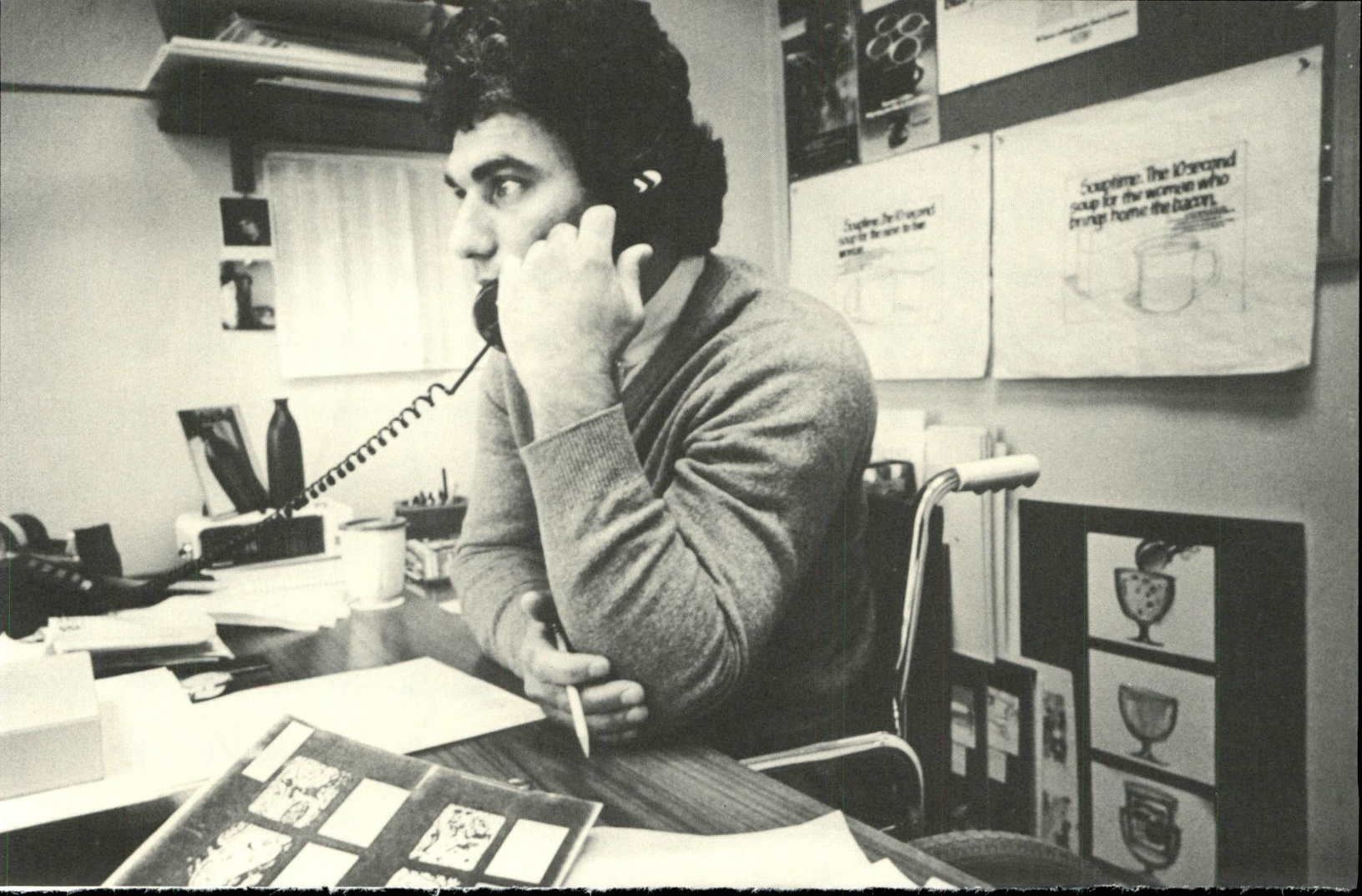
An additional problem for people in wheelchairs is the presence of architectural barriers—the reality of doorways too narrow to enter, cluttered inaccessible interiors, and insurmountable stairs. These physical barriers pose frustrations to all disabled people by making it difficult to live as active a life as possible. It is encouraging that many new buildings are now being constructed to meet the accessibility needs of the disabled.

Each individual will find personal ways to cope with some of these problems. Spinal cord injured people may find that they need to be more assertive than before to get what they want. If an injured person displays self-confidence, other people will show confidence, too.

Is sex possible after spinal cord injury?

Yes. From the psychological, emotional and hormonal standpoint, the person with a spinal cord injury remains a sexual human being. The desire for love, intimacy and romance, and the capacity to enjoy and share these aspects of life remain unimpaired.

The physical act of sexual intercourse may be altered by the spinal cord injury, but sexuality includes a broad range of attitudes and behaviors. Physiologically, most cord injured men can attain erections, and women of childbearing age retain their full reproductive functioning. Many spinal cord injured persons who have impaired sensation in the genital area report developing heightened feeling in other areas. Even with impairment


Soupreme. The Kherpond soup for the woman who brings home the bacon.

of sensation or the inability to produce an erection, a satisfying sexual relationship is possible if one wants it and is willing to work for it.

Good and trusting communication, important in all relationships, becomes essential in the case of a spinal cord injured person and his or her partner. Sexuality is a personal matter, and an individual's feelings are very important in determining what to experiment with. A trained professional can help deal with these feelings and suggest different ideas and techniques, but in the end it is up to each person and partner to develop a relationship which is mutually satisfying.

Can spinal cord injured persons work or go to school?

Yes. Spinal cord injured persons work in a great variety of employment areas—although for some people this may require returning to school to obtain high school diplomas, college degrees, or specialized training.

Vocational counseling and placement assistance are available through the Spinal Cord Injury System. State Vocational Rehabilitation Offices offer these services and may also help fund schooling, transportation and vocational training programs.

Is financial assistance available after spinal cord injury?

The rehabilitation services that may be required following a spinal cord injury are very expensive. If a person does not have "catastrophic" or maximum insurance coverage, it may be necessary to apply for Medicaid to help meet the medical costs both in and out of the hospital. To learn about eligibility for Medicaid, contact a local Department of Social Services or Welfare office. Many hospitals have Medicaid representatives in their business offices. Funding through the State Department of Vocational Rehabilitation may be available for those who are eligible.

The spinal cord injured person may qualify for some financial assistance because of the resulting disability. Your local Social Security Office will determine eligibility for Social Security Disability (SSD) or Supplemental

Security Income (SSI). It is also important to explore State Disability benefits, which are usually applied for by employers. If injured on the job, Workers' Compensation may provide coverage.

For someone with a dependent spouse or children at home, public assistance (such as Aid to Families with Dependent Children) may be applied for at the local Department of Social Services. Other programs, such as Food Stamps, can also be applied for at the local welfare office. When there is a problem meeting rent payments, a state or local Housing Authority should be contacted to determine eligibility for assistance. Housing developments and rent subsidies (such as Section 8 Housing) may be available in the community. Unfortunately, there is not enough accessible housing to meet the present demand.

It is extremely important for the injured person to become aware of the right for services in the community. Eligibility requirements are always changing. By remaining in contact with community agencies, local rehabilitation hospitals, and organizations for the disabled, spinal cord injured people will know and be able to assert their rights.

What are the legal rights of the spinal cord injured?

The disabled person is protected by the same laws governing all citizens of the United States. To assure legal and civil rights of disabled people, the *Rehabilitation Act of 1973* was enacted to protect the disabled against discrimination because of their handicap. It further mandated that all new facilities receiving Federal funds be constructed or adapted so as to be wheelchair-accessible. Although these special regulations apply only to recipients of Federal funds, they have established a guideline to be followed by other builders. As the disabled have mobilized to urge favorable legislation, their needs and abilities have become more visible and their demands more acceptable.

The National Center for Law and the Handicapped is one of several organizations that is fighting for the legal rights of the disabled. Another organization,

Mainstream Inc., has established a toll-free number—800-424-8089—available Monday through Friday from 9:00 AM to 5:00 PM, to provide information on legislation concerning the disabled.

How does one live with a spinal cord injury?

Spinal cord injury can cause dramatic changes in many physical capabilities and bodily functions including loss of movement, loss of sensation, and loss of bladder and bowel control—but each person's injury affects him or her a little differently. What doesn't change after spinal cord injury is the basic person whose needs for love, laughter, self-esteem, sex, and human companionship are unchanged.

How, then, does one live with a spinal cord injury? There are no easy answers. Learning to adjust to being disabled is a personal process, a struggle, which varies with each individual. The following summary of suggestions, however, may be helpful to you in coping and coming to terms with spinal cord injury.

1. After spinal cord injury, self-esteem can be badly shaken. Give yourself time to restore it.

2. Concentrate positively on your abilities, rather than on your disability.

3. Adjust personal goals to realistic limits that will permit you to achieve what you seek in life. Only you can set these limits.

4. Measure your successes by what it's possible for you to accomplish, not by what others are able to accomplish.

5. Although you should not dwell on your problems, it is nonetheless important to openly express your anxieties, fears, and concerns to people close to you—spouse, friends, or a professional.

6. Be willing to ask for help and accept it when needed, but do not demand assistance unless it is necessary. You may have to be more assertive than before to make your needs understood by others.

Suggested Resources

The following is a list of some excellent sources of information.

National Resource Directory—Published by the National Spinal Cord Injury Foundation, 1979. This is an excellent guide to resources and information on many aspects of life for the disabled including financial assistance, transportation, organizations, housing, equipment, and more. For copies (and charge) write to National Spinal Cord Injury Foundation, 369 Elliott Street, Upper Newton Falls, Massachusetts 02164.

Paraplegia News—Published by the Paralyzed Veterans of America, regularly has information on such things as accessibility, spinal cord research, sports for the disabled, etc. For subscription information, write to Paralyzed Veterans of America, Inc. 4330 East-West Highway, Suite 300, Washington, D.C. 20014.

Accent on Living—This magazine is published quarterly and is very lively and informative, covering many topics concerning the disabled. For subscription information, write to Accent on Living, P.O. Box 700, Bloomington, Illinois 61701.

Amicus—A bi-monthly journal which is devoted to promoting awareness of legal rights of the disabled. It is available for $10 a year through The National Center for Law and the Handicapped, 211 West Washington Street, Suite 1900, South Bend, Indiana 46001.

Books

Sexual Options for Paraplegics and Quadriplegics by T. Mooney, T. Cole, R. Chilgren, Little Brown & Company, Boston, Massachusetts, 1975.

Female Sexuality Following Spinal Cord Injury by Elle Friedman Becker, Accent Press, Bloomington, Illinois, 1978.

Spinal Cord Injury: A Guide for Care—Published by the New York Regional Spinal Cord Injury System, New York University Medical Center, Institute of Rehabilitation Medicine, 400 East 34th Street, New York, New York 10016, 1979.

The Source Book for Disabled—An illustrated guide edited by Glorya Hale, Paddington Press, Ltd., New York & London, 1979.

The Rights of Physically Handicapped People by Kent Hull, An ACLU Handbook Discus Avon Books, New York, New York, 1979.

Options – Spinal Cord Injury and the Future by Barry Corbet, Hirschfeld Press, Denver, 1980. Available through: National Spinal Cord Injury Foundation, 369 Elliot Street, Newton Upper Falls, MA 02164.

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