First Person

Life Care Planning for the Spinal-Injured

A personal perspective

Paul Pateracki

Developing a Life Care Plan for a newly spinal injured person is no easy task. There are a number of factors to consider that can make the task difficult or easy. I have been a quadriplegic for forty-three years and have been living independently for thirty-six. I have known many people with SCI at all levels and will use my experience to give you a number of suggestions.

Getting Started

First, consider the injury level of the patient. This is critical, since differences between a paraplegic and a quadriplegic will have a dramatic impact on a Life Care Plan. I will focus on my level of quadriplegia: C6-7 quadriplegic with biceps, no triceps, wrist extensors but no flexors and no finger movement. A paraplegic with full arm and hand capabilities may not need parts of the plan; higher-level quadriplegics will need extra assistive care. Also, consider that due to variations in physiology between people, patients with the same lesion level may have different residual capabilities.

Once the patient is stable, planning for rehabilitation begins. The first factor to consider is the patient’s adjustment to the new situation. The phases of grief associated with the physical manifestations of a spinal injury are similar to those receiving a terminal cancer diagnosis or losing a loved one. For additional insight, re-read Kubler-Ross’s classic, “On Death and Dying.”

Rehabilitation considerations

Putting a patient who is still in denial into a rehabilitation facility may be ineffective. In my case, I did not enter a rehabilitation center until over two years after my injury. By then I was highly motivated and took full advantage of the opportunities that rehabilitation afforded. Because insurance dollars available to pay for rehabilitation may be limited, seek psychological counseling beforehand. The closer injured per-

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sions are to acceptance, the more likely they will take full advantage of the rehabilitation setting.

It is important to pick the right facility. Recommend only a rehabilitation center that specializes in spinal injury. Many so-called rehabilitation facilities are springing up and chasing scarce insurance dollars. Many of these facilities are set up to treat little more than common orthopedic conditions and strokes. SCI persons need physical therapy, occupational therapy, vocational counseling, psychological counseling, and a wide range of ADL skills training. The facility should demonstrate experience developing personalized rehabilitation plans.

**Individualization**

Beyond selecting the right facility, consider the patient's age, educational level, job history, skill set, and available support systems. It's unrealistic to assume that a rehabilitation facility will discharge its patients ready to take full charge of their lives with or without assistance. In almost every case, rehabilitation facilities are the starting point from which the individual will continue the rehabilitation process for years to come.

**Age** Age can present a particular challenge. Clearly it will be easier to develop a plan for a younger patient—most young people are more adaptive than older ones. When you have most of your adult life in front of you there is more of an incentive to cope with your disability. On the other hand, I have seen older spinal injured people in their forties, fifties, and sixties who seem to lose interest in starting a new career or even becoming active in life. This presents a challenge. I wish there were an easy answer to convince older patients that because they have a spinal injury their lives need not end. This is a harder sell for an older patient. Things seem harder when you're older. I am sixty years old and still manage on my own for most of the day. I have someone who comes in at night to help me with my nightly routines. I could probably do them myself and maintain my total independence but it has become increasingly difficult and would consume too much of my energy. For older newly-disabled patients, it can be a challenge to get the support necessary to give them time and energy to go out and live their life.

**Educational level** This can have a profound effect. A more highly-educated individual is likely to imagine more options for the future. Persons with a college degree will likely have more employment options available and be able to see themselves and the world around them differently. I have seen a number of spinal injured people with barely a high school education neither able nor willing to push themselves further. They are content to let someone else, usually the government, take care of them. Today, universities and colleges are wheelchair-accessible, opening the door to any level of education.

**Job experience and skills** Job history and skill sets go hand in hand. The person with significant work history and/or acquired skills that are not dependent on lost physical capabilities will find reha-

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bilitation and mainstreaming back into society much easier.

**Support systems** One of the most important factors is the patient's support system— or lack thereof. I was fortunate enough to have family willing to take care of me for the interim period between my accident and the time I was willing and able to take charge of my life. It is incredibly rare for a quadriplegic to be able to do that without a support system. Paraplegics will have an infinitely easier time managing their daily care. Even so, I have seen many paraplegics who could not manage well without the help of family of friends.

Effective support available from the outset makes planning much easier. For those without a support system, getting financial help for assistive care can be a challenge. However, a variety of options are now available, from assistive care facilities, group homes, or simply regular home health aide visits.

**Reevaluate, Reevaluate, Reevaluate**

Let's assume that you have written a Life Care Plan and it is being implemented. The patient is well past rehabilitation and involved with a new life. The Life Care Plan should also include periodic evaluations after rehabilitation. No patient or support system is static for long. Health may change. Technology advancements may become available. Unforeseen circumstances can have dramatic effects.

**Mental health and coping** One issue that needs to be addressed on an ongoing basis is depression. I would suspect there is not a spinal injured person in this country who has not been depressed at one time or another. Our lives can be a constant struggle. When I was driving a car at the peak of my skill I timed myself how long it took me at top speed to get in the car, fold up my chair and pull it into the back seat, slide over behind the wheel, buckle up and start driving. The quickest I ever got was seven minutes. Consider how long it takes an able-bodied person to do the same thing. Probably less than 10 seconds. For one who is inclined to focus on these differences, depression will be a constant companion. It is essential for the Life Care Plan to provide resources to assess for depression and plan for regular counseling for both the SCI person and any significant others.

**Critical areas of concern** As a person who has seen much in 43 years, I find there are three critical areas of concern for a person in a wheelchair which need to be addressed with the utmost seriousness. I

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have read about many individuals who have lost their jobs, homes, families, and life savings because they ignored these issues, particularly those of pressure sores. Be sure to include periodic reevaluations for these critical areas: a viable and practical urinary control system, a dependable bowel routine, and a wheelchair and seating system that minimizes the possibility of pressure ulcers.

**Urinary management** A friend of mine who was suffering from polio and was nearly totally paralyzed once told me there is no reason I should worry about urinary failure. He said I should be able to go through my entire day without worrying about wetting my pants. This was back in 1968. Since then the number of products and procedures to make this possible has increased dramatically. The Life Care Plan must include regular consultation and evaluation by a competent urologist experienced in spinal injury. There is no reason why even a quadriplegic cannot maintain their own “gizmos,” as we call them. Even if someone who needs help still should be able to achieve an adequate level of confidence. I, myself, without finger dexterity, am able to change a urostomy wafer without assistance. Whichever system is appropriate, SCI persons need to drink enough fluid per day to keep the kidneys flushed in order to minimize the risk of UTIs.

**Bowel management** I wish my friend could say the same about bowel maintenance routines. It is the one thing I cannot achieve total confidence about. I do well but am not inclined to travel long distances away from home or travel where I cannot stop to recover from a bowel movement. The best routine in the world cannot save you from the effects of eating the wrong foods. I have learned over the years that certain foods tend to trigger an unsolicited BM. I stay away from them and am careful about eating unfamiliar food where I don’t know how it’ll affect my intestinal motility. This is probably the only bane in my life. Every SCI person needs to know that this too can be controlled with trial and error. One important thing to know is everybody is different. What bowel routine works for one person may not work for another. What type of suppository works for some may not work for others. The answer is, if it doesn’t work, try something new.

**Pressure management** The last and most important item is the wheelchair and seat cushion. Both active and inactive wheelchair users could spend quite a few hours per day sitting in a wheelchair. This translates to pressure on the bottom. For someone of thin stature with prominent ischial tuberosities a proper seat cushion is critical.

I have read many cases of individuals who got a pressure sore that put them in the hospital or in bed for six months to a year or more. These horror stories have scared me enough to make sure I check my backside with a mirror every night when I go to bed. If I see a red spot I’m going to spend a good part of the next day in bed. One time I saw the makings of a sore that scared me enough to stay in bed for a week. My employer didn’t like it but because I took action quickly I was back to work after only seven days. Had I ignored

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this and convinced myself it would be okay, this might have been a different story.

I believe there are a sufficient number of seating systems on the market today to accommodate most everyone who sits in a wheelchair all day long. This includes those who are higher quads who have less mobility and are not able to lift themselves periodically.

I must add a caution here: Even the most effective cushion that has worked for years can still not be enough to prevent a sore. One thing I’ve noticed is that the type of pants I wear can affect whether I get a sore. I learned early on that the coarser pant material is harder on my skin and can cause sores. Tell your patients that jeans are out! Also, when it comes to pants and wheelchairs there is something called the “hammock effect.” If pants are too tight they will act like a hammock and pull tight against the skin. Even with the most effective seat cushion this can cause a pressure area. So the “bottom” line is to wear smooth fabric that is not too tight.

**Technology and assistance** Most of the preceding discussion has focused on midlevel quadriplegics. Clearly a paraplegic with full arm and hand movements will not need the same level of rehabilitation and assistance as a quadriplegic. It will be much easier for a Life Care Planner to eliminate the needs that a quadriplegic would have. Conversely, a higher-level quadriplegic with less mobility will need far more assistance. Ironically, they will probably need less rehabilitation. The challenge for writing plans for a higher level quadriplegic is becoming familiar with many of the assistive devices that allow them to function as independently as they can. Some of the equipment you’ll need to know are power wheelchairs, computers that interface with household appliances, automated phones, and light switches. In some cases, quadriplegics who are nearly totally paralyzed have trained service monkeys to help them around the house. The more you know about these options, the better you will be equipped to develop an appropriate Plan. (see sidebar below)

**A Final Note** I have always felt that it is a rare person faced with this kind of disability who can, without outside input, imagine their way to a happy and prosperous future. I have always looked to others for creative inspiration to help myself to solve my own problems. When I was lying in the hospital weeks after my car accident I remember thinking to myself, “What will ever become of me?” I saw no future. The best I could come up with was sitting in the cor-

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ner of a nursing home. I didn’t want to be a burden to my family and this was the only option I saw. Fortunately I came across others who convinced me that I could have a very different future. Your Life Care Plan can help convince your patients that there is a good life out there and that there are plenty of examples of people who are spinal injured living good, productive lives.

As Life Care Planners I encourage you to research and read as much as you can about the lives of spinal injured people. They will help point you in the directions you’ll need to take when writing a Life Care Plan. As you familiarize yourself with the capabilities and needs of people with every level of spinal injury, writing effective plans will become easier.

Please note that these recommendations for resources are the author’s own and do not represent endorsement by the Journal of Nurse Life Care Planning or the American Association of Nurse Life Care Planners.

Wheelchairs:
- Invacare (www.invacare.com)
- Sunrise/Quickie (www.sunrisemedical.com)
- 21st Century Scientific (www.wheelchairs.com)
- The Bounder wheelchair SpinLife (www.spinlife.com)

Wheelchair Cushions:
- ROHO (AIR) (www.roho.com)
- Jay (air, foam, gel) (www.sunrisemedical.com)
- Invacare (air, foam, gel) (www.invacare.com)
- Supracor (foam) (www.supracor.com)

Van Conversions:
- Ride-Away (www.rideaway.com)
- BraunAbility (www.braunability.com)
- Drive-Master (www.drive-master.com/vanconversions.htm)

Lifts:
- SureHands (www.surehands.com)
- Bruno (www.bruno.com/bruno-vehicle-lifts.html)

Clothes:
- Blair (www.blair.com)
- LandsEnd (www.landsend.com)
- Able2Wear (www.able2wear.co.uk)
- Silverts (www.silverts.com)

Schools:
- Reference (www.new-horizons.org/educal.html)

Catalogues:
- Sammons-Preston (www.sammonspresto.com)