



# Craig Hospital

Redefining Possible for People with Spinal Cord and Brain Injuries

Provided as a courtesy of  
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## As the Years Go By: Accepting New Help

*The world we live in—and we ourselves—place a very high value on physical independence. We're raised on the expectation that we will ultimately take care of ourselves. As toddlers, we learn to dress and feed ourselves, as teens we learn to drive and to think for ourselves and finally, as adults, we assume responsibility for our lives. Hallelujah, we've finally grown up.*

### Add Spinal Cord Injury . . .

Then, somewhere in there, spinal cord injury arrives and everything gets turned around. Many survivors have to hand back a large measure of control—to hospital staff, caregivers, parents and even government. Some fight a sense of being returned to childhood, and most have to deal with the concept of living on the edge—of being independent now, but only a breath, a fall, a skin sore away from losing a big hunk of that independence. What if you injure one of your shoulders and can no longer do transfers? What if you lose the manual dexterity for bladder care, or the range of motion for dressing, or maybe just the energy to keep up with household tasks?

### . . . and aging too . . .

Add aging to the mix. What then? Even those who aren't disabled eventually come to realize that as the years go by, the buffer that separates independence from dependence grows progressively thinner and thinner. If we live long enough, we all eventually become dependent, for a greater or lesser period of time. With a spinal cord injury, that realization comes early. You don't have to add many years to your injury to become painfully aware that your independence is fragile, that at some point, the only thing that will stand between you and an impossible living situation is the help of another person. Yet you fought a long, valiant battle to win your independence after injury, and you'll do anything to preserve it. Any compromise seems like fundamental failure.

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## The dilemma:

For most survivors, weaned on the holy grail of self-sufficiency, that's a terrible dilemma. The dilemma doesn't go away. But it may not be so terrible, either.

## The facts:

Like it or not, the need for help is as much a part of the spinal cord injury picture as wheelchairs. About 40% to 45% of SCI survivors use some kind of personal assistance, and the percentage increases with age. The British Longitudinal SCI Aging Study of survivors injured 20 or more years found that 22% had an increase in the amount of assistance they needed— regardless of how much help they did or didn't need initially.

Why? A quarter of the 22% blamed fatigue or weakness; another quarter blamed some other medical condition. Weight gain was another major cause. The areas they needed more help with tended to be with transfers (if they were paras) and mobility in general (if they were quads). Other problematic areas: dressing, toileting, homemaking, and eating.

## The mindset:

So, given the weight society places on independence, how do you deal with the prospect of more dependence?

The key is mindset. Try thinking about what determines your self-worth and quality of life: do you have to be able to do everything yourself, or is it enough to know that you can get the job done? Realize that you alone are responsible for that determination.

Consider two people:

- Gary is a 20 year old college student with quadriplegia. Each morning his alarm wakes him at 4:00 a.m. He then spends over three hours getting ready for his first class. He seldom has time for breakfast.
- Jon is another quadriplegic student. He sleeps in until 7:00—when the personal care assistant he hired and trained arrives. Thirty minutes later he is up, washed and dressed. His bed is made and he is on his way to the cafeteria or breakfast.

To a large extent, Gary's self-esteem comes from his fiercely held physical independence. He likes knowing that no help is needed.

But Jon knows that, regardless of who does each task, he – Jon - has complete control. He also has the freedom to spend the time and energy he once used for self care on activities that are more important to him.

## Accepting New Help

## The source of esteem:

Self-esteem and accepting help may not be so incompatible after all. For most of us, as we get older, knowing we have the control and the resources to get things done becomes progressively more important than doing everything ourselves. We learn to interact with our environment by consuming services, and think little of it. Most of us are comfortable with not being able to replace the transmission in our cars; we can hire a mechanic for that. Most of us don't raise our own food, haul water or produce fuel to heat our houses either—we hire those things out, and we don't lose too much sleep over it.

## What comes first?

If personal care services are looked at in much the same way, perhaps you can hire out that early morning dressing routine, that tub transfer or whatever it is that impedes getting on with the day—and spend your energy on your education, career, or serving your community instead.

The point: ***hang on to the activities that really matter to you and delegate or negotiate away the ones that don't.***

### ***For example:***

- You have the skills to work, but don't have enough energy to do your self care as well. If your work is your first interest, and especially if it will generate money to pay a helper, where is the defeat in hiring a personal care attendant to get you ready for the job?
- The volunteer time you put in is the most gratifying thing you do, but you need someone to help with showering and dressing before you can get there. Doesn't it make sense, if you can afford it, to accept help and the richness it enables you to experience?
- Perhaps you work for an independent living center. But you need a dresser, driver, gofer and leg bag emptier. Your work is helping people, so why should you balk at accepting help yourself?
- You love sit-skiing and you're totally independent. But there's no skiing without some assistance on the hill. Can't you continue to be bullheaded about your independence at home, and lighten up for a weekend of fun?

## Independence is relative:

Independence is a relative thing. How many of us are truly independent of other people? Physically, psychologically or financially—and in a host of other ways—we are all *inter*dependent. It's part of being human. And accepting help, of course, in no way prevents us from helping others ourselves. From this perspective, a decision to use more help is not an admission of failure, but an act of empowerment. In fact, accepting additional care may provide optimal independence. For many, taking responsibility and control over an appropriate level of physical assistance brings more freedom and flexibility than rigidly refusing all help.

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