LIFE WITH A SPINAL CORD INJURY: FROM THE PARENTS’, DAUGHTER’S, AND CLINICIAN’S PERSPECTIVE

Bridget Harrington, Michael Harrington, Jan McCreary and Heather Russell

Case vignette
Bridget is a 21-year-old female with a T1 American Spinal Injury Association Impairment Scale (AIS) C spinal cord injury as a consequence of a brain and spinal cord abscess at the age of 14 years. Bridget was otherwise healthy until the age of 14 years when she developed a frontal lobe brain abscess with right hemiplegia subsequent to a sinus infection while she was living abroad with her parents owing to her father’s sabbatical. She underwent neurosurgical repair to drain the abscess, and subsequently demonstrated some improvement of the right hemiplegia. Approximately two weeks later, she experienced further deterioration, at which time computed tomography demonstrated an occipital lobe abscess, necessitating a second neurosurgical procedure. Postoperatively, Bridget experienced visual problems along with upper and lower extremity paralysis. After this second surgery, Bridget remained in the intensive care unit for 7 weeks, requiring ventilator support and a tracheotomy. After being weaned off the ventilator, she received in-patient rehabilitation and, approximately 10 weeks after onset of her symptoms, she was transferred back home for further in-patient rehabilitation in Australia in a children’s hospital. Her diagnosis at that time was an incomplete spinal cord injury (C5 sensory level, C7 motor level) with neurogenic bladder and bowel, neuropathic pain, and spasticity. She remained hospitalized for rehabilitation for approximately 9 months and during that time underwent placement of an intrathecal baclofen pump, and tendo-achilles and hamstring lengthenings. She has since also undergone Mitrofanoff (appendicovesicostomy) and Malone antegrade continent enema procedures. Bridget has experienced slow but continued recovery in her upper extremities, with her right arm functioning more strongly than her left. In addition, she has some functioning in her lower extremities (i.e. her left leg being stronger than her right leg). Her current presentation suggests an incomplete T1 spinal cord injury AIS C. Bridget’s primary mode of mobility is a power wheelchair, although she also has a manual wheelchair. Prior to the onset of her illness, Bridget was a high-functioning student with excellent grades. Her premorbid level of functioning was estimated to be
The parents’ perspective

**INTRODUCTION**
Bridget’s illness, surgery, and ensuing recovery over the past 6 years has gone through several phases. There was the initial acute phase in the Netherlands that lasted 3 months, followed by the return to Australia and 9 months of hospitalization. Upon her release from hospital, we had a challenging 2-year period in which she completed high school and attempted to re-establish the life she had before the illness. The fourth, and current, phase has centered on university life and ongoing rehabilitation, including periodic visits to the USA for treatment. As she is physically stronger and increasingly independent, for Bridget it has been a time of developing new interests, passions, and friends.

**COPING**
Treatment of Bridget’s brain injury required two operations, the second of which left her totally paralyzed from the head down. Over 7 weeks in intensive care she regained enough function to speak, eat, and use her right hand. The severity of her condition meant we were in a state of near shock, and this was compounded by the fact that we were on our own in a foreign country. The initial diagnosis was a myopathy and prognosis of an ultimately successful recovery, and we were thus driven by a level of hope that might not have been there in different circumstances, for example following a severe car crash.

Once we arrived back in Australia, Bridget’s neurologist confirmed that she did in fact have a spinal cord injury (SCI) and one that would lead to other medical issues, including tight tendons, spasticity, and the need to insert a baclofen pump. In addition, she needed to undergo a cranial reconstruction for the previous surgery. In the early days our emotional energy was focused on these matters but, after a time, life started to return to some routine, as we balanced work with a constant presence at the hospital. It was at this time that the life-changing nature of Bridget’s condition began to be felt. Jan was overcome by profound guilt for what had happened to Bridget and grief for the impact the injury was having, and possibly would have on her for the rest of her life. Speaking to social workers helped but she found she needed to deal with her grief more privately. For his part, Michael coped largely by focusing on the immediate medical condition and by explicitly avoiding thinking about the future. The present was enough to deal with. Family, friends, colleagues, and employers provided tremendous emotional and financial support. But, on perhaps too many occasions, well-meaning individuals would attempt to assure us with the observation ‘It must have

within the high average to superior range. Repeated neuropsychological assessments have demonstrated cognitive improvements across all domains relative to her initial performance after illness onset; however, she continues to be adversely impacted by an impairment in speed of mental/motor processing and, to a modest extent, weakness in perceptual reasoning ability.
happened for a reason’. Words intended to comfort instead provoked the most visceral of emotional reactions. Jan often wanted to scream: ‘This hasn’t happened to your child. What possible reason could there be for it happening to mine?’. One of the most comforting comments for Jan came from one of Bridget’s specialists who simply and quite dispassionately pointed out that no one was to blame, that these things happen. (His actual words were ‘It is not your fault. Shit happens and this is a lot of shit’.)

The trauma of Bridget’s injury and the demands of the recovery process placed an enormous stress on our relationship. During the initial phase in the Netherlands, a social worker warned us that marriages are often a casualty in these situations and that we should be aware of the toll the stress will take. Our experience certainly bore that out, as we went through a long period when it felt like our daily lives were totally defined and absorbed by Bridget’s recovery. In retrospect, we realize how important it was that we each had time and space to come to terms with the huge change in our life in our own ways.

Bridget has made huge improvements over the last 6 years. She has been studying part time at university for the past 3 years and is doing well in her classes. She has gone from being completely paralyzed from the neck down to being able to use both hands (including writing), get in and out of bed and her wheelchair using a frame, and even walk 30 feet with the aid of parallel bars or a walker. After being dropped off at university, she is completely independent and, in the last 6 months, she has started going to town on the bus on her own.

It is still difficult to come to terms with the consequences of her illness. But, at the same time, there is always hope that she will continue to become more independent.

Dealing with the Healthcare System
Over the course of Bridget’s treatment, recovery, and rehabilitation, we have had experience with the Dutch, Australian, and American healthcare systems. Bridget was initially treated at a major university hospital in the Netherlands. Overall, we felt we received excellent care. Despite not speaking Dutch, we never felt that language was an issue and every effort was made to keep us informed. However, we did feel great frustration at not knowing what caused the paralysis after the second operation. An SCI was ruled out in favor of a myopathy or neuropathy arising from the second surgery, although neither diagnosis was conclusive. When we returned to Australia, the issue had still not been resolved and, indeed, follow-up tests in Australia indicated that she did sustain a high-level SCI as result of the infection, the surgery, or a combination thereof.

Upon our return to Australia, Bridget was treated by a complex care team in a local children’s hospital. The complexity and severity of Bridget’s condition meant that rehabilitation could only be undertaken after the more pressing medical issues had been addressed. Working with a large team was frustrating. Despite the team leader working very hard to keep us and the team on the same page, we often felt that communication only happened when we pushed it. In retrospect, we feel that we were not adequately prepared for the wide-ranging medical, physical, and psychological consequences of an SCI. Vital information, particularly regarding the long-term bowel and bladder issues experienced by patients suffering from an SCI, was either mentioned in passing or ignored. We would have preferred to have been given too
much information, even if at times it was difficult to deal with, than to have been left, as we were, unaware of issues that may (and did) develop later.

Dealing with a complex care team and then with a large out-patient rehabilitation program meant we interacted with a number of therapists, working both as teams and as individuals. There was limited continuity in personnel and the interactions came to take on a predictable pattern. At the initial encounter, the first question was invariably ‘What are your goals?’ Our first instinctive reaction was ‘We have a daughter with an incomplete SCI of unknown etiology. We want her to walk, to be independent. That is our goal. What other goal could there be?’ Of course the person posing the question wanted to identify specific needs relevant to her current condition. The frustration we often felt was that we didn’t know what was possible. We found it frustrating and quite stressful to be asked to identify goals without having any idea of what might be useful and achievable. After about the third such encounter we also learned that there would never be any attempt to monitor or assess whether the goals are met, or any attempt to provide us with tools to do that monitoring and assessment ourselves.

Healthcare in Australia is provided jointly by the state and federal governments. On Bridget’s 18th birthday, her care was transferred to the adult spinal cord unit at another hospital in our city. In Queensland, there are no out-patient SCI rehabilitation services. However, funding is provided for biweekly treatment from a private provider as well as for in-home care, both of which we manage. We have been lucky to have a neurophysiotherapist who has been a perfect fit for Bridget both professionally and personally.

Bridget has a support worker who comes to the house for about 25 hours a week, funded by the state disability agency. The support worker helps get Bridget up, showered, and dressed in the morning, takes her to her physiotherapy sessions, and then drops her off at university for the rest of the day. The support worker makes an enormous difference to our lives. It has allowed Jan to continue working full time and has reduced the physical demands on both of us that caring for someone with an SCI brings. We have also received funding for home modifications, transportation, and medical supplies. The complexity of her case has meant we have interacted with many agencies and our experience has confirmed the importance of a patient having a strong advocate who is persistent, and on occasion insistent, that her voice is heard.

Since 2008, Bridget has also been extremely fortunate to be able to receive treatment periodically from an adolescent SCI unit in a children’s hospital in the USA. We have made five visits over the past 3 years for in-patient rehabilitation treatment for periods of 2 to 3 weeks each. The program complements and reinforces her therapy treatment in Australia, provides her with the chance to interact with other patients her age suffering from an SCI, and provides us with some peace of mind that comes with having an additional informed perspective on her rehabilitation.

In conclusion, having a child with an SCI is a life-changing experience in the literal sense of the phrase. The change is continuous and the end is uncertain. We have often been told that our journey with Bridget is like running a marathon and not a 100-m dash. You need to take each day as it comes.
The daughter’s perspective

INTRODUCTION
When people see someone in a wheelchair, they assume that the worst part of sustaining an SCI is not being able to walk. As someone with an SCI, I can tell you that there are many other aspects of the injury that are far more challenging. Sustaining an SCI can mean that everything in your body below the level of your injury can be affected. One of my greatest physical challenges is bladder and bowel dysfunction. The incomplete nature of my injury is another aspect of my condition that is hard to come to terms with. Finally, my SCI has greatly affected my relationships with my parents and my friends.

PHYSICAL CHALLENGES
The most obvious aspect of an SCI is the physical changes to your body. For me, the most frustrating aspect of my injury has been my bladder and bowel dysfunction. At the end of 2009, I underwent a Mitrofanoff procedure to allow me to catheterize through a hole in my navel. Prior to the surgery, I managed my bladder with an in-dwelling catheter and a leg bag. The Mitrofanoff has been fantastic, as it has given me independence and control over at least one aspect of my life.

During the Mitrofanoff operation I also received a Malone antegrade continent enema (MACE) to allow me to manage my bowels more effectively. The MACE was promised as an effective and relatively efficient means to manage a process that had, up to that point, been neither. In fact, the MACE experience has been an extremely frustrating one. At the best of times it has worked adequately, but at the worst of times it has been hellish. My day is dominated by sitting on the toilet, and the procedure itself has at times made me feel so ill I have had to lie down for half an hour. The unpredictability of the process keeps me constantly on edge; consequently, I often feel as though my bowels are holding me captive.

Before sustaining an SCI I always thought that it simply meant you lost leg function. I know now how incredibly complex SCIs are. The location of your injury and whether it is incomplete or complete can drastically change your level of functioning. Having an incomplete SCI is both a good and bad thing. It has been around six and a half years since I sustained my injury, and I am still making considerable, albeit painfully slow, physical improvements, where I have gone from being paralysed from the neck down on a ventilator to being able to step with my left leg. I know this would not be happening if I had sustained a complete injury. At the same time, however, is the uncertainty of whether the progress will continue. One of my doctors recently told me he expects I will walk again aided in some capacity and, while I have great confidence in his expertise, deep down I am no more certain of this than the doctor who told me in 2006 that I would probably never walk again. I know there are probably some people who have complete SCIs who would read this and consider me ungrateful for not appreciating the improvements I have made, but it is hard to always feel positive when I know that any given improvement could be my last.
SOCIAL REALITIES
As an only child of two parents who work full time I have always been independent. My parents and I have always had a close relationship but when I sustained my SCI that relationship changed. I was forced back into a dependence on my parents that I had never had, at least not since infancy. In the past 6 years I have spent most of my time in close contact with my parents and I feel as though this forced closeness has strained our relationship. At my age many people are considering moving out of home, but I know that, physically speaking, that is not something that is possible for me right now. I still feel close to my parents but my physical dependence on them has meant that I do not have the same chance for space when I am in a bad mood.

Sustaining an SCI at 14 years of age has meant that not only did I have to spend a year in hospital recovering from and trying to accept my injury, but I also missed out on a year of school and socializing with my friends. This loss meant that, when I went back to school a year after my injury, I felt as though I was suspended in time. I did not have the space to grow as a person because of my injury and my unwanted ‘celebrity’ status at school. Everyone, even students and teachers I did not know, knew my name and what had happened to me. Although my friends had been very supportive during my hospital stay, once I was back at school I felt a distance between us. I do not know if this distance came from my feeling that everything in my life had changed irrevocably or that my friends were treating me differently given the change in my physical situation; I suspect it was a combination of the two. It was an incredibly lonely time.

While I still keep in contact with some of my friends from high school (and not just through Facebook), I have also made a number of new friends through the clubs and societies on campus. I have noticed that I approach my friendships with these people very differently to those I had with people who knew me before my injury. The most obvious difference is that very few of my friends at university know why I am in a wheelchair. It probably should not matter, but the fact that I do not talk about it makes me feel as though I am holding something back from these people. I think this reservation partly stems from the desire to be known as more than ‘Bridget in a wheelchair’; I would rather be remembered as ‘Bridget the psych major who cares about the environment and just happens to be in a wheelchair’. Despite my conscious choice to distance my university self from my injury, I sometimes feel as though I have created a barrier and this barrier means I do not feel as close to my university friends as I might otherwise.

Since 2008, I have made periodic visits to a children’s hospital in Chicago that specializes in pediatric SCI rehabilitation. During these visits I undergo intensive in-patient rehabilitation for a period of 2 to 3 weeks. The staff and the rehabilitation program are fantastic, but the best thing about the experience has been the chance to interact with other people my own age with SCIs because in Australia I do not have that opportunity.

Meeting and interacting with other young people has helped me to better come to terms with my injury. The people I have met are dealing with similar physical challenges and – in psychosocial terms – are at similar points in their lives. At the same time, the experience has also made me realize how different my SCI is, caused as it was by a brain infection and its treatment. Many of the young people I have met have a complete SCI caused by trauma.
This difference affected how connected I felt to the others, even though when we have talked about our injuries and our lives we all seem to be going through similar problems at school and feel the same insecurities.

I do not think I have ever really ‘come to terms’ with my SCI. Part of the reason is because the effects of my injury have been constantly changing as I have regained function, but part of it comes down to the fact that I spent 14 years living without an SCI. During this time I developed close relationships with many people and my injury changed all of that. Two years after I sustained my injury someone who had received their SCI decades before told me that, one day, I would see my SCI as the best thing that ever happened to me. After six and a half years of living with an SCI, I doubt I will ever feel this way. My SCI changed me physically and psychologically, and has left its mark on all of my relationships. However, it has happened and it is something I cannot change. All I can do is make the best life I can.

The clinician’s perspective

INTRODUCTION
The profound life changes involved in pediatric SCIs are clearly illustrated in the story of Bridget and her parents, Jan and Michael. Like Bridget’s family, most families coping with an SCI report that things are never quite the same after the injury. It is important to note, however, that, overall, young people living with an SCI do not experience poor psychological outcomes (Anderson et al 2009). Young people are highly resilient and adaptive. Children often view themselves as differently abled rather than disabled and, although things may never be ‘normal’ again, for most young people with an SCI, they find a ‘new normal’ that can be rich and satisfying. In fact, after a child’s SCI, it is often the parents or caregivers who experience the most distress (Kelly et al 2011). The job of the pediatric rehabilitation professional, therefore, is to help families cope with the changes brought about by an SCI, adapt to them successfully, and manage expectations for the future. The story of Bridget and her parents highlights a number of key points to be addressed in this process. These will be discussed in three sections: (1) the concerns shared by both Bridget and her parents; (2) the concerns presented by her parents; and (3) Bridget’s individual concerns.

SHARED CONCERNS
Bridget and her parents describe frustration with uncertainty about her prognosis, an issue that is commonly distressing to children and families after an SCI. Making matters more difficult for this particular family is that the etiology of Bridget’s injury was unclear. As a result, medical personnel were not always able to provide straightforward answers and explanations. From experience, families want to know what they can expect in the future, whether this comes in the form of good or bad news. Indeed, Jan ‘would have preferred to have been given too much information, even if at times it was difficult to deal with, than to have been left, as we were, unaware of issues that may (and did) develop later’. Concerns about the lack of information run through each account. For example, Jan and Michael describe being asked what their rehabilitation ‘goals’ for Bridget were without knowing what was possible. An SCI was uncharted terrain for them and they did not always feel they were given a usable map.
For Bridget, she expressed feeling unprepared for the new realities of her life and a lack of clarity on the part of the medical staff providing care. The conflicting needs of patients and medical professionals are visible here. For example, information regarding specific strategies for management of SCI complications may be viewed as immediate concerns by medical staff, but are sometimes seen as secondary to patients and families who want to know more of the ‘big picture’ of what daily life with an SCI will look like. Although the family felt they had generally received excellent care, it is clear that they struggled with uncertainties in what to expect from the future.

The perception of a lack of information on the part of Bridget’s family has important implications for the rehabilitation professional. Of course, there are simply no answers to some questions. Pediatric SCIs are complex and recovery is highly variable. Families and medical professionals may have different perspectives regarding information needs. Knowing that anxious families are likely to have trouble remembering detailed information, medical personnel are rightly hesitant to offer speculation about the future. However, the entire team can work together to foster acceptance of the unknown in each family member and in the family as a whole over time.

A corollary concern also shared by both Bridget and her parents is the difficulty in contending with the complexities of the medical system. An SCI in a child is a multifaceted condition that requires input from numerous specialists of various disciplines. As a result, families unfamiliar with the medical system may feel lost in the shuffle, with the unfortunate effect of constantly shifting the locus of control in a child’s recovery amongst a cast of peripheral characters not well known to the family. Because Bridget needed medical care in several different countries, her experience may fall on the extreme end of this spectrum. However, Bridget’s and Jan’s accounts bring up issues commonly encountered: Jan describes ‘limited continuity in personnel’ and Bridget was told to expect very different outcomes depending on the clinician. This is understandably confusing and frustrating to all family members. Furthermore, many families, especially those of low socio-economic status and/or those who do not speak the predominant language of the hospital, may feel intimidated by medical staff and reticent to ask questions. In short, the patient and the family may perceive barriers between themselves and medical professionals that may interfere with treatment and increase uncertainty and anxiety. In this context, it is most important that the treatment team makes itself available to answer questions and to repeat information as needed.

A further area of difficulty presented by both Bridget and her parents could perhaps best be described as isolation. SCIs are life altering and all family members are likely to experience a period of grieving for the former life that was lost. Although Jan and Michael state that their extended family was extremely supportive, they also recall that ‘well-meaning individuals would attempt to assure’ them with unhelpful comments, including that the injury ‘must have happened for a reason’. Support from other parents who had gone through similar situations would have been helpful. For Bridget, sustaining an SCI in adolescence ‘meant that not only did [she] have to spend a year in hospital recovering from and trying to accept [her] injury, but [she] also missed out on a year of school and socializing’. Furthermore, she notes that, when she returned to school, she ‘felt a distance’ with her peers. These concerns are shared...
Life with a Spinal Cord Injury: from the Parents’, Daughter’s, and Clinician’s Perspective

by other young people after an SCI (Mulcahey 1991). Children’s social worlds move quickly, such that any time away can seem like an eternity. When a return to normative social activities is possible, the presence of noticeable physical limitations can feel highly isolating. Bridget wants to be defined by her peers as Bridget ‘who just happens to be in a wheelchair’, but the barrier of difference in a child’s development often feels insurmountable. Bridget regrets the limited opportunities to interact with people her own age who are living with an SCI. Furthermore, she notes some intragroup isolation; although the young adults she knows with SCI ‘are dealing with similar physical challenges and... are at similar points in their lives’, her SCI is ‘different’. Because the etiology of her SCI is uncommon, she does not feel complete kinship with her peers with spinal cord lesions. Nevertheless, Bridget illustrates the resilience of many young people in her description of successfully seeking out new friendships after her injury and developing a rewarding social circle. Members of the treatment team can facilitate this socialization process by connecting the family with other families who have undergone similar experiences.

Finally, although Bridget’s entrance into university is a success story, both Bridget and her parents struggle with issues surrounding independence and future goals. In typical development, generally, parents expect children and children expect themselves to become more independent as they get older. Unfortunately, SCI subverts that process. The emotion surrounding these issues for both Bridget and her parents is clear in their individual accounts; Jan and Michael state ‘we want her to walk, to be independent’, while Bridget notes that she was ‘forced back into a dependence on her parents that [she] had never had, at least not since infancy’. It is clear that neither Bridget nor her parents had pictured living with what Bridget calls ‘forced closeness’ at this stage of their lives. Moreover, it should be noted that this is in the context of a health aide who helps Bridget approximately 25 hours a week; many families without this resource are likely to experience much more uncomfortable ‘closeness’.

Some families experience a rather opposing challenge, in terms of independence, than that described by Bridget’s family. That is, many parents of children with SCI become uncomfortable with a child’s normative needs for separation and autonomy; it is difficult for parents to let go of children they may have come to view, through years of caregiving and medical treatment, as frail and delicate. Some parents want to protect their children from the realities of life with a disability. Furthermore, in their own lives, parents have not had the benefit of knowing individuals with SCI who lead full and rich lives with positive outcomes (e.g. attaining higher levels of formal education than able-bodied peers; Zebracki et al 2010). As a result, parents may not encourage their children to pursue opportunities (educational, occupational, social) outside of the home, and children may feel guilty about their desire to separate from their parents. Conversely, a child may become enmeshed with their well-meaning but overprotective parents such that they are reluctant to consider opportunities to live a fuller life. They may come to internalize their parents’ views of their disability or subconsciously fear hurting their parents by beginning to separate during late adolescence and adulthood. As part of the rehabilitation process, the team can work with the family to help set reasonable goals and expectations, provide encouragement, access educational and occupational resources, and assist families with tracking progress.
Parents’ Concerns
Although Jan and Michael note that their family was blessed with ‘tremendous’ financial support from family and friends, it is hard to overemphasize the financial burden of pediatric SCI. This burden usually is a primary focus of the parents when more pressing concerns (e.g. the child’s immediate health and treatment) should be the focus of attention. Often, one or both parents must take time off work in order to care for the child, further compounding the family’s monetary worries. In addition to acute care costs, children with SCI require a lifetime of specialized medical care to prevent secondary complications and address self-care needs. As full-time SCI caregiving by family members can result in decrements in family members’ mental and physical health (Nogueira et al. 2012), hiring a health aide may be necessary. Jan and Michael state that even a part-time health aide has made ‘an enormous difference’ in their lives, allowing both parents to maintain full-time work.

Jan and Michael also report substantial marital strain in the aftermath of Bridget’s injury. Very perceptively, they note their different coping styles, stating that Michael tended to ‘focus on the immediate medical condition’ while Jan needed to ‘deal with her grief more privately’. In addition to shock and grief following a child’s SCI, parents may report a great deal of guilt surrounding a child’s injury. Although a parent can cognitively understand that a child’s injury was either unavoidable or an unintended accident, parents often experience significant trauma when their child sustains an SCI. The tendency for parents to become completely absorbed in the child’s recovery, to the exclusion of maintaining the committed partnership, may also contribute to distance between the partners. These factors, when combined with differing coping styles and financial strain, can create a tenuous relationship.

On the other hand, a committed partnership or marriage can be an extraordinary support system for dealing with the distress of a child’s SCI. The team should make every effort to help parents make decisions together about a child’s treatment and needs, and work on communication skills between the couple. There is a tendency after a child’s injury for one parent to become the primary caregiver. Although this may be unavoidable, the ‘non-primary’ parent should still take an active role in decision making. All decisions and care being the designated provenance of one individual is a pattern that should not become engrained. Additionally, frustrations caused by differing coping styles can be addressed with the goal of helping each partner understand that grief and trauma responses can take many different forms.

Jan and Michael’s account of their marital progress since Bridget’s injury speaks of their strengthened relationship. This is an ideal outcome. The couple speaks with mutual sympathy, perceptiveness, and understanding. It is important to note that many parents of children with SCI are no longer involved in a romantic partnership with each other. In these cases, fostering mutual understanding and a team approach to managing the child’s care can be difficult. Both parents should be advised that effective teamwork is vital to the child’s physical and mental health. If necessary, family counseling should be recommended to achieve this goal. Finally, in working with single-parent or non-traditional families, it is desirable to bring in other family members for support. Raising a child with an SCI is a team effort.
In addition to grief, shock, and loss, children may be traumatized by the circumstances of the injury. Furthermore, some children are injured in circumstances that result in serious injury and/or loss of life to loved ones, immeasurably compounding challenges to recovery and adjustment. Bridget, fortunately, was not one of these children, but notes a number of adverse emotional consequences of her injury. Bridget is sensitive to the interruption of her emotional development, stating ‘I did not have the space to grow as a person because of my injury’. She astutely observes an extremely important point in pediatric SCI recovery: adjustment changes as the child changes. Children are not static physically or emotionally and the child’s world is constantly changing. Although Bridget does not specifically mention this factor, as a child enters adolescence, dating, sexuality, and fertility are often confusing in the best of circumstances. For a child with SCI, this can be compounded immeasurably.

Acceptance of different abilities is extremely important to a child’s adjustment. Bridget is clearly a young woman with a wide range of problem-solving skills at her disposal, but this is not true of all children who sustain an SCI. Research suggests that some coping strategies, specifically cognitive restructuring, are related to positive mental health outcomes in adults with SCI (Kennedy et al 2003). Proficiency in evaluating negative cognitions and accurately reframing challenges are extremely helpful skills for the child with SCI. Simple psychoeducation – for example helping the child to understand that behavioral activation works wonders for a depressed mood – can have wide-ranging benefits. Children with SCI tend to be isolated socially. It is important that they feel able to seek and obtain social support from peers and family members. These skills are likely to benefit the child in adulthood, as research suggests that adults with SCI are at a higher risk of mental health difficulties (Fann et al 2011). As in any other child, seeking professional help when necessary cannot be overstated.

In conclusion, on behalf of myself, the editors, and SCI rehabilitation professionals everywhere, I offer my deepest gratitude to Bridget, Jan, and Michael for sharing their story. In doing so, they have provided a wealth of information to introduce this book. More importantly, they are a wonderful example of the willingness of families who have ‘been there’ to share their stories – even the most troubling parts – to help other families in similar situations. It is important for rehabilitation professionals to remember that people with SCI and their families are truly at the front lines of rehabilitation research. They are our most important resource in learning how to better treat SCI. Their strength, courage, and resilience inspire me every day, and I am continuously grateful to work with these extraordinary children and families.

REFERENCES


