Families after SCI - a Child’s View

How will my children react to my spinal cord injury and my using a wheelchair? This is a real concern of any parent after their injury. In talking with several young people whose parent has a spinal cord injury, their outlook was very positive.

Adam Sartain - now 19, 3 when his dad, Scott was injured (C-5/6 tetraplegia).
Beth Sartain, now 18, 2 at time injury.
Emily Sartain, now 16, born 1 month after injury.
Heather Thomas, now 15, 9 at time of dad’s, Kirk, accident (T-12).
Lauren Thomas, now 13, 7 at the time of injury.
Melanie Leonard, now 18, 4 when dad, Jimmy, (T-12/L1) was injured.
Megan Hallman, age 9, born 2 months after dad, Mike H.,(C-6/7) was injured.
Myka Drummond, age 9, 2 when dad Mike D. (para) had a spinal disease.

For those children who were old enough to remember when their parent was injured it was a time of change and feeling frightened . . . But those feelings did not last long.

“My mom was 8 months pregnant at the time of dad’s accident. I remember having to go from house to house, place to place for about 3 months after dad was hurt. Then he came home with a halo and it blew my mind. I knew I had a new sister and a dad in a wheelchair. It was a big change for a 3 year old.” A.S.

“Everyone was crying at first. I was just scared. I remember going to the hospital and asking mom if dad could still spank us when we were bad! Mom tells me I asked her if it meant we could now park close to the store!” L.T.

“When it first happened I thought life would never be the same, but it is. A couple years after the accident nobody even thought about it anymore.” H.T.

“I remember crying but I don't think I really understood at the time. It was confusing because I was kept by a variety of relatives and did not get to see dad at first. I just wanted my dad to be all right and come home.” M.L.

TIP: If possible, keep the child’s routine as normal as possible. Explain what is happening in simple terms. Reassure them and let them know that you (the adult) also are sad or scared, but that things will be OK.

There are many changes that the family goes through, yet for all of the young people, what was initially different quickly became the routine. For several families it meant some role reversals. Scott Sartain and Jimmy Leonard assumed the roles of “Mr. Mom” as their wives went to work outside the home. Mike Drummond, now divorced, stays home and cares for his daughter after school and during the summer while her mom works.

“It is adventurous. It is not different for us. It is what we know. We go with the flow. He’s just papa!” E.S.

“We all have to do handy work in the house. But really mom does most of the work around here and dad is our supervisor! Our mom goes nonstop from 5am to 11 at night. We don’t appreciate her enough.” B.S.

See Children, page 4
Epidemiology of Antimicrobial Resistance in Spinal Cord Injury
by Ken Waites, MD

There is an increasing concern about the resistance of bacterial infections to the antimicrobial agents (antibiotic drugs) commonly used to treat them. Ken Waites, MD, received a grant from the Paralyzed Veterans of America Spinal Cord Research Foundation to establish a Spinal Cord Injury Infection and Antimicrobial Resistance Database. The research is examining information related to the infectious complications of persons with spinal cord injury. The database contains a wide array of demographic, injury related, clinical, and laboratory information on inpatients and outpatients at UAB over a 3 year period (1994-1997). In studying the information from this database, many critical issues related to the epidemiology of infectious complications post-injury are being examined.

The findings from this research have important implications for individuals with spinal cord injury since they are prone to develop bacterial infections in the urinary tract, subcutaneous tissues (resulting from a pressure sore), and respiratory tract. Treatment of bacterial infections in persons with SCI is complicated. This is due to the neurologic damage associated with this traumatic injury. A spinal cord injury usually impairs bladder function, affects motor activities and sensation, and may limit respiratory function, depending on the level of the injury. In addition, the types of bacteria that cause infections in persons with SCI are likely to develop resistance to many antimicrobial agents (drugs) because of their repeated use and often prolonged exposures.

The specific objectives of the research using this database are to determine:
1- the characteristics of infections in persons with spinal cord injury.
2- the relative impact of hospital-acquired versus community-acquired infections on the risk of developing drug-resistant infections.
3- the frequency of drug-resistant infections in persons with SCI versus other patient populations.
4- the relationship between demographic and injury-related variables including race, gender, level of injury, completeness of injury, type of bladder management, occurrence of secondary medical complications, and costs of medical care with the types and frequency of infections.

Information obtained from the analysis of this database will be useful to guide appropriate management of infections. It will also help to determine preventive methods to reduce their occurrence.

Dr. Waites is a pathologist at the UAB School of Medicine & an investigator with the RTC in SCI.

TV Sport Shows focus on individuals with disabilities

Individuals with SCI and other disabilities are taking to the air waves! Two new television programs are airing sporting events featuring individuals with disabilities.

Wheelin’ Sportsmen Outdoors is a new production that airs weekly on the Liberty Sports FOX Network and the American One Network. Larry Shoup, host of the former Southern Showcase Outdoors show, joins forces with Kirk Thomas and Wheelin’ Sportsmen of America. Together they deliver a new program that spotlights individuals with disabilities and able-bodied persons in a variety of outdoor recreational activities. Topics range from hunting, fishing, shooting, and human interest stories, to educational programs on a variety of outdoor activities. The goal of each program is to demonstrate that individuals with disabilities can enjoy the outdoors, regardless of their impairment level through partnering with able-bodied persons. Wheelin’ Sportsmen Outdoors combines action packed footage and special individuals to deliver a program that builds character, self-confidence, and disability awareness. To check for this program in your area, contact your local cable company.

PVA In Pursuit airs twice a month on ESPN, reaching more than 70 million households. Their shows cover more than 60 different sports and events, featuring skiing, skydiving, wheelchair basketball, wheelchair tennis, wrestling, quad rugby, and golf. The programs also profile the athletes and their stories. PVA in Pursuit profiles the top stories and competitions in the world of disabled athletes. There will be 24 air dates in 1998. You can check the PVA web site for a listing of upcoming shows and their scheduled air times. [http://www.pvainpursuit.com/html/previews.htm]
Am I more likely to get colds and respiratory infections just because I have a spinal cord injury?

You are not at any higher risk for catching colds but you are at greater risk for developing complications from a cold, like bronchitis or pneumonia. When you breathe you use muscles in your neck, chest, and stomach (abdomen). These muscles have nerves that run to the spinal cord. Your spinal cord injury affects how these muscles work to move air in and out or your lungs. The injury also affects your ability to cough. Coughing and sneezing cause the chest and stomach muscles to increase pressure in your lungs. This helps force any mucus from the lungs and out through the nose and/or mouth. It is nature’s way of keeping the lungs clear.

An injury at the C1-C5 levels causes a loss of muscle use in the neck, chest and upper abdomen. An injury at the thoracic level, T1 - T12, can cause loss of some use of muscles in the chest and upper abdomen. Injuries below the T-12 level do not effect either the respiratory system or the cough reflex.

What can I do to prevent respiratory problems?

1. Do not smoke. Smoking decreases the ability of the lungs to work properly.
2. Drink at least 2 - 3 quarts (8-12 eight oz. glasses) of liquids daily. Fluids keep the respiratory system moist and secretions (mucous) from becoming too thick.
3. Do deep breathing exercises every day. Get in the habit of doing these 3 to 4 times each day. Ask your doctor for some breathing exercises if you do not know how to do them.
4. Stay active and mobile. Movement helps keep the lungs clear. Sitting in your wheelchair is better than laying in bed. If you need to stay in bed, follow a regular turning schedule.
5. Keep the air in your house and workplace moist. Breathing moist air keeps lung secretions from drying out.
6. Coughing helps to keep the lungs clear. Have someone help you if you cannot cough on your own. Be sure your personal care assistant knows how to do assisted coughs and how to place you for proper postural drainage.

How should I take care of myself when I get a cold? Do I need to see a doctor?

At the first signs of a cold, drink plenty of fluids and get your proper rest. Do not stay in bed, but stay up in your chair and keep moving. Continue your deep breathing exercises and coughing. If you take any cold medicines, monitor your bladder function. The medicine can effect how your bladder empties.

Contact your doctor if your cough continues, if you are coughing up any green-yellow mucous, or you have a fever.

What are the other respiratory problems that I need to be aware of?

The main problem that individuals with SCI have is pneumonia. This is an infection in the lung where fluids collect in the lung. This blocks air from getting oxygen to the body. Signs of pneumonia are shortness of breath, a heavy feeling in the chest, excess fluids in the lungs, and a fever. To prevent pneumonia you should be vaccinated. In a recent study done at the UAB-RRTC, it was found that the vaccine that prevents bacterial pneumonia works well in persons with SCI. [See Pushin’ On, Vol 16(1), January, 1998]. All persons with SCI should receive the vaccine soon after their injury. Check with your doctor to be sure you have been vaccinated since your injury.

Another respiratory problem is the flu. You should get a flu shot each Fall to protect yourself from the flu “bug”. Check with your doctor first before getting the flu shot, especially if you have any allergies.

NOTE:
Remember that pulmonary complications have replaced renal failure as the most common cause of illness and death in individuals with SCI. Take care of yourself to prevent colds, flu, and pneumonia!

Peg Hale is Clinic Nurse at the UAB Spain Rehabilitation SCI Outpatient Clinic.
Children, continued from page 1

**Megan and Mike Hallman**

“People come over and say, “Oh your dad is in a wheelchair, and I say, Oh, I didn’t tell you, cause I forget.” L.T.

“Dad still gets in the yard and throws with us. He just can’t show us how to do some things. At softball practice, as our coach, he would have to try to talk us through something, like how to stand. We wouldn’t understand and he would have to get someone to show us. He gets aggravated at that.” H.T.

“It is something that you live with and get used to.” M.H.

**TIP:** Explain the need for changes in the family routines . . . then treat this as normal for your family.

While the youngsters may dislike some limitations their parents have, they all accept the disability. They continue to see their parents as very capable and very adaptable.

“When we go to Six Flags I want dad to go on all the rides with me, but he can’t. But he has a lot of fun winning hats and prizes. I’m glad I have him because we go on a lot of field trips for school and I want him to go. He makes a way to go and will drive us.” M.H.

“Other parents can do more but dad has more time for me. He goes to my ballgames, takes me swimming, fishing, and hunting and to Braves games. He is also a City Council member. He helps me with homework and school projects.” M.D.

“Here was the time when the lift on the van broke. Dad wanted to get to my ball game. We borrowed a friend’s pick-up truck with a lift on the back. I’m warming up in the outfield and see my dad riding down the street in the back of the truck. Emily and Beth, riding in front, kept ducking down so friends wouldn’t see them. Dad is waving to everyone. He wasn’t embarrassed!” A.S.

“I am learning to drive now. Dad tells me to slow down. At least he can’t act like he is hitting the brakes like mom does. He just turns up the radio and sits and dances!” H.T.

**TIP:** Continue to enjoy doing as much as you can as a family! Stay active and involved in your children’s lives.

The parent’s spinal cord injury does not have to interfere with the youngster’s social life. These young people see their parent in a very positive way!

“Our friends love him. They say ‘Your dad is so cool!’ If we are at a ballpark my friends come up and go straight to my dad, not because he is in a wheelchair, but because of his personality. My boyfriend and dad went fishing and they “bonded”. He was amazed how dad can get in the boat and catch more fish than anybody.” H.T.

“Dad substitute teaches at my school. The kids got used to him real fast. Everybody loves him.” M.H.

“Dad jokes around about using a wheelchair, he’ll say, ‘I’m so old I can’t walk!’ He gets others to laugh. The only difference about our dad is he is sitting down . . .the only thing.” Thomas

**TIP:** Keep a positive attitude. Your child sees you, not your chair.

Learning to make adjustments and adapt becomes a part of everyday life. These young people have developed responsibility and awareness.

“When we go on trips it takes planning and is a lot more work. But where there is a will there is a way. Sometimes it can be a hassle but we’ve been to a lot of places, like Six Flags and Gatlinburg. Sometimes dad has to sit and watch us, but we’ve even gotten dad out on the beach!” Sartains

“Getting dad a seat for ceremonies at school takes planning. For my high school graduation I had to ask the teacher if I could save seats in front.” B.S

“Dad can do a lot of things, like drive. On a field trip to Atlanta my friend’s mom was going to ride in my dad’s van. She was nervous to get in the van because she didn’t know how he drove. But once we got on the road she was OK.” M.H.
“I find myself helping other persons who might need help when in public places. Since dad’s accident I will go up to people who are in a wheelchair and say “Hi”. Before I used to stare or look away.” Thomas’

“Through dad’s organizing Wheelin’ Sportsmen, I have met some neat people with all types of disabilities and we have become good friends. I’ve met people who have been in the Paralympics, it’s cool.” H.T.

“I used to get mad when people would stare. But I’ve learned that they are curious. I’ve gotten very good at explaining and putting people at ease.” E.S.

“I wrote a story in English class about dad. My teacher has a nephew in a chair, now she has gotten him involved in Wheelin’ Sportsmen.” H.T.

A major “Pet Peeve” for all the youngsters is people misusing the handicap parking places!

**TIP:** Turn your problems with accessibility and accepting your SCI into learning experiences for your children and their friends. Awareness helps break down barriers.

There can be a fine balance between the child being a caretaker and a helper. All of these families gave their children suitable responsibilities that kept the roles of parent and child separate.

“I will do things to save him trouble. If dad is in bed and asks me to carry something to the kitchen for him, I do it. It’s easier for me. But if he is getting up anyway, he does it!” L.T.

**Lauren and Kirk Thomas**

“I help my dad out in the yard; feed the birds, feed the cat, empty the garbage, and sometimes I help with the laundry. When we are shopping, I have to move things out of dad’s way in the stores.” M.D.

“When we were little, dad had an electric chair and we would want to drive it. We would clean it for him and argue over whose turn it was to go for a spin around the kitchen.” Sartains

“Dad doesn’t let the chair slow him down. He likes to do things for himself but he’s not afraid to ask for help.” M.L.

**TIP:** Give the children typical responsibilities i.e., helping with household chores. Ask for their assistance when you need it, but do not make your care their main responsibility.

From their years of experience, here is some excellent advice to the children of parents with an SCI . . . and to those parents who have an SCI. The Leonard Family - Jimmy & Deb; Jamie, Ronnie Gipson & Melanie

To children whose parent has a spinal cord injury . . . .

• “Love your parents, help them around the house. Put up your clothes and toys.” M.D.
• “Your lives are going to change. It is hard to accept but the sooner everyone does, the easier it will get. The wheelchair is just an addition to their lives. Your mom and dad are still your mom and dad.” M.L.
• “Things do get back to normal.” L.T.
• “Keep an open mind. Don’t let the chair get in the way of your relationship with your parent. Communicating is very important - talk.” M.L.
• “It is not the end of the world. Your parent is the same person, it is just that he/she uses a wheelchair.” B.S.
• “Don’t treat them any different. Dad won’t let us do anything for him that he can do for himself. We know if he can do it, we don’t.” Sartains
• “Trust in God because he will take care of you.” M.L.

**Reminders for Parents:**

• “It’s OK, you can still take care of your kids, do as much as you can for them, teach them how to do what you can’t do for them.” M.D.
• “Talk to their children. The kids need to know what is going on.” M. L.
• “Make sure the children get what they need. Just listen to them. Have fun with them.” M.D.
• “If you worry about yourself, the children will probably worry. If you get over it, the children will get over it.”L.T.
• “You are still their parent, and they are still your kids. You are still here.” H.T.
• “Parents should talk about it with their kids. Let them know what has happened and why they are in a chair. It helps if the parent explains. There will be frustrating times. Be open.” Sartains

What is clear from these interviews is that each child first saw a loving parent, not a person with a spinal cord injury. The wheelchair did not interfere with building a strong relationship between the parent and the child. There was a mutual love and respect between these parents and their children.
This column provides readers with updates on current research conducted by the RRTC in Secondary Complications in SCI at UAB and the UAB Model Regional Spinal Cord Injury Care System. For additional information regarding this study, contact Tim Elliott PhD, UAB-Dept of P.M.& R., Birmingham, AL 35233, 205-934-3454 or email: elliott@sun.rehabm.uab.edu

By: Timothy Elliott PhD, Richard Shewchuck PhD, J Scott Richards PhD, Andrew Palmatier BS, and Kim Margolis BS

Background:

Individuals who see themselves as effective problem solvers experience less distress, depression, and anxiety under general and stressful conditions. Research has shown that problem solving abilities predict adjustment to long-term health problems. Using the problem solving approach has been a way that individuals cope with a variety of chronic health problems, like spinal cord injury (SCI).

Recent changes in health care now place a greater burden and responsibility on the caregivers. The caregiver has become an informal part of the health care delivery system. The caregiver now provides both the physical care as well as the emotional care and support. Caregivers of persons with severe and disabling conditions often experience high levels of distress and maladjustment. This may in turn impact the patient’s health and quality of life.

Rehabilitation lengths of stay are increasingly shorter. This allows less time for the coping/adjustment process to take place for both the patient and the family. Patients may only be beginning to understand what has happened to them at the time of discharge.

Individuals with spinal cord injury are living longer and surviving with higher level of injuries. 60% of these individuals are on Medicaid or Medicare 10 years after their injury. With the given health care trends, the responsibility for the care of the individual with SCI is, and will continue to be, placed on unpaid caregivers, mainly family and friends.

Objectives:

Our goal is to develop meaningful interventions and programs for caregivers. To do this we studied characteristics associated with caregiver distress. This information could help us develop ways to assist caregivers.

Prior research predicted that effective problem solving would be related to caregiver distress. This study examines the relation between problem solving and the adjustment of caregivers of persons with recent spinal cord injuries.

The ability to problem solve has been found to lessen the effects of stress on individuals. Caregiver adjustment is often measured in terms of anxiety, depressive behavior and health complaints. We predicted that caregivers with poor problem solving skills would experience greater depression, anxiety, and have more health complaints, regardless of the level of injury/severity.

The plans were to evaluate the effect poor problem solving skills had on depression, anxiety & health complaints among caregivers of persons with SCI.

Methodology:

Participants in the study were caregivers of individuals with recent SCI who were receiving inpatient rehabilitation services. Each completed a series of questionnaires on their own and returned them to the interviewer.

The following instruments were used. The Social Problem Solving Inventory Revised (SPSI-R)- This questionnaire uses the following scales: Positive Problem Orientation (optimism, competency, can control emotions), Negative Problem Orientation (pessimistic feelings, less confident, incompetent, can’t control moods), Rational Problem Solving, Impulsivity/Carelessness Style, and Avoidance Style. The higher scores on each scale showed a greater tendency for that trait.

Center for Epidemiological Studies - Depression Scale (CES-D;Radloff, 1977) Used to assess depression. Higher scores showed greater depressive behavior.

Pennebaker Inventory of Limbic Languidness (PILL,Pennebaker1982) Used to measure health complaints. Higher scores reflect more health complaints.

State-Trait Anxiety Inventory (STAI) Used to assess caregiver anxiety. Higher scores showed greater anxiety. Advanced methods of examining correlations were used to analyze the data.

Caregiver Participants

<table>
<thead>
<tr>
<th>Category</th>
<th>Women</th>
<th>Men</th>
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<tbody>
<tr>
<td>Women</td>
<td>46</td>
<td>8</td>
</tr>
<tr>
<td>Men</td>
<td>37</td>
<td>17</td>
</tr>
<tr>
<td>Patient’s Mother</td>
<td>18</td>
<td></td>
</tr>
<tr>
<td>Patient’s Wife</td>
<td>16</td>
<td></td>
</tr>
<tr>
<td>Average age of caregiver</td>
<td>41.16 years range 18 - 74 years</td>
<td></td>
</tr>
<tr>
<td>Patient level of injury</td>
<td>paraplegic 19 tetraplegic 31 other SCI 3</td>
<td></td>
</tr>
<tr>
<td>Age of patient</td>
<td>average= 35.15 years range = 15 - 72 years</td>
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Problem Orientation (optimism, competency, can control emotions), Negative Problem Orientation (pessimistic feelings, less confident, incompetent, can’t control moods), Rational Problem Solving, Impulsivity/Carelessness Style, and Avoidance Style. The higher scores on each scale showed a greater tendency for that trait.
Results
On the average, persons with a greater negative problem orientation also showed greater depression, more anxiety, and had more caregiver distress.

The health complaints of the caregivers were related to the injury characteristics of individuals with SCI. Caregivers of individuals with complete levels of injury, recent injuries, and tetraplegia (quadriplegia) had more health complaints.

Summary:
Results of this study showed that caregivers with a negative problem orientation are likely to experience distress and ill health. This may result in more health-related problems for both the caregiver and the patient. This could damage the health of the individual with SCI and place greater cost on the family, the health care delivery system, and society in general.

Interventions for the caregiver based on the problem solving model are indicated. There is a need for more research to evaluate the effectiveness of problem solving training for caregivers of persons with disabilities. We are currently studying the effects of problem solving interventions for caregivers over a longer period.

The information about the impact of caregiving for persons with spinal cord injury is limited. Very little is also known about the emotional burden for the caregivers of the person with SCI.


**SCI Research Update Conference - 1998**

for **Individuals with SCI, Families & Providers**

**When:** Friday, September 25, 1998
11:30 am - 4:30 pm

**Where:** UAB - Great Hall
at Hill University Center
1400 University Blvd, Birmingham, AL.
Limited free accessible parking available.

**Who:** Individuals with spinal cord injury, family members, personal care assistants, service providers. No child care available. Please do not bring children under 16 years of age.

**What:** A program that looks at ways to continue a healthy & productive lifestyle after SCI. Time will be allowed for questions after each speaker.

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### Agenda

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<th>Time</th>
<th>Session</th>
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<tr>
<td>11:30–12:30pm</td>
<td>Registration &amp; Exhibits</td>
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<tr>
<td>12:30–12:35pm</td>
<td>Welcome - Barbara Key &amp; Dr. Amie Jackson</td>
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<tr>
<td>12:35–1:10pm</td>
<td>Shoulder and Joint Pain-“Oh My Achin’ Bones”- Dr. Amie Jackson</td>
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<td>1:10–1:50pm</td>
<td>Posture Changes After SCI-“Getting Straight”- Dr. Amie Jackson &amp; Gayle Benson, PT</td>
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<td>1:50–2:30pm</td>
<td>Stress Management -“Chill Out For Your Health”- Tim Elliott, PhD</td>
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<td>2:30–3:00pm</td>
<td>Break &amp; Exhibits</td>
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<tr>
<td>3:00–3:40pm</td>
<td>Preventive Nutrition-&quot;Preventing Weight Gain&quot; - Beth Bussey, RS, MS - UAB EatRight Program</td>
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<td>3:40–4:20pm</td>
<td>Research-&quot;What is on the “Cure” Horizon?&quot;- Jean Peduzzi-Nelson, PhD</td>
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<tr>
<td>4:20–4:30pm</td>
<td>Summary &amp; Evaluation - Barbara Key</td>
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**Exhibits:** Health and Wellness Exhibits will provide information on prevention of heart disease; nutrition; and personal safety. Get your **blood pressure and cholesterol checked**! Take a **Computer Wellness Questionaire**! Exhibits are open during registration and the afternoon break.

**CEUs:** Approved for 4.0 CRC/CCM contact hours for Rehabilitation Service Providers.

**Sponsors:** UAB Research & Training Center in Secondary Complications in SCI; UAB Model SCI Care System; UAB Dept of Physical Medicine & Rehabilitation and UAB Spain Rehabilitation Center.

**Register:** Pre-registration is required. **Complete and send in the registration form on page 7.** The **deadline** for registering **September 8, 1998.** A letter confirming your registration will give parking instructions. For additional information, please contact the UAB-RRTC Training Office at 205-934-3283.