

Miniwakan E-Newsletter

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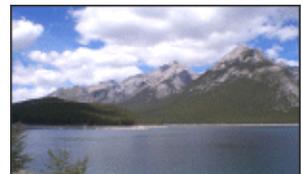
January 1-31, 2005

EDITOR'S NOTE

THE MISSING PIECE

AnnMaria De Mars, Ph.D., SLC Vice-president, Technical Services

It is my fault that this newsletter is delayed. As I read through the articles, it felt as if we had missed some essential point.



The other articles have an upbeat, positive tone, but no matter how much I thought about it, to me there was something missing.

A week ago, I was driving down the same stretch of freeway I used to drive every night - 130 miles each way, from Minot down to St. Alexius in Bismarck where thirteen years ago my husband, Ron, was in intensive care for months. He died four years later.

The drive still gave me nightmares – and it was eight o'clock in the morning.

A few months ago, I met a mother whose son had a traumatic brain injury due to a car accident. He had been in the hospital for months and she had a look I totally recognized—one that is hard to describe to a person who hasn't seen it—as if she just could not understand what was happening, or why.

It reminded me of a poem, by Ina Hughes:

We pray for children...

Who sneak Popsicles before supper,
Who erase holes in math workbooks,
Who can never find their shoes...

And we pray for those...

Who watch their parents watch them die...

I think that is the missing piece. There are those months of waiting and watching, when you don't know if someone will live or die. I knew the look that mother had, it was the sick, screaming inside look you have when you love someone and they are in pain until they get drugs, and then they aren't really there, until the drugs wear off and they are in pain and it starts all over again.

Maria Burns, an SLC writer who contributed to this edition, and I were talking about this issue. She said the reality is that when someone dies or is disabled, a person is faced with the choice of trying to find some kind of meaning in the event or to be depressed for the rest of one's life. Clearly, she says, one choice is healthier and more sensible than the other.

Lance Armstrong, the cyclist that overcame cancer and went on to win the Tour de France bicycle race six times, said in his book, "People die. That truth is so disheartening that at times I can't bear to articulate it. Why should we go on? Why don't we all just stop and lie down where we are? But there is another truth, too. People live. It's an equal and opposing truth. People live, and in the most remarkable ways. **When I was sick. I saw more beauty and triumph and truth in a single day than I ever did in a bike race.**"

Maria is right, of course, and so is Lance. All of the articles on inspiring people we read in researching this edition, as well as our own amazing Willie Davis are people who have stories that need to be heard.

But for myself, and for that mother whose son was in the car accident, and for all of the other family members just like us, I needed to add this missing piece. Sometimes a person gets sick and cannot do the things they used to do, and they don't get over it and they never overcome it or learn to adjust to it. They die.

My youngest child was eight years old when her father died. The next year, her friend lost her father. My daughter wrote her a letter in which she said, "The grown-ups say it will be okay after a while. They lie. It will never be okay. It will be better, even if it seems hard to believe right now, it will be better. But it will never be okay."

I have been in this field too long, and looked into the faces of too many mothers after they have watched their children die not to know the other side of the story. Yes, I suppose I am a stronger person because of my husband's death, but I don't know that I am a better person. I am not sure that my children are better people.

In this same way, an acquired disability may be not one drama of adjustment to a disability, but a continuing series as a family member becomes more and more disabled, until, in the end, he or she dies, in many cases slowly and painfully.

Years ago, when I asked a mother why she had not placed her severely disabled adult daughter in an institution, she answered simply, "Ella es un parte de mi corazon." (She is a part of my heart.) When this young lady dies, I doubt her mother will do anything outrageous, or even noticeable. She will get better, day-by-day. However, for the rest of her life, she will always be missing 'a part of her heart'.

We need to remember this missing piece, because those clients and their families, too, are people who need, and fully deserve, the best services we can give them.

FEATURES

AND THEN MY WHOLE LIFE CHANGEDACQUIRING A DISABILITY IN ADULTHOOD

Jessica Holmes, SLC Research Associate

When one least expects it, a life can be changed in an instant. Within moments, an accident has the shocking ability to physically harm a person to the point of disability. Accidents such as a car crash, or a fall from a horse, can cause one to be robbed of a body part or function. This is an incident that can change the person's life forever.

It is important to know, although easier said than done, that this unfortunate accident is not the fault of the victim. We as humans do not have total control and power over what happens to us in our lives. After all, this is not a perfect world. Everything happens for a reason and even if you had not gotten in that car, or saddled that one horse, this accident actually has the capability to show a person how to get through this world in a different, yet positive light.

Believe it or not, this new, disturbing disability can actually lead to a affirmative awareness of one's self. The person may need to find different skills that adapt to his new capabilities in a job situation. A person might have to switch from a job that includes physical labor to a job that has to do with research and typing. This switch can be

upsetting because it is a change of lifestyle, yet enlightening because it demonstrates to the person that he has had these capabilities all along. It is important that the person does not let it spoil his/her spirit, as there is always a job that needs to be done and a disability only means impairment, not a complete loss of self. This disability can actually open one's world to a new skill that might not have been discovered before an accident.

Every employee has a certain flaw, such as an inability to type fast or be punctual. As long as the person presents his/herself to a company with admirable, strong assets, the employers can work around disabilities. It is important to research options for alternate jobs and disability accommodations that an employer can provide. It not only makes the disabled seem motivated, but able to do the job just as anyone else can.

There are in fact negative aspects to this sudden and drastic change in one's lifestyle due to a disability. The person can be hit with a number of emotions; shock and denial that this could actually happen, anger that he/she was the "chosen" person for this disability, then the anger will eventually lead to a realization that this disability will not go away, no matter how much anger is put into it. By exploring other assets such as new job skills and a stronger utilization of other senses, the realization will lead to a newfound appreciation and respect for the person's body, no matter how disabled.

Hopefully.

It takes a while to get to that life appreciation when someone's life has been so badly shaken up. After all, a disability is most times permanent and can change a life in many ways. Financially, she may not be able to make as much money due to this job adjustment. Socially, a person's friends and family often times do not know how to act towards a newly disabled person. They want to make sure not to extend pity and try to overlook the disability. Yet this ignorance can cause a suppression of emotions for both the victim and the loved ones, which can eventually cause resentment and depression. Independently, one may experience disturbing flashbacks of the event, feel less capable and more dependent, and have to rethink plans for the future. This rethinking can be positive for soul-searching, yet might be discouraging because one feels less competent than before the accident.

At the same time, the victim is also enduring physical pain, and all the inconveniences that go along with being disabled. Modern society expects only what is perfect; which can be observed by flipping through the latest fashion magazines. One must be thin, fit, and beautiful, which can be achieved thanks to plastic surgery and a couple of diet pills. However, a disability cannot be fixed with a simple Slimfast shake. This knowledge can lead to depression in a disabled person and feeling less socially accepted. The real world does not accept as much as it should, thus the victim can be left with feelings of despair and a lack of normalcy, when in fact a disability means different, not strange.

A disability can be frustrating to get used to, yet one needs to trust that everything will turn out fine in the end. It is important to focus on the productivity that can stem from a victim, despite her disability. Through research of alternate job skills, medical assistance, and environmental accommodations, a person can discover that life does not have to worsen because of a disability. Different does not necessarily have to mean inferior.

If one feels like life will never get better, psychological help can be sought. This does not mean that the person is "crazy"; he/she just needs assistance in coping with the alarming transition. By speaking with a psychologist, one can receive support and work through his/her thoughts verbally, creating a path for acceptance. This release can help eliminate other destructive behaviors that may arise from this depression, such as substance abuse.

If one does not have access to a psychologist, speaking to a person that he/she trusts can also serve the same purpose. Anyone who has an ear to lend can provide a great deal of therapy and emotional improvement for the disabled, as well as encourage feelings of acceptance. It may be difficult to cope, but is not impossible, with the help of loved ones and the community.

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ARE YOU THE CHILD'S MOTHER? I AM AFRAID I HAVE SOME BAD NEWS...

Maria Burns, SLC Staff Writer

It may be one of the hardest things for parents to hear. That as a result of a sudden trauma, accident, infection or number of other causes, their normal, well-adjusted child is suddenly physically handicapped and will never walk again, or has suffered from a brain injury and will have limited cognitive abilities for the rest of his or her life.



However, knowing how to help parents deal with the issues as well as other places they can turn for advice can make a very difficult process a little bit easier.

At first, parents will likely experience a variety of feelings ranging from shock and disbelief to anger, blame and guilt. It is not unusual for a parent to put the blame on him or her self, feeling that possibly something could have been done to avoid the situation. Feeling despair and extreme sadness is normal, as are feelings of helplessness and/or frustration at being unable to fix the situation.

These emotions are extremely common and may linger for months or even years. To some extent these feelings are completely normal, especially early on. However, if a parent is still experiencing these feelings intensely after several months or years and it is affecting her family's life, it might help her to speak with a professional.

People should remember that when a child is suddenly disabled, it is important not to forget to care for their own needs and those of their other children as well.

There are several stages that take place when sudden disability occurs. First, there is likely to be a long hospital stay--either to treat the accident or the illness that brought the disability on.

From the very beginning, parents should get information on their child's condition and on the potential conditions that could result. For example, if a child has been in a car accident and appears to be paraplegic, parents should obtain regular updates on the child's condition and learn about the likelihood of the child walking again. It is important that a professional be on hand and available to speak with them at length about their child's injury or illness, if parents so desire.

Often parents will be very worried in the first hours or even days after a child has been admitted into a hospital. It is important to recognize that although parents may have received information, they may not have absorbed any of it. With this in mind, medical staff or other professionals should ask parents if they understand their child's condition and answer any questions they might have. Providing parents with written material, such as pamphlets or booklets to help give them an overview, can be helpful.



If a child will be staying for an extended length of time at a hospital, recommend that parents bring favorite toys, blankets or posters from home. This can make children feel more comfortable. Having friends, family and other people visit will also likely brighten up a child's day. Developing a routine or schedule involving work, the hospital, home, etc., can help parents and children regain a semblance of order during this chaotic period.

Make sure that parents are involved in every decision and encourage them to ask questions. Make sure that parents know that every person recovers in his own way and time. While there are some averages, just because their child may be progressing slower than the norm, that is nothing to be concerned about, especially early in recovery.

It is also important that parents know what kind of care their child will need after leaving the hospital and where they can turn for that care as well as for further information and questions in the future.

Once children are brought home, it is important to remember that life goes on and to try to get into some sense of

normalcy, although it would be naïve to assume that things will go back to the exact definition of “normal” parents had before the disability. Assessing what changes need to be made and putting them in place is necessary. If there are physical therapy appointments, medications, doctors' appointments, etc., make a schedule and try to establish a routine.

Creating a support system is vital. Parents may find themselves consumed with helping their child, which is completely normal, but is also important that parents find time for themselves or spend time with friends to avoid feeling exhausted or “burnt out”. Parents can't forget to look out for their own health and mental well-being too.

If children are school-aged, eventually, they will need to return to school. This does not need to be a major concern right away, but parents may want to know that schools and school districts are willing to make changes needed to accommodate a disabled child. In some cases, such as when a traumatic brain injury leaves a child with serious cognitive damage, more changes will need to be made. But school districts are required to help parents.

Some helpful places to get information are:

The **National Spinal Cord Injury Resource Center** (<http://www.spinalcord.org>) provides information and referral on many subjects related to spinal cord injury and can be contacted through the Web site or by calling (800) 962-9629.

The **National Dissemination Center for Children with Disabilities** can be a good place to look as they have information on a number of disabilities, like this piece on traumatic brain injury (<http://www.nichcy.org/pubs/factshe/fs18txt.htm>).

EVERYTHING HAPPENS FOR A REASON: A PERSONAL VIEW ON ACQUIRED DISABILITY

Willie Davis, SLC Consultant, Turtle Mountain Site Coordinator

"Everything happens for a reason", is what I will always believe. After the car accident that changed my life, I went from being an 18-year-old young man with a college scholarship and baseball prospects to starting my life over. It was as if I had to go back to childhood and learn how to do everything again, from the everyday like getting dressed in the morning to major decisions such as figuring out all over again what now to do with my life.

Somehow, just as so many disabled individuals do, I turned my life into something positive. My accident and the life changes that resulted have made me a better person and took my life in a totally different direction than I ever imagined. Through these experiences, I have made some observations and have some opinions I would like to share to help other disabled persons make positive changes in their lives as well.

Career and vocational rehabilitation counselors need to look at creating jobs and accommodating disabled individuals with jobs that match their needs and skills. If communities worked together to incorporate policies--in fact, if they just used some common moral thinking like creating job banks and other community resources--then agencies such as vocational rehabilitation and their clients would not have to beg for employment opportunities. Positions could be setup that would allow these individuals (maybe in pairs or threes) to split the work into part-time hours to make up the equivalent of one full-time employee. I believe this would lead to better work productivity and stronger business ties to the community.

Additionally, for disabled individuals having a sense of community is very important, not just in the workplace, but



in every aspect of life. I have always felt that support groups provide the greatest tool in resolving or discussing problems about your disability and daily concerns. Getting others involved is another important part of the process, but many times family members or friends do not understand, or in some cases even want to be a part of, your rehabilitation process.

People with disabilities experience many issues in their lives and some people, no matter what they may be experiencing--able-bodied or disabled--just do not want to talk about it. This is important to recognize so that you can help include those who want to be involved or talk. It is also important to realize not everybody will want to be involved and it is necessary that you respect their wishes.

Willie Davis, Disability Consultant

End of E-Newsletter

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