

To Everything There is a Season...

A Guide for Caregivers of Farmers and Ranchers with Disabilities



Hearts Grown Cold
May Be Warmed by the Summer Sun
Dreams You Hold
May Be Closer Than You Know
Seasons Change...

~ *Ray Boltz*

Caregiving: Celebrating the Difference We Make*

By Sally P. Karioth, Ph.D., R.N.

I've learned that caring is the hardest and easiest thing I've ever done.

I've learned to take caring seriously but myself lightly.

I've learned that MY daily actions are extraordinary, because I do ordinary things so magnificently.

I've learned that a person doesn't get ataxia (a disability), a family does.

I've learned that whatever you need in a hurry will be in another room in the house.

I've learned that if I'm there before it is all over, I'm still on time.

I've learned that the spirit of the law may be more important than the letter of the law.

I've learned that everyday I can make a difference in someone's life, and I choose to make it a positive difference.

I've learned that the more unloving a person acts, the more they need to be loved.

I've learned that no one says on their death bed, "I wish I'd spent more time at the office."

I've learned that a man will only ask directions if he's seen the same corner four times.

I've learned that if I don't take care of myself, I can't take care of anyone else.

I've learned that time flies whether you're having fun or not.

I've learned that if I don't celebrate the exquisiteness of each day that I've lost something I'll never get back.

Purpose

Purdue University's Breaking New Ground Resource Center in cooperation with the Minnesota AgrAbility Project* has developed this publication, *To Everything There is a Season*, to encourage individuals and families who are caring for another family member. It contains practical ideas for farm and ranch families who are involved with the joys and struggles of caregiving following a disabling injury or illness. The contents are designed to put into perspective unique opportunities that come with the different seasons of being a caregiver. It will provide hope for the challenges that are part of caregiving and equip you, as the caregiver, with information and resources that will enrich your life and the one receiving care. Since so many caregivers are also the spouse, or a family member, special consideration is given to strategies that will strengthen your relationships as you go through this new season together.

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“There are four kinds of people in this world: those who have been caregivers, those who currently are caregivers, those who will be caregivers, and those who will need caregivers.”

~ Rosalynn Carter, former first lady and author of Helping Yourself Help Others

* The U.S.D.A. AgrAbility Program is a national project designed to assist people with disabilities employed in agriculture. Projects are in place in over 20 states. For more information on AgrAbility call 1-800-825-4264.

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Introduction - A New Season



“You have to climb up the rough side of a mountain to get to the top.”

~ Paul Bradshaw, Jr.,
Jetmore, Kansas

The road we travel, regardless of our plans and dreams, is highly unpredictable and full of surprises. There have been no promises that the seasons of our life would be free of cloudy days, droughts, or storms. The unpredictable and often uncomfortable events of our life reflect one of the most predictable characteristics of life. It should, therefore, come as no surprise that everyday hundreds of farm and ranch* families, like yours, face the beginning of a new day knowing that a family member has experienced an injury or illness that is unlikely to go away. Disease, injury, or maybe the loss of hope has resulted in a permanent disability that will forever change your life. The difference is that today it's your family, it's your husband, wife, son, daughter, or friend who has been disabled. No matter how much you would like things to be different, or to return to their former ways, it might not be possible. With little or no opportunity

for input from you, you have become a caregiver.

“A spouse, parent, child, or friend who gives a helping hand willingly with friendship and love, they are people who care...”

~ Marjory Fritz, Venice, California

Time is not going to stand still, life is going to go on. In some capacity you will respond to this new role as a primary caregiver for someone who has gone through a significant change but remains very important to you. This will probably mean giving up some of yourself and your time to assume new responsibilities. It may mean putting your personal dreams on the back burner, while undertaking additional tasks such as unfamiliar farm chores, machinery repairs, marketing crops, paying bills, preparing meals, and transporting children.

* The term farm or ranch is used to define all types of agricultural operations including: farms, ranches, orchards, vineyards and vegetable operations.

You may be asking yourself, “Will I be able to muster the determination and courage to weather this storm and the ones to come? Will I have the patience to make the very best of the existing circumstances that I cannot control? Will I have the humility to seek a helping hand when it becomes necessary? and, Will I have the faith to believe that maybe the best is yet to come?”

“Nothing splendid has ever been achieved except by those who dared believe something inside them was superior to circumstance.”

~ Donna Direst, Wisconsin

You are not alone. More than 49 million Americans have some type of disability. Many require some type of assistance or care from a family member, friend, or professional. As a caregiver you would probably identify with many of the basic aspects of caregiving. These include:

- Giving more assistance in time, energy, and costs, than family members usually provide
- Caring for an individual who has some physical or mental impairment that will last a long time
- Helping with many basic daily activities, such as going to work, getting out of the house, completing personal hygiene and care, attending church or social activities
- Having your family member depend upon your care for their well-being (1)*

As a family that has been involved in agriculture, your work has probably been more than just an occupation, it has been

a way of life. The farm or ranch, the land, and even the family home are all an important part of your life, your heritage, and even your identity. As you consider whether life will ever be “normal” again, this publication will provide ideas, resources, and suggestions that will assist you, the caregiver. Hope is offered by others who have weathered the same storms and overcome barriers with the support of family, friends, neighbors, community agencies, and their faith. Each year, thousands of farm and ranch families encounter the impact of disability on a family member and continue to work and live productive lives. This resource contains real life stories and practical suggestions to help you face and actually begin to enjoy your days as a caregiver.

As your family begins this journey toward a new season of life, we urge you to consider the advice of Sir Winston Churchill to the citizens of Great Britain during one of their darkest periods. In one of his most famous, and shortest speeches he encourages them to: “Never Give Up, Never, Never, Never Give Up.”

“Suppose you arrive at your door with your arms full of packages. It is an inconvenience that you do not have a third hand to open the door, but you wouldn’t consider yourself handicapped or feel sorry for yourself because you lack three hands. You must learn to consider your blindness (or disability) in the same way, an inconvenience at times but no cause for self-pity.”

~ Ralph Teetor, Hagerstown Indiana (2)

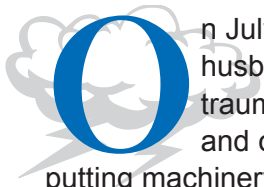
* See footnotes on page 77.

When the Storms Strike - Impact of Disability



“Of course, my first reaction was one of utter shock. For a time I was just traveling on remote control.”

~ Libby Miller,
Decatur, Illinois



On July 18, 1995 my husband was involved in a traumatic accident. He and our son Roger were putting machinery away when a cultivator they were parking collapsed. Bob's head was caught between a tractor tire and the wing of a cultivator. That changed our life completely. As a result of his severe injury, my husband lost sight in both eyes.

Of course, my first reaction was one of utter shock. For a time I was just traveling on remote control. I look back now to my reaction and I think, God had to be with me because I did all the right things. At the time I was just simply doing what I had to do.

This new role was rather a frightening one for me because Bob was a person who did everything. He repaired everything around the house. He did all of our bookkeeping and with income tax coming on, I was very skeptical of how I was going to handle it all.

For a while I was still pretty much in shock and I'm sure that I went through depression. I cried a lot every day. That's one of the things I thought of the other day. I haven't had a big teary session for a while and evidently I'm healing. But it takes a long time, it's been over a year now and I think after the depression, reality sets in and you do the best you can in positive ways because life has to go on.

Later, I stressed to the people in rehab that nobody ever warned me what the reaction of others would be to my disabled mate. I was really overwhelmed and distressed when I found that people were ignoring him. They would speak to me but they would ignore him. I wanted to yell at them, "He's not dumb, his brain is great. Just because he can't see doesn't mean that he is not a whole person."

Probably anyone who is disabled needs to know this. Whenever there is a disability, of any kind, to the body, you're going to get some negative reactions from other people. We have friends that to this day don't feel comfortable talking to Bob. And this hurts so badly.

It took me a little while to think of myself as a caregiver. And I'm sure that I'm giving care but I'm doing it as a partner, wife and friend. I try to act in a positive way instead of a negative way simply because it's my personality. I'm a positive thinking person so I've tried to get Bob into new situations, to constantly keep him in a social atmosphere and not let him just sit at home, which sometimes is the easiest thing to do.

I think probably the most helpful thing from day one was having our faith. Through our faith we have a church family that has supported us every moment since Bob's injury. Our family and our friends have surrounded us with their love and their care and they have been invaluable to us.

My motto every day at the hospital was, and it continues to be, take one day at a time. You can't look too far ahead. You have to just take each day as it comes, do the best you can with that day. This is the way I got through that period of depression and change.

The commitment to our marriage has been strengthened enormously. Before the accident we were both so busy just trying to keep the farm going. We now have all this togetherness, and it has been a wonderful asset that I never thought of before. Verbal communication, of course, is basic, but the communication of love and hugs, and friendships is wonderful and most helpful.

~ Libby Miller, Decatur, Illinois

Impact of Disability

“My new role was a rather frightening one for me because Bob was a person who did everything.”

~ Libby Miller

The period immediately following a disabling injury or illness is a critical time of transition for your family and the farm operation. A disability brings enormous change to the entire family, often with little warning or time for preparation. In a rural setting you may be especially frustrated with the lack of nearby medical or rehabilitation facilities, long travel times to obtain necessary medical supplies, and few supporting agencies or disability groups. You may struggle with getting “anything” done and be completely overwhelmed with your expenses. Initially, much attention will be given to the physical and emotional needs of the person with the disability. As a caregiver you may feel left out and neglected. The impact of a disabling injury or illness leads to many changes.

Disability can bring about...

- Changes in the pace of life and personal freedom
- A need to be more patient with yourself and others
- A need to reassign responsibilities
- A feeling of being burdened and at times overwhelmed
- A reduction in social interaction
- A decrease in income
- A renewed commitment to the family
- An exchange of love and respect

- Joy based on serving one another
- More time for family
- An opportunity to learn new skills
- Time to listen and care

“I haven’t had a big teary session for a while and evidently I’m healing.”

~ Libby Miller

Each of us reacts differently to a traumatic or life-changing event. Common stages of emotions that your family may experience following a disabling injury or illness include:

- **Shock** – disbelief or denial that anything serious has occurred
- **Expectations for recovery** – hope that the injury or condition is temporary
- **Mourning** – grieving the loss of previous abilities or good health
- **Defense** – anger, aggressiveness, and struggle with dependence/ independence
- **Adjustment** – acceptance, and interest in future goals and the quality of life



Realize that others are experiencing similar feelings. These feelings can be a part of the normal process of adjusting to the disability. Do not become discouraged because you are in a certain stage or that a stage reoccurs. It's even possible that you may not relate to any of these. Regardless of which stage you are at, an important question to ask may be: "How can I best adjust to the impact the disability has had on my family?"

"But it takes a long time, it's been over a year now and I think after the depression, reality sets in and you do the best you can in positive ways because life has to go on."

~ Libby Miller

Regardless of how you approach the impact of disability, you may experience stress to the point of weariness and you feel that you have nothing more to give. There are many reasons you may experience stress. One reason is that a person with a disability may require more care than you are able to provide. Another is that no matter how well you are handling the situation, you are experiencing intense and difficult times. A third reason is that you may give in to unreasonable demands from the person being cared for because you are experiencing many strong feelings.

Some of these feelings may include:

- Guilt because you are still healthy
- Responsibility for keeping your loved-one happy
- Hopelessness and the belief that you have no other option
- Burdened and believing that you have to do it all

- Confusion about expectations
- Victimized by the person with a disability
- Fear that others will view you as neglectful
- Anger, weariness, and resentment of your spouse or loved one

All these feelings add to the impact the injury or illness has on the entire family. It is normal for you to feel extreme emotions during the changes you and your family experience after a disabling injury or illness. It is OK to feel angry, frustrated, tired, and resentful. However, caregivers who allow themselves to be dominated by unrealistic expectations or negative emotions are likely to become "burned out or stressed." It's time to start "caring" for yourself! (3)

I am thankful for those who understood that tears, or lack of them, do not measure the depth of my grief. Those who were able to put aside their own agendas and feelings of loss, to listen to me speak about my sadness, gave me a gift of presence. Those who admitted their discomfort with my grief opened the door to real communication. Tears were more comforting than "answers," hugs more healing than reason. Those who talked about my loved ones as if they really existed and understand the value of each individual help to keep memories of them alive. I am grateful for those who have allowed me to choose my path through grief, who have not urged me to hurry because they felt uncomfortable. Those who offered concrete assistance when they observed I needed it helped to preserve my low energy supply and offered hope. Those who have continued to call, visit, and reach out when the crowd has dwindled have helped me to feel less alone.

~ Sara Wengard, *Grief in Community*,
Reunion Summer 1996

Activities

Brightening the Season

Desired Outcome

This activity will help your family discuss both the positive and negative aspects of the disability. It will also encourage dialogue even when it may be difficult or there is little desire to address important issues.

Activity

Since it is not possible or healthy to discuss all of the important issues related to a disability in one discussion, consider focusing on one topic at a time over several weeks. Set aside a specific time, such as after dinner to spend 10 – 20 minutes on one topic. You may want to put each topic of concern on separate cards and place them all in a jar to draw from at the beginning of each discussion. Use the list below as a starting point.

- What is really important to our family?
- How will this disability affect our farm, home, and plans for the future?
- Will we be able to take a vacation?
- How do we communicate what has happened to others?
- Should we develop a budget?
- How should we share anger and frustration?
- How should we reassign responsibilities around the home and farm?

Assignment

After everyone has had an opportunity to talk and share their feelings, decide as a family on one area that you want to work on together to improve or overcome one of the negative aspects of a specific issue. Pick one positive aspect and explore ways that it can be enhanced to strengthen your family. Remember when sharing your feelings, there are no right or wrong feelings. Allow everyone to share without fear of having their feelings criticized. In a few weeks, assess what you have accomplished. Determine what you need to keep working on and try again!

Note: Developing an honest open relationship takes time and patience. Progress comes in small steps and the effort is more important, in most cases, than the outcome. It is critical that you be completely honest if you expect others to be likewise.

Activities

Personal Thoughts

In the space below, attempt to describe your feelings at this moment about your situation as a caregiver. Then list a few ways that you plan to respond to them. Revisit your notes at the end of the month and assess your accomplishments. If some of your feelings, such as anger, have become more intense, find someone you trust to talk to about them.

Feelings

How I plan to respond to them.




A Season of Rest - Caring for the Caregiver



“Life outside of rehab is not the same. You don’t have perfect exercise equipment, everything is not accessible, and you don’t have the rehabilitation professionals around. So you have to take care of yourself – establish your identification right away and have the person with the disability do that also.”

~ Kimberly Zimmerman,
Courtland, Minnesota



When I got the call in June 1986 that David had been in an accident, I told my boss the circumstances and left work. A car had turned into David while he was driving a motorcycle. When I got to the hospital, I was told that with every hour that passed there was an increased chance David would not walk again. We have never said he will not walk again. You have to have hope.

Before the accident, my job was to take care of the children and the house and I was working full time in town. After the accident, I still had to do that, and a lot of farm chores too.

We had Jessica, our daughter, two days after David's release from rehabilitation. We taught our oldest daughter, Brittany, to climb up the spokes of his wheelchair like a ladder.

At first I had to ask people to back off so I could deal with my own emotions. I was told I was the support and could not break or they all would break. I finally had to admit that I couldn't handle it alone. It was tough to go to family and say can you do this or will you do that. You wonder if you have used people too much. You have to allow people to offer help. My mom reminded me I was not superwoman.

We did tap into public health nursing. That was hard. I felt I should be doing it, being his wife. Not only did the nurse help with David, but I was able to bounce things off her when I was stressed. David's grandma was always good for words of wisdom. She, along with other family members, helped with the chores. We also went to the social worker to discuss what David could do. We saw a modified tractor in a Breaking New Ground manual.* My dad was a mechanic, and I asked him if he could build one – he did.

Life outside of rehab is not the same. You don't have perfect exercise equipment; everything is not accessible, and you don't have the rehabilitation professionals around. So you have to take care of yourself. Establish your identification right away and have the person with the disability do that also.

I would encourage other caregivers to maintain their sense of self-worth. Keep a positive light on things. It can be a growing experience for all, and things can change for the better. Dave has more time now and has his priorities set better.

~ Kimberly Zimmerman, Courtland, Minnesota

* See Resource Section.

Caring for the Caregiver

Many people accept the role of a caregiver gladly, while others view it as a significant burden and intrusion into their lives. Devoting yourself to caring for another individual can either enrich your life or leave you bitter and angry. Linda Berina, R.N., states, “Stress affects the extent to which a disabling condition becomes a handicap.” (4)

You need to recognize negative emotions and signs of burn out early so you can begin to deal with them. Recognition of the first warning signs may prevent a sense of being overwhelmed.

Caregiver Needs Help! (5)

If you notice any of the following danger signals, consider seeking help from a friend, your pastor, a counselor, a support network, or one of the organizations listed in this resource.

- Your family member’s condition is worsening, despite your efforts
- No matter what you do, it doesn’t seem to be enough
- You have no time alone
- Family relationships seem to be breaking down
- Communication between family members is negative, tense, or sarcastic
- You have no social life because of your caregiving duties
- You have shut out everyone who has offered to help
- You have self-destructive thoughts about yourself or the person who needs you

- Your coping methods are destructive such as overeating, not sleeping, or abusing drugs
- Loving and caring have given way to exhaustion and resentment

Don’t wait until you are sick or until you have reached the end of your rope. Seek out help today and take positive steps toward overcoming the stress. The following are additional ways to deal with negative emotions and prevent yourself from becoming burned out.

Maintain A Positive Approach

One way is simply choosing a positive approach. Keeping a positive attitude will reduce the buildup of negative feelings and the effect of stress. It has been said, “Life is 10 percent what happens to us and 90 percent how we react to it.” Begin to react with the most positive statements and attitudes you can muster.

“Keep a positive light on things.”

~ Kimberly Zimmerman

However, the reality is you will continue to have some negative emotions. If you can use that emotion in a positive manner instead of denying it or acting on it negatively, you can go a long way toward keeping your mental and physical health. Consider the following thoughts from Gary Smalley, President of Today’s Family:

“Negative emotions can remind me I am expecting fulfillment from people, places and circumstances. It is learning that people, places and circumstances are gifts of life not the source of our life... the freer we are of others’ expectations to make us happy, the more honest our love for others will become.” (6)

Concentrate on the Important – Forget About the Rest

Another approach to reducing stress is to sit down with a friend, mentor, or counselor and express how you feel and write out what is causing stress in your life. Decide which factors are not important enough for you to worry about at this time. Then brainstorm on ways you can begin to give more attention to the items causing the most stress and choose to leave the other issues for another day. Concentrate on the moment at hand. As one farmer put it – “live one minute at a time.”



“Before the accident, my job was to take care of the children and the house, and I was working full time in town. After the accident, I still had to do that, and a lot of farm chores too.”

~ Kimberly Zimmerman

Make Time For Yourself

The most effective caregivers learn to make time to care for themselves physically, emotionally, spiritually, and socially. By making time for yourself you will actually have more energy and patience for caring for your family. Make time for activities that refresh you such as spending time with a friend or walking alone in the woods. Making time for yourself will recharge you and make you more effective.

Diet and Exercise

Proper diet and exercise are essential to your physical and mental well-being. One of the best ways for you to take care of yourself and your family is for you to take time to exercise at least two or three times each week. Eating healthy nutritious meals and eliminating junk foods will actually give your body more energy and strength to face the demands of your family. If you need ideas for developing a better diet contact your cooperative extension office or Public Health Department.

Music in Your Life

Music has wonderful therapeutic effects as well. It has the potential to encourage and brighten up the dreariest farm or ranch home. The long periods of caregiving may also prove to be an opportune time to learn how to create music on your own. If you have not played an instrument before, even a harmonica, try it; if you can whistle, do it; and if you sing, let'er fly. Buy a kit and build a dulcimer and learn how to play it! Get the whole family involved, one on the piano, one with a harmonica and one with spoons. Create your own tunes. No doubt you will be laughing before it is all over and you will have drawn your family closer together at the same time.

“Little by little time goes by,
Short if you sing through it,
Long if you sigh.”

One pianist, Dino Kartsonaskis, produced a “therapeutic” album for his daughter, who has multiple sclerosis. He has recorded the *Peace Series*, which includes classical, hymns, and nature sounds to provide a therapeutic effect (see the Resource Section for more information). Experiment and see whether music brings laughter and a healing effect in your home.

Helpful Hints to Prevent Stress *

- Focus on the positive
- Learn to laugh more
- Find someone to confide in
- Keep connected with friends
- Enjoy what you do accomplish
- Leave unimportant tasks undone
- Don't try to do everything yourself
- Allow for time by yourself everyday
- Ask others for help and accept help offered
- Seek financial, legal, spiritual, and medical advice
- Maintain activities that do not include the person you care for
- Practice good health habits – exercise, rest, and eat a proper diet
- Reward yourself by reading a book or having lunch with friends

“The toughest part of taking care of a loved one is remembering to take the time to take care of yourself.”

~ Diane Thomas, R.N

Summary (7)

Hopefully you will realize the importance of taking care of yourself. Part of caring for yourself is finding that there is joy in being a caregiver. Possible means of joy and satisfaction may come through:

- Self-satisfaction from being useful
- A greater sense of self-worth
- The appreciation from the individual with a disability
- The ability to take your mind off yourself and your own worries
- An exchange of love and respect
- The feeling that you are making a difference

Finding joy may begin with admitting you can't do it alone. It is OK to give attention to some of your needs. And by taking care of yourself, you will be refreshed and find it easier to care for others.

“Real joy is not dependent upon the outward events in our lives. When we help and care for other people, the one who cares is the person who benefits the most.”

~ Gary Collins, Family Counselor

* Adapted from ideas from the *Caregiver Survival Series*, by Dr. J. Sherman; *When You're the Caregiver*, by James E. Miller, and from farm families who shared their ideas and lives.

Activities

Keeping Your Eye on the Sky

Desired Outcome

Through this activity, you will identify those characteristics in your life that need more attention in order for you to become a better caregiver.

Activity

Remember the old saying:

Red sky at night shepherd's delight

Red sky in the morning shepherd's warning

Being able to read the warning signs can help avoid trouble by making you better prepared. Review the following list of qualities related to good caregiving. Put a check mark after each quality under the headings **clear sky** or **storm coming** for the areas you are doing well with or areas you need to work on. Notice that many of these qualities relate to taking care of yourself.

As a caregiver I:

	clear sky	storm coming
Realize that sometimes it is best to take a break and try again the next day	<input type="checkbox"/>	<input type="checkbox"/>
Help the person receiving care to Find and develop new resources	<input type="checkbox"/>	<input type="checkbox"/>
Encourage others to master new tasks and accept new responsibilities	<input type="checkbox"/>	<input type="checkbox"/>
Tolerate failure both in myself and the one I am caring for	<input type="checkbox"/>	<input type="checkbox"/>
Do not solve problems that others can solve themselves	<input type="checkbox"/>	<input type="checkbox"/>
Do not take bitterness or anger from others personally	<input type="checkbox"/>	<input type="checkbox"/>
Maximize the abilities of the one I am caring for	<input type="checkbox"/>	<input type="checkbox"/>
Focus on what can be done not the impossible	<input type="checkbox"/>	<input type="checkbox"/>
Remember I have needs too	<input type="checkbox"/>	<input type="checkbox"/>

Activities

Keeping Your Eye on the Sky (continued)

Assignment

As you review the list on the previous page, which item(s) suggest that a storm may be brewing? Acknowledge the things you are doing right. Now is the time to take care of yourself and prevent a future storm!

Pick one item that suggests that a storm may be brewing and work on it this week. Tell a friend what you are going to do and ask for help. Encourage him or her to hold you accountable in the area selected.

During the coming week, I will work on the following warning sign:

The specific steps I will try to take are:

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____

Activities

Personal Thoughts

In the space provided, write out a few specific goals relating to your life that you would like to accomplish over the next 30 days and over the next six months. Revisit your notes at the end of the month and assess your accomplishments. You might be surprised by the progress you have made.

Personal goals for the next 30 days:

- 1. _____
- 2. _____
- 3. _____
- 4. _____
- 5. _____

Personal goals for the next six months:

- 1. _____
- 2. _____
- 3. _____
- 4. _____
- 5. _____
- 6. _____



After the Storm - Asking For Assistance



“Such an outpouring of community spirit and thoughtfulness was indeed both touching and humbling. I had always found asking for assistance very hard to do. But in such a situation, you soon admit you can’t do everything. You learn that occasionally you must swallow your pride and request help.”

~ *Debbie Bell, Hagerstown, Indiana*



After Ed was injured in a crime (from a gunshot), I found it necessary to adapt quickly to several changes in my life. Not only was I a young city-born woman about to begin married life in the country, but my husband-to-be was now paralyzed from the waist down. He had suffered a permanent T1 – T2 spinal cord injury in the shooting.

As many couples have done when one becomes disabled, we struggled together and learned along the way. During the weeks immediately following Ed's injury, we received lots of help from relatives and friends in the community. A ramp was built, an accessible bathroom installed, a sidewalk poured, and a van with a wheelchair lift was purchased. Church members, merchants, the local vocational rehabilitation service, family and friends, and even those unknown to us came to our rescue.

Such an outpouring of community spirit and thoughtfulness was indeed both touching and humbling. I had always found asking for assistance very hard to do. But in such a situation, you soon admit you can't do everything. You learn that occasionally you must swallow your pride and request help. Usually, the assistance given initially tapers off after a few weeks. This doesn't mean people have deserted you. It just means others are busy with their own lives. Family and friends will still respond to your needs, although it may not come as quickly as you wish.

~ a wife's thoughts

As a caregiver, you soon learn there are a number of responsibilities to shoulder. Time is always at a premium, and the many tasks you must perform require a great deal of energy if you are to keep up. The trick is not to let the job overwhelm you. An exhausted caregiver becomes inefficient. So look for someone (or several someones) to provide you a break from the routine.

Some people find caregiving easier than others. Those who bring a cheerful, energetic spirit to the task each day are blessed and deserve our praise. After all, caregiving is one of the most Christian acts an individual can perform. And doing it on a daily basis, with patience and love, is certainly giving of oneself.

Along the way, you learn it is much easier to help others because of what you have been through. As a registered nurse, I can now provide more understanding and support to others. Often, just listening is one way to help those undergoing difficult times.

~ *By Debbie Bell, wife of Ed Bell*



When my 21-year-old son received a T1 – T2 spinal cord injury, our immediate concern was, of course, for his life and then his rehabilitation. As time went on and reality began to set in, we realized that in addition to the pain and trauma of watching our son struggle to rebuild his quality of life and independence, we were also faced with financial devastation.

Help came quickly from many sources. Family, of course, church friends, and neighbors, supplied many of our needs. They harvested our crops that Fall, and one Saturday truckloads of them descended upon the farm and replaced old broken sidewalks with smooth new ones as well as a concrete pad to ease the access to and from the new handicapped van purchased from a local car dealer at cost. The town folks had even raised the down payment for the van.

Because of the time required away from our large farrow-to-finish hog operation, the profits were lost. We were facing unpaid bills to feed companies as well as the astronomical hospital and medical bill, which a \$65.00 a day insurance policy didn't even make a dent in. The feed company continued to deliver feed for the animals even though they were well aware of our situation. They even refused to charge interest on the escalating bill. All of these things, which we did not ask for but were so freely given, were indeed humbling. But the real lessons in humility were yet to come.

~ a mother's thoughts

Because our son had just finished his schooling and had not begun to pay Social Security, there were no benefits available. With help from family and friends, and by liquidating all our livestock and equipment, and cashing in all life insurance policies, we were still short nearly a third of the \$175,000 debt. I found myself facing mountains of paperwork and forms to fill out in order to help my son qualify for Medicaid and SSI, (not something that we ever dreamed could happen to us). Ultimately, I found myself sitting across from our attorney signing papers that would declare us bankrupt.

In addition to all that was happening to us, there was the constant fear that my husband could not physically cope. Just a few months before our son was paralyzed, George, my husband, had spent many months in the hospital with a serious heart problem.

In summary, I need to tell you that it is important to accept help when it is offered. Do not rob others of their opportunity to give and be blessed. I have learned that God sends angels in many different forms. Put your trust in Him, allowing Him to lead you through the maze, and while your life will never be as it was before, much can be learned. There is happiness to be found in any circumstance.

~ Nonalee Bell, mother of Ed Bell

Asking For Assistance

“The hardest thing to do is to ask for help”

~ Debbie Bell

Being a caregiver can be hard work. Making transfers, loading and unloading wheelchairs, and lifting heavy medical equipment all take time, energy, and effort. When an injury or illness to a family member results in a long-term disability, there are many new tasks to be completed. In addition, the farm or ranch requires daily attention that does not wait until the family is “ready” to work. Yet you may be avoiding asking others for help.

Characteristics that previously helped you succeed as a farmer or rancher may now be the very characteristics that make it difficult to seek help from others. How many of these characteristics can you identify with?

- Do not usually seek help for personal matters
- Have always “done fine” on your own
- Usually keep “private” matters in the family
- Fiercely independent
- Don’t like asking others for assistance

This independence and self-reliant strength is evident in the words of one farmer with a spinal cord injury, “If you can’t pull your own weight, pull what weight you can...” There is truth and encouragement in those words. However, even though these traits may have served this farmer or your family well in the past, you need to see the value of reaching out to others. For example, few of us have any reluctance

calling 911 when we see smoke coming from the hay mow or calling the veterinarian when a cow is down. Think how easy it is to call the equipment dealership to solve a problem with the combine or baler, or the county Extension Educator when a weed control program is not working the way you think it should. The well-being of you and your family are more important than the weeds in the corn or the life of a cow! As a caregiver, you may need help from others to successfully meet upcoming challenges.

If you don’t ask for help, it won’t get done! And I think asking for help also helps other people – because a lot of people sit back waiting for you to ask them – it makes them feel better when they can help you.”

~ Debbie Bell

Asking for this help may be extremely difficult for you, however, managing the farm or ranch and completing day-to-day operations is a big job. With the additional tasks and energy required to meet the new needs of a disability, it may become overwhelming without help and support from others.

“It is real important to ask others for help so you’re not stressed and just to get things done.”

~ Debbie Bell

Seek out Friends and Support!

Some caregivers find help from friends, family, church or other local organizations. Begin to seek out support so you are not pulling all the weight alone. At some point, you must decide that it is OK to ask others for help!

We all need friends. During some of your toughest days you will need the type of friend who will stick “closer than a brother.” In addition, seek out others who have a family member with a similar disability. Share common experiences, learn from each other, and ease your isolation. A close friendship with just one other person can make a big difference in “making it” through tough times. Spend time every week with your friends; they will be good medicine.

Consider trying one of the following activities to help you break out of an isolation cycle and renew friendships and develop new ones. If it is successful, try another one. If it is not, try one more!

- Buy or bake cookies and take them to a neighbor
- Call an “old” friend and talk about the good times you have shared
- Participate in church activities, and invite a friend
- Schedule a weekly visit to the local coffee shop
- Attend an educational or inspirational meeting with a friend or neighbor
- Join a support group, bowling league or Extension Homemaker Club
- Demonstrate hospitality – remember, good friends are more interested in you than the condition of your house

“Two are better than one... If one falls down, his friend can help him up.”

~ Solomon

Some people you have considered close friends in the past, may not deal well with the disability and may drop out of your life. On the other hand, you may find individuals who were formerly mere acquaintances become close friends because of their common experiences. Prior to the disability you and your spouse were probably part of several naturally occurring “support groups.” This might have included people from church, bowling league, Farm Bureau, volunteer fire department, 4-H, Extension Homemakers, Lions, Optimist, or the morning coffee hour at the elevator. These groups represent some of your closest friends and supporters. Don’t withdraw from them now. They needed you before, and they need you now – and you need them. As soon as possible, return to the groups you enjoyed.



“Usually, the assistance given initially tapers off after a few weeks. This doesn’t mean people have deserted you. It just means that others are busy with their own lives. Family and friends will still respond to your needs although it may not come as quickly as you wish.”

~ Debbie Bell

Other sources of support include groups that have been established for the purpose of meeting the needs of persons facing specific issues such as disability. These range from groups addressing illnesses such as arthritis, cancer, or diabetes to amputation support groups. Check with your local physician, hospital, Cooperative Extension office, or telephone book for information on contacting these groups. Take the plunge! Show up at their next meeting. What you will most likely find is a group of people like you. They are facing similar struggles and want to encourage and help you in any way possible. Caregivers with a support system live happier lives than those who are isolated.

More Ideas for Pulling Together after the Storm (8)

As you look for a group to join, consider the following ideas that can help make your involvement in a support group successful:

Confidentiality

Find out if the group has a reputation for keeping private matters confidential. You need to be able to trust your support group.

Shared leadership responsibilities

Does the group provide for shared leadership? Leadership experience helps build self-worth and will bring more creativity to the group.

Realistic expectations

Don’t be discouraged if there are only two or three people in attendance at the meeting. Enjoy learning from those attending.

Responding to the group members’ needs

Determine if the meetings are practical and helpful to those participating. It should not be a gripe session just for vocal members.

“Friendship improves happiness and lessens misery, by the doubling of our joy and the dividing of our grief.”

~ Cicero

Activities

Pulling Together After the Storm

Desired Outcome

This activity will demonstrate the value of getting together with others who have experienced similar storms in their lives.

Activity

In many communities a wide variety of support groups have been formed because people have sensed the need to share their burdens with one another and to encourage those who are passing

through a difficult time. At some point during the week make the commitment to attend one of these groups that relates to the disability or the situation you find yourself in. This might require finding someone to fill in for you for a few hours or to arrange transportation. The result, however, is worth it. The strength and encouragement that these groups can provide is essential to your well being as a caregiver.

Assignment

Task Completed

1. Check the yellow pages and community events section of the newspaper, or call the local hospital to find out what groups meet, when and where.
2. Call the contact person and confirm the next meeting date, place, and time.
3. Attend a meeting of a support group this week.
4. As you talk to someone who has already been through a similar storm, be grateful for what you are doing right and learn from the experience of those who have passed through this storm before you.

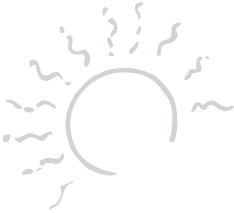
Activities

Personal Thoughts

Identify one group that has meant a lot to you. It might be a group of neighbors, a Sunday school class, an Extension Homemaker Club, or a civic group. List the ways that this group has made you a stronger, more mature person.

- 1. _____
- 2. _____
- 3. _____
- 4. _____
- 5. _____
- 6. _____

What are your feelings toward this group and how have they responded to you in your new role as a caregiver?



Hang in There Come Rain or Shine - Commitment to Marriage



“I married him for life! The Golden Rule is the law I follow in life. I believe in doing unto others as you would have them do unto you. That’s what I would have wanted Ron to do if I had been the injured one.”

~ Helen Thomas,
Tangier, Indiana

As I watched Ron lay helpless in the hospital, a T-11 paraplegic, I decided that I would make things happen for him. I married him for better or for worse and if love is true, it just doesn't stop when the person needs you most.

I went home and started knocking the plaster off the bedroom walls and making an accessible bathroom and wheel-in shower. I drew on all the strength I could muster. I would remind myself that this was a labor of love. And with my prayers I found strength to continue the work.

We didn't have the money to hire the work done. Ron lost a good paycheck and major medical policies when he was injured. Later our church and friends helped us finish the work. We sold a tractor, a motor home and other things and took out another loan on our home to build Ron an accessible wood shop.

The Breaking New Ground Resource Center at Purdue University (see Resource Section) shared creative ideas to modify the work area. With the help of Vocational Rehabilitation, a lift and driver controls were added to our Ford van. A friend, who was a medical salesman, brought in a hospital bed and in time we had Ron all fixed up. This took about two years.

With each step I could see the light come back into Ron's eyes. I helped him with most of his personal needs until he learned how to care for himself, and in time he did achieve this. I would not do for him what I thought he could do for himself. At first that made him angry, but now he jokes about it.



My decision to make things happen for Ron has been refreshing and gratifying. Making Ron happy was the reason I married him. Why would I stop now, even if he isn't the strong man I married. Old age brings it on anyway.

The counselor told us many marriages end in divorce after a disabling injury. I married him for life! The Golden Rule is the law I follow in life. I believe in doing unto others as you would have them do unto you. That's what I would have wanted Ron to do if I had been the injured one.

~ Helen Thomas, Tangier, Indiana

Commitment to Marriage

“I decided that I would make things happen for him. I married him for better or for worse and if love is true, it just doesn't stop when the person needs you most.”

~ Helen Thomas

Ron and Helen Thomas have set a good example for all of us to follow. Because of their commitment they have kept their home loving and have enjoyed many new seasons planting and harvesting their crops together. One survey conducted with individuals with spinal cord injuries found that those persons who had made an excellent mental adjustment had come from “exceptionally warm and loving backgrounds.” (9) Maybe you are wondering, “How can I be warm and loving during this time of turmoil?” “How can I really be committed like Helen?” Family counselor, John Trent states, “Remaining tender during a trial is one of the most powerful ways to build an intimate relationship.” Look at the following suggestions and talk about them with your spouse. Ask him if there is one thought that you both could work on together.

Thoughts to Keep Your Marriage Strong (10)

- Difficulties do not mean something is wrong with your marriage
- Your response to difficulties will either drive you apart or bind you together

- Become dedicated to “binding” together
- Your mate's needs are opportunities for personal growth, not inadequacies or problems that makes him less desirable
- Find your mate's #1 need and strive to meet it
- Remember your mate is not your enemy
- Don't focus on your mate's weaknesses but rather on his strengths
- Never criticize your mate in public, discuss your differences in private
- Walk in the other person's shoes... think about what it would be like to be married to someone like yourself!
- Do not harbor secrets or anger. Be honest and sensitive in sharing your feelings
- Never play games to “get even.” Instead build trust, respect and security through your actions and words



In Helen Thomas' story she states that she decided that she was going to start making things happen for Ron. She used her energy to even start remodeling and modifying their house. An important part of any marital commitment is serving one another. As a couple, discuss ways you can commit to serving each other. It can be as simple as treating your family with common courtesy and respect or as important as "sticking it out" together no matter how hard the winter winds blow.

"I believe commitment is for life and when something terrible happens to you I feel like part of that commitment is sticking it out, staying in there, helping that other person."

~ Helen Thomas

As part of the rehabilitation process, plan to attend a Marriage Encounter weekend. These special weekends are held all over the United States and are designed to strengthen good marriages by improving communication skills. You will meet with other couples with a strong commitment to their marriage and be led through a series of exercises to encourage regular and meaningful dialogues on issues effecting your marriage.

The YMCA, community college, hospital or a local church may offer a course on communication or listening skills. Go to an enjoyable class together and commit to strengthening your marriage.



Sweat trickled down my back as I grabbed a hay bale from the wagon, planting it on the elevator. Turning back for another, I was greeted by my husband's smiling, wind-burned face and a glass of iced tea. "Let's take a break," he suggested, heading for the porch swing. "Thank you for your help," I said, smiling through the dirt on my face. "That's OK," he replied. "When I said those vows 20 years ago, I knew it included kids, hay bales and horses. I still think it was worth it." I hugged him hard, dirt and all. Thank you, Lord, for the special people you place in our lives. I pray everyone be as blessed as we were in finding that someone.

~J. Rhodes

Activities

Hang in There Come Rain or Shine

Desired Outcome

The purpose of this activity is to encourage you and your spouse to make a stronger commitment to each other even during the tough times.

Activity

Read the following story by Robertson McQuilkin. Like Ron and Helen Thomas, this story is written to encourage you to be committed to your spouse – especially during the hard times.

Sustaining Love in Marriage*

It had been a decade since that day, during a Florida vacation, when Muriel, my wife, repeated the story she told just five minutes earlier. “Funny,” I thought, “that’s never happened before.” But it began to happen occasionally. Three years later, when Muriel was hospitalized for test on her heart, a young doctor called me aside and confirmed that she had Alzheimer’s.

Trusted, lifelong friends urged me to arrange for institutionalization. “Muriel would become accustomed to the new environment quickly,” they said. Would she? Would anyone love her at all, let alone love her as I do?

Years later Muriel cannot comprehend much or express many thoughts. But she

knows whom she loves, and she lives in happy oblivion to almost everything else. She is such a delight to me. I don’t have to care for her; I get to. One blessing is the way she is teaching me so much about love, God’s love.

Muriel cannot speak in sentences now, only in phrases and words, and often words that make little sense: “no” when she means “yes,” for example. But she can say one sentence, and she says it often: “I love you.” She not only says it, she acts it.

During the last two years it became increasingly difficult to keep Muriel home. As soon as I left, she would take out after me. With me she was content; without me she was distressed, sometimes terror stricken. The walk to work is a mile trip. She would make that trip as many as ten times a day. Sometimes at night, when I helped her undress, I found her bloody feet. When I told the family doctor, he choked up. “Such love,” he said simply.

As Muriel needed more and more of me, I wrestled with the question of who gets me full-time, Muriel or work. When the time came, the decision was firm. It took no great calculation. It was a matter of integrity. Had I not promised, 42 years before, “in sickness and in health... till death do us part.”

* Reprinted with permission from Dr. Robertson McQuilkin, President emeritus Columbia Seminary.

Activities

Hang in There Come Rain or Shine

Assignment

Write your mate a love letter. Express to him how important he is to you and identify two or three characteristics that you especially appreciate. Thank him for what he has done for you. Remind him that you desire to go through this difficult time together – no matter what.

Don't expect a response. Then follow-up with short notes on the mirror, on his plate at breakfast, or stuck in his hat or boot. Love notes will often soften even the toughest heart.

Personal Thoughts

Are there couples in your community that you admire? What aspects of their marriage could you emulate?

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____

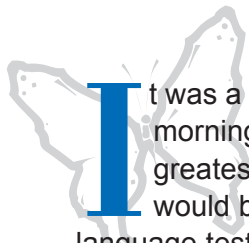


Sharing About More Than the Weather - Communication to Keep Families Working Together



“After the accident, there was rehabilitation, the loss of a job, paralysis, then all the financial burdens. I was overwhelmed. I knew the answers... I had read the books. But I needed to express my needs to my spouse first. I had said it in my mind, but there is something healing about grieving out loud...”

~ Janice McManigal,
Veedersburg, Indiana



It was a cold, rainy January morning, and I assumed the greatest challenge of the day would be my third grader's language test. We never saw that test. My husband, Kim, was driving his van when it hit some ice, slid and rolled over four times before stopping. Kim was thrown from the van, and this resulted in permanent paralysis from the chest down. Little did we realize, as the door of our world as we knew it slammed shut and this new world of paraplegia was ushered in, the barrage of communication that was to lie ahead.

Our first challenge was finding and talking to doctors. We quickly realized some doctors weren't good communicators and that we were going to have to assume the role of the initiator. We made lists, talked to nurses, and read to form a base of understanding and a source from which to draw questions. We even taped all conversations with doctors so we could listen again and make sure communication was clear. This was necessary to assist us with our new disability.

During those 16 months of rehabilitation we had to learn to communicate grief. This task is multifaceted. We found cards a good means of sharing our hearts. We also discovered others could enter in by sharing their music with us. Then there was silent grieving. As friends would praise our new accomplishments our hearts ached because we just wanted to wake up and see the whole thing was a bad dream. There was the grieving that had to be done out loud as well.

I remember the night Kim told me that our insurance company was fighting to keep from assuming worker compensation responsibilities. That was

it! I had had it! I just wanted to get in God's face and yell at Him. I held onto that anger until Kim asked me to verbalize my grief allowing me to get release. My soul was lifted because I was free to communicate my anger, and my husband was able to comfort me through that night. We found much healing in crying together as we reminisced on what we had lost – things great and small. We cried as we tried to figure out how to make inroads to the future.

My soul was lifted because I was free to communicate my anger, and my husband was able to comfort me through that night.

~ Janice McManigal, Veedersburg, Indiana

Our next task was to communicate with our children. We found the long rides home from rehab provided a safe environment for them to share their feelings. We watched videos to teach principles of hardship and rising above them. When someone disabled was on TV we would watch as a family and discuss issues. We would include our children in some of our discussions on the future and get their input. We always tried to encourage honest feelings, words, and emotions. We didn't always have all the answers. The important thing was that we were going through this together, not separately living in the same house, but together.

Communication with friends, family, and church took on new meaning. We had to humble ourselves and be vulnerable. We had to share our pain, the frustrations, the anger, the accomplishments, and our needs (physical, emotional, spiritual). These

lwere times they carried us. Those who loved us needed to know these things; otherwise we were keeping them from their full capacity of helping and commitment.

Last, we needed to communicate with our community. We found if you could make those you spoke to feel what we felt they had a better listening ear. This is a key when trying to show a restaurant owner the frustration of being blocked in to a “handicapped” parking space, or share with a department store manager that boxes in the aisle blocked passage

for a wheelchair. We found many people responded if given the facts that were presented in a kindly manner.

Our disability reached from our lives to the lives of our family, friends, church, and community. All were affected. The truest gift of communication is its ability to bond people and even make catastrophic disabilities conquerable.

~ Janice McManigal,
Veedersburg, Indiana



Communication

“There’s a delicate balance between giving in, hanging on, and graciously accepting the inevitable. We had to recognize that our different emotional needs couldn’t be ignored – not his, not mine.”

~ Suzanne Mintz, co-founder,
National Family Caregivers
Association

Effective communication is a key to a happy and successful home for any family. With the added stress of depending upon one another and of spending extended periods of time together because of a disabling injury or illness, communication between you and the care receiver is vital.

One approach to consider in trying to assess your level of communication is to ask your children. Their honest answers may hurt but could prove helpful.

The following ideas can provide a good foundation for communication to keep your family working together: (11)

- Practice listening to every word and then restate what you heard
- Avoid using sarcasm, criticism, avoidance and teasing
- Share your feelings and offer a solution to a troublesome problem
- Touching is an added accent to communication
- Keep your complaints short and end them with an expression of appreciation
- Remember – this is not a tractor pull – you should not be out to see who can win! Your purpose should be to understand each other

“Interpersonal issues are a lot like weeds – they don’t go away unless you root them out...”

~ Roger Williams,
University of Wisconsin

“Even though my illness was a trial to you, you did not treat me with contempt or scorn. Instead, you cared for me as if I were an angel of God...”

~Paul

Communication takes work, just like a good garden does. Even if you have the best soil and the finest seeds, without constant weeding you could lose your whole garden to neglect. Similarly, good communication takes constant attention and effort, even with your own family members. Because you are in the caregiver role, there may be some things that you or your spouse are taking for granted. Look over the list below. Which idea would you most like to communicate to your spouse? When the time is right, communicate that idea to your spouse. Then a week or so later share another one. Sharing the following thoughts with your spouse may help pull some of the weeds that are creeping into your communication.

- Tell me what helps you – be kind, be patient, but be clear
- Let me know you appreciate specific things I do for you
- Praise me openly and often and criticize me privately and infrequently
- Do as much for yourself as appropriate
- Every task that you do is one less thing for me to do
- Offer me whatever you have to offer – encourage me
- Try to imagine what it is like for me
- Allow me to give suggestions

- Learn new skills or take on new roles around the house and farm
- Take greater responsibility for yourself; call the doctor or pharmacy, or complete other tasks that may be helpful to me and the family



“You don’t even know what help you need... for example one night my husband spent 45 minutes telling me how to wire a light that he could not reach from his wheelchair... he had the knowledge and I had the hands. But after 45 minutes of frustration, a friend came over and fixed the wiring in 45 seconds.”

~ Janice McManigal

“The truest gift of communication is its ability to bond people and even make catastrophic disabilities conquerable.”

~ Janice McManigal

Communicate to Make Your Home Loving (12)

In their book, *Love is a Decision*, Gary Smalley and John Trent make suggestions for communicating love in your home. Read the following strategies. Is there one that your family can try this week? Remember, changing habits and behaviors isn't easy! You must be committed to positive communication everyday of every season.

- Be kind with a spoken word – “You're special to me.” Be kind with an action – a hug, a gentle touch, or holding a hand. Combine a kind word with a hug and the results can be fantastic!
- Ask your family: to define tenderness, to describe the best way to be held to feel safe and loved, and when is the best time to show sympathy or comfort. After a disabling injury, communicating these key concepts can keep a relationship “warm and loving”

- Avoid mixing lectures and tenderness. Instead of a lecture, what a family member needs in times of frustration is a shoulder to lean on, comfort and encouragement, and a tender touch, not a pointing finger

“We need to understand that when someone is going through a trial, they sometimes express that emotional draining of energy through their anger, discouragement, hurt feelings, or anxiety. The last thing a hurting family member wants from us is a lecture, especially one that's delivered in harshness and anger.”

~ Gary Smalley,
President, Today's Family

Activities

Sharing About More Than the Weather...

Desired Outcome

This activity is designed to encourage you and your spouse to share on a deeper, more intimate level.

Activity

Communication that strengthens your relationship with your spouse and family takes work! If you really desire better communication with your spouse, you probably should start by looking at some of your own habits, attitudes, and motivations. Read through the following list, and put a check by the items you need to work on. Now put a check by the areas you would like your spouse to work on.

	You	Spouse
Steps to Improve Your Communication:		
• Make listening a habit.	<input type="checkbox"/>	<input type="checkbox"/>
• Let my words be windows, not walls.	<input type="checkbox"/>	<input type="checkbox"/>
• Never blame my spouse for problems.	<input type="checkbox"/>	<input type="checkbox"/>
• Sometimes truth is best served by my silence.	<input type="checkbox"/>	<input type="checkbox"/>
• If I will change my attitude, it will change my spouse.	<input type="checkbox"/>	<input type="checkbox"/>
• When speaking to my mate, don't manipulate but encourage!	<input type="checkbox"/>	<input type="checkbox"/>
• I must allow freedom for differences in communication styles.	<input type="checkbox"/>	<input type="checkbox"/>
• Conflict is normal and useful. How I manage it determines my whole life pattern.	<input type="checkbox"/>	<input type="checkbox"/>
• Demonstrate listening by putting aside distractions and focusing on the other person.	<input type="checkbox"/>	<input type="checkbox"/>
• Encouragement means specific acts of building my spouse up, it says, "I believe in you!"	<input type="checkbox"/>	<input type="checkbox"/>
• Communicate in a way that will teach my children to communicate during their own trials.	<input type="checkbox"/>	<input type="checkbox"/>
• Respond kindly when ill-treated. I will make it a habit to return a kind word from an insult.	<input type="checkbox"/>	<input type="checkbox"/>
• The difference between responding and reacting is 10 seconds... I wait 10 seconds, then respond.	<input type="checkbox"/>	<input type="checkbox"/>

Activities

Sharing About More Than the Weather... (continued)

Assignment

During the next month, set aside 30 minutes as often as possible to get beyond the basics by sharing your feelings with each other. Use quality time when both of you are rested and when you have the fewest distractions. Use the time to talk, listen, and enjoy each other. Remember feelings are neither right or wrong, so avoid judgments. Check off each day that you are able to complete the assignment. If it works, try it again.

1	2	3	4	5	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28
29	30	31				

Activities

Personal Thoughts

Do you remember when you were first dating and would talk until 2:00 in the morning? Recall a favorite date and write down what made it so special.




Changing Seasons - Accept Changing Roles in Your Family



“I remember several days last summer when I came into the house announcing, ‘I am finished with chores and I’m hungry!’ And my husband would say, ‘I’ve set the table, and dinner is in the oven.’ What a laugh we had about our change in roles!”

~ Carol Hulsenbeck, Kendallville,
Indiana



On January 25, 1996, life was dramatically changed. My husband, Martin, was run over by a gravity bed wagon full of corn. I sat under the oak tree with our dog and cried as the helicopter from the hospital landed. We had no idea if Martin would live at first since his injuries included a crushed left shoulder, a broken forearm, five broken ribs, a crushed pelvis, nerve damage to the right leg, and contusion of the kidneys. Martin was in intensive care for six weeks. As Martin got better, he was moved from intensive care to a regular hospital room, where he would stay for four months.

Martin was on a ventilator for four weeks and kidney dialysis for three weeks. He had nine surgeries from eight different doctors. The time required for rehabilitation, trips to the hospital, and trying to keep the farming going was incredible.

Our children had to accept the fact that our family was different now and needed help, not just with farm chores but financially and spiritually as well. One day I just wanted to sit and cry, but I couldn't do that. Crying would take too much time, and I had a lot of work to do.

In the past I was just a tag-a-long for Martin. Someone to keep him company. I grew up a city girl and had never really done a lot of the farm chores, but Martin and I always talked, and I basically knew what needed to be done. Martin and our three children took care of the chores while I worked as a preschool teacher and a full-time mom, wife, and homemaker.

All that changed when Martin was injured. The tasks were still there. The chores of feeding the animals and doing the field work all had to be done. I immediately took a leave of absence from

work. For the first eight weeks after the accident I wasn't home much. I spent days and evenings at the hospital, sleeping at my mother's house nearby. The chores were completed by relatives, neighbors, friends, and our two sons.

Martin was unable to talk for six weeks. Every decision about our farm rested on my shoulders.

I ran the farm by phone from the hospital intensive care lounge, calling in feed orders, purchasing nitrogen for wheat, and marketing corn. At night my son and I would discuss with our volunteer farm hands the plans for chores, field work and selling of livestock. Fortunately, I had always handled the books. I couldn't imagine having to learn all of that on top of taking care of everything else.

It was not until the first of June that I took over doing chores with the children, Hans-16, Heidi-15 and Karl-11. Now, it is not unusual for the animals to see me with fingernail polish, jewelry, and a new hair cut. From June through August, our two sons did all the summer field work. Our daughter did all the housework and mowed the yard.

Then one day shy of four months after the accident, Martin came home. It was a great day, one we thought would never come. But more changes needed to be made. The children had to help more too! Not just with farm chores, but with all the daily tasks around home while I was taking Martin to therapy and taking care of him at home. All the care the nurses and rehabilitation professionals provided, now needed to be done by us. Martin had so many changes to go through as well. He was use to doing all the chores and now was at home in a wheelchair. He had to provide instruction and direction and manage the farm from inside.

It has only been about a year since the accident and so much has changed. But now many things are changing back to “normal.” I have returned to teaching at the preschool, and the kids are all in school. This fall, with the help of a lift, Martin was able to get back on a tractor and combine for the first time in a year.

I know there will be more changes to be made. I would just recommend that you accept help from others graciously. They want to help. It is, after all, part of God’s plan that we take care of one

another. Keep a journal of progress. Always be thankful for what you have. Take time for yourself. Keep a sense of humor. I remember several days last summer when I came into the house announcing, “I’m finished with chores and I’m hungry.” And my husband said, “I’ve set the table, and dinner is in the oven!” What a laugh we had about our change of roles!

~ Carol Hulsbeck, Kendallville, Indiana

Accept Changing Roles

“I know there will be more changes to be made. I would recommend that you accept help from others graciously.”

~ Carol Hulsbeck

After a disability impacts your home, it often becomes necessary to change roles within your family. Overcoming stereotypes of male and female roles may be vital to relieving burdens on the family and marriage. Rethink family, household, and farm chores. As a family, discuss: Which tasks are essential? Can some tasks be eliminated? Can some tasks be postponed? What new tasks can each family member learn? Who is the best person to do these tasks? The entire family needs to rethink who can do each task best, because of this new season in your family’s life. Communication is a key element in successfully “changing roles.”



“So much has changed. But now so many things are changing back to normal.”

~ Carol Hulsbeck

Example of Changing Roles

As you read the story of Martin and Carol Hulsbeck, you may have been struck with the many changes they had to make. These included: changes in job responsibilities, changes in who did the farm chores, and changes in who did the

cooking and cleaning. With changes comes the need to learn new skills and to set realistic expectations. There will be some uncomfortable moments, more than one burnt meal and many farm chores completely overlooked. To keep your farm and household successful make the role changes with the sense of humor and determination that the Hulsens used!

To help with the changing roles, involve your care receiver in as many meaningful tasks as possible. This provides a positive feeling of self-worth to him or her and reduces the caregiver's burden. Begin with jobs that can be accomplished successfully. Avoid unattainable tasks that could lead to more frustration or unnecessary failures.

I have returned to teaching at the preschool, and the kids are all in school. This fall, with the help of a lift, Martin was able to get back on a tractor and combine for the first time in a year. I know there will be more changes to be made.

~ Carol Hulsens

Changing Roles for the Caregiver Who Works Off the Farm

An increasing number of farm women work off the farm in order to supplement farm income and often to gain access to affordable health care insurance. When a disability occurs this source of income and the health plan may become even more important to the family. However, there will also be changes that will need to be made and expectations to fulfill

from both the family and employer. The following are some tips for the caregiver who is trying to maintain a job, keep a home in order, complete farm chores and handle the tasks of a caregiver.

- Focus on what is really important to your family
- Establish priorities for each area of your life (home, farm, work, church, etc.)
- Talk about your concerns and expectations with the entire family
- Schedule "telephone time" at work to talk with your family and friends
- Talk with your employer about how your situation may impact your schedule and your performance
- Consider some form of flexible work hours or the possibility of doing work at home
- Seek support and assistance from others, including other caregivers
- Explore techniques that improve your efficiency, but do not expect to accomplish everything you did before!

"The changes in my journey keep unfolding like the petals of my rose bush. Who I am – really am – keeps changing. But in a nice sort of way. Trusting, obeying, submitting – I am finding my life. Like that rose, I am a bud being transformed from glory to glory."

~ Joni Eareckson Tada, author of *Choices and Changes*

Activities

Changing Roles During Changing Seasons

Desired Outcome

This activity will help you focus on the different roles that members of the family have traditionally played and how they

may change due to the impact of a disability. It will also assist in identifying tasks that are less important and can be eliminated or done less frequently.

Activity

Gather the family around the kitchen table. Give each person a pad of paper and a pen.

Across the top of the paper write out three headings:

Mom/Wife		Dad/Husband		Children	
Before	After	Before	After	Before	After

Write out the main responsibilities and chores each family member did before the disability. After everyone has completed their list, read each list aloud. What are the similarities and differences? Now write down the responsibilities after the disability. Discuss the following questions:

- What roles have changed?
- What roles still need to change?
- Who is best suited for each particular task?
- Who can learn to do a task that needs to be completed?
- What chores can be eliminated?
- What tasks can be done less frequently?

Assignment

First, thank each family member for what they have contributed. Based on your family discussion, assign the tasks discussed and have a trial period for a week or so and see if the tasks are being completed. Talk about what happened. Then reassign the tasks as needed. Remind everyone you are on the same

team. At this particular time some role changes may need to be made to keep the home and farm operating smoothly. If you think about it, those who succeed in life are those who learn to change with the different roles that they face through the seasons of life.

Activities

Personal Thoughts

Write down your feelings about what your changing responsibilities have meant to you.

Be specific, list any new responsibilities that you actually enjoy doing.

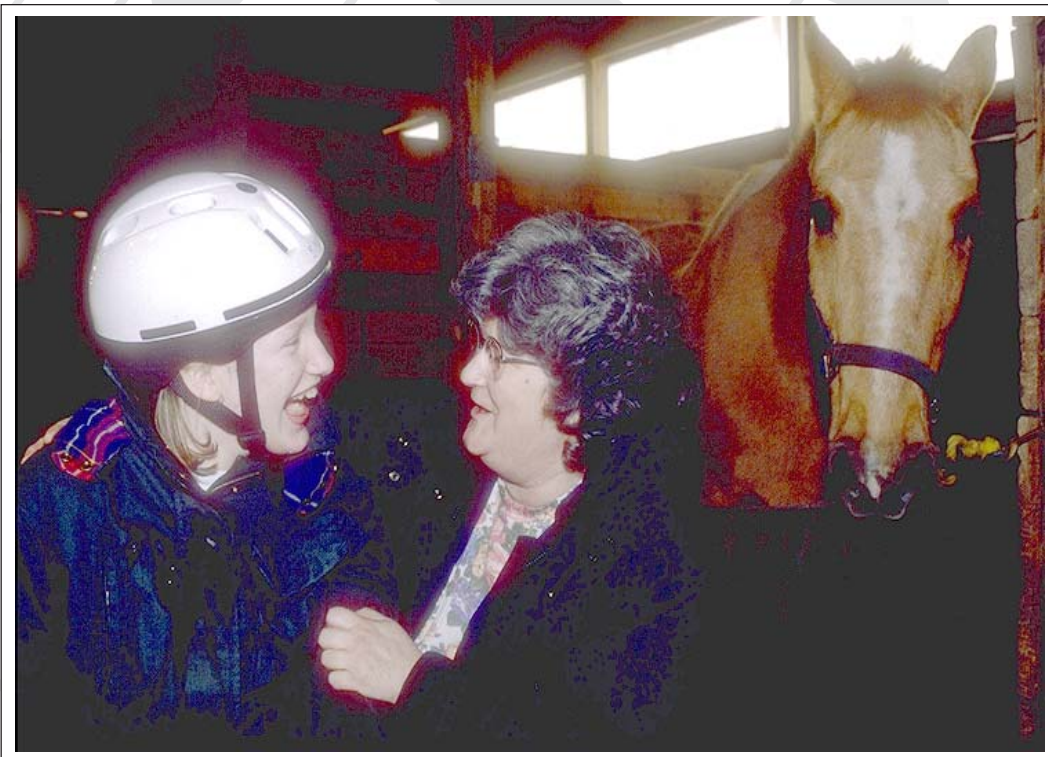
- 1. _____
- 2. _____
- 3. _____
- 4. _____
- 5. _____

Are there new responsibilities that you don't enjoy?

- 1. _____
- 2. _____
- 3. _____
- 4. _____
- 5. _____



Hugging in the Rain - Thoughts for Children with Special Needs



“When Robin was first placed in my arms as an infant I marveled at how cute she was. Now Robin is 11, and I still marvel at what a completely beautiful person she is, both inside and out.”

~ Becky Ehresman, Brookston, Indiana

I sat down with a pencil and a piece of paper last year and started to write in a “stream of thought” fashion: “When Robin was first placed in my arms as an infant, I marveled at how cute she was. Now Robin is 11, and I still marvel at what a completely beautiful person she is, both inside and out.” This line of thought was in response to a particularly difficult day for me and my daughter. She was entering puberty, a difficult time for any kid. I am so glad that Robin had already developed a positive self image and a strong network of caring and supportive people; a support system that has seen us through some pretty tough times.

Tough times come in all shapes and sizes throughout a lifetime. Being able to problem-solve rather than surrender; being able to establish and maintain a holistic balance in life; building courage by never fearing to try; taking due pride in all successes, great and small. These are valuable weapons in the war against despair and watching a much loved child battle with severe physical disability is certainly fertile ground for despair. The very foundation of my ability to regard my child with love and optimism is built on a firm belief in a loving God, Jehovah, with whom I talk daily regarding my fears, my hopes and my gratitude for being chosen to parent this special child.

The nicest thing that I can do for myself is recognize and accept my humanity. I can't fix all problems; I can't



be perfectly understanding all the time, and I may be a bit difficult for Robin's school system to deal with from time to time. But hey, it's O.K.!!!!

I think that the best thing that I can do for my daughter is to be a role model based on the strength of integrity, courage, and deep, abiding love. I need to remember to treat her in an age appropriate manner and be mindful of her emotional and intellectual normalcy. Well...whoever said it would be easy?

*~ Becky Ehresman, Parent,
Brookston, Indiana*

Thoughts for Children



“I think that the best thing that I can do for my daughter is to be a role model based on the strength of integrity, courage, and deep, abiding love”.

~ *Becky Ehresman*

Another group that has additional needs is the family with a child with a disability. Whether the child’s disability results from an injury or illness, some things remain the same – the disability affects the parents, siblings, grandparents, and friends. You will need to find as much help and assistance as possible!

Although the most common response to being told that your child has a severe disability is shock, disbelief, guilt, and a sense of loss, some parents choose to respond differently. Some of your family’s closest times and greatest joys can be the result of spending time together with your child who is disabled. Family members learn to work together effectively and find a special bonding, while other siblings may become more mature and caring.

When a child has a disability, the development of a positive self-concept may be difficult. Parents are usually so exhausted from the daily routine of lifting, helping, therapy, giving medication, and providing care that they sometimes forget activities necessary to develop a child’s positive self-esteem.

If you and your family accept, embrace, and show unconditional love for the child with a disability, the child’s self-concept tends to be good. The

following suggestions will foster a positive self-concept in your child.

- Focus on the positive aspects of your child’s body
- Focus on your child’s positive temperament traits
- Focus on the skills and abilities your child has
- Look beyond the disability and accept your child just as he or she is (13)

“I am so glad that Robin had already developed a positive self image and a strong network of caring and supportive people; a support system that has seen us through some pretty tough times.”

~ *Becky Ehresman*

Life on the farm can be a great place to build positive self-esteem. Spending time around plants and animals provides therapeutic benefits for children. A child sitting astride a horse, for example, experiences a sense of freedom and accomplishment that often cannot be duplicated through any other activity. Therapeutic horseback riding has shown benefits in improved general health and well being. Caring for livestock, having a 4-H livestock project, or even having a service animal can all benefit children with disabilities. Gardening, even if done in containers, can demonstrate to children the miracle of life as it grows through its seasons. A child’s self-concept can benefit from completing daily responsibilities around the farm.



Seeds That Will Help Your Child Grow into a Healthy Adult (14)

There are many seeds that you can plant in your child's life that will help them grow and mature into a healthy adult. Read the following list for "seeds" you can sow in your child during this season of their life.

- **Balance** – There's more to life than your child's disability. Find time for family fun and recreation
- **Communication** – Spend time listening to your children. Focus on understanding each other
- **Fun** – Find family routines that are fun for everyone (Friday night-pizza night)
- **Unity** – Commit to keeping family unity by sharing farm chores, responsibilities, and looking at the "bright side" of situations
- **Overcoming** – Learn new ways and identify new resources to assist you in overcoming barriers
- **Friends** – Maintain strong relationships with old friends. Children need relationships with other caring adults
- **Sharing** – Teach your children to share their time and resources with others

- **Service** – Encourage your children to participate in community service activities
- **Goals** – Help your children to set realistic goals
- **Involvement** – No one knows your child better than you. Develop quality relationships with the physicians and medical caregivers and share your child's medical information that will be helpful for the best possible care. Ask lots of questions including, "What benefit will my child receive from this procedure?"
- **Keep these thoughts in mind** – Don't second guess yourself by asking "what if?" Some things are out of your control; accept this situation instead of beating yourself up. When things are spinning out of control, remember you don't have to go through this alone, ask for help!

Resources for Children

There are many resources for children with disabilities. A few unique resources for farm children include, *A Perfect Fit: 4-H Involvement*, *Bridging Horizons – An FFA Advisor's Guide to Involvement for Members with Disabilities*, and *Backyards and Butterflies – Ways to Include Children with Disabilities in Outdoor Activities* (see Resource Section). All of these resources provide practical ways to include youth with disabilities in school and extracurricular activities. Another source is a comprehensive textbook, *Children with Disabilities – A Medical Primer* (Batshaw and Perret, Brookes Publishing). This text includes topics on home care, sources of funding, types of medical technology, caring and coping for the family of a child with disabilities, and additional chapters on more than ten different disabilities. Visit

your local library and browse through the resources and books available to help and encourage you.

There are also many community groups for parents of children with disabilities. Ask your pediatrician, special education teacher, or county health department for additional resources. Consider seeking help from inhome care agencies, visiting nurses, and rehabilitation counselors. Some groups will be informal and advertised only by word of mouth, while others can be found by contacting agencies listed in the Yellow Pages. As a parent or guardian of a child with a disability, you must seek

and develop as many partners in raising your son or daughter as you can.

“Being able to problem-solve rather than surrender; being able to establish and maintain a holistic balance in life; building courage by never fearing to try; taking due pride in all successes, great and small. These are valuable weapons in the war against despair.”

~ *Becky Ehresman, Parent*

Activities

Hugging in the Rain

Desired Outcome

This activity will prove without a doubt that a hug can make even a rainy day seem brighter and warmer.

Activity

Imagine the last time someone who you really care about gave you a great big bear hug. How long did the effects last?

_____ 1 minute

_____ 1 hour

_____ 1 week

_____ I still remember it!

Activities

Are you aware hugging is good for you?

Hugging is healthy: it helps the body's immune system, it cures depression, it reduces stress, it induces sleep, it's rejuvenating, and hugging is nothing less than a miracle drug.

Hugging is all natural: it is organic, naturally sweet, no preservatives, no artificial ingredients, and 100% wholesome.

Hugging is practically perfect: there are no movable parts, no batteries to wear out, low energy consumption, high energy yield, non-taxable, and fully refundable.

Assignment

Start with someone you care about and surprise them with a "reckless act of kindness" – give them a hug. Don't say anything. Don't expect anything.

Just give unselfishly. Make a list of at least five people that you will give a special hug during the next two weeks.

1. _____
2. _____
3. _____
4. _____
5. _____

Caution! Some folks are fearful of a hug. Respect those who want to maintain their "own space."

Personal Thoughts

Can you remember a time when you picked up a hurt child and soothed their pain and you were rewarded with a big bear hug? How did it make you feel?




Spring is in the Air - Teamwork and Laughter



“Love of family, joy of living, faith in God, trust in each other, and respect for the bond of family teamwork were proved to us...”

~ Marilyn Shankster,
Silver Lake, Indiana

 Carl was 32 when injuries in a car accident left him a T-12 paraplegic. At the time, we had eight young children to raise, ranging in age from nine months to eleven years.

Carl tried not to let the injury slow him down much. A teacher during the school year, Carl also operated a ditching and backhoe service. He always says the family was a great help to him both in the business and in his daily routine. Today, the oldest son is married, and the next eldest boy is planning to assume part of the family's business. Here's how our family recalls one event shortly after their father was injured...

Six months after Dad's injury, we decided to go camping. So onto our flatbed truck went all the supplies. At the last moment we realized we hadn't loaded one important item – Dad's four-wheeler, called "Sam." Off came three-fourths of our load to make room for "Sam." Then someone noticed "Sam" had a flat tire. So off to the tire shop we went – and another removal of half the load to get the tire repaired.

Finally, we were off to the camping site, a drive of some 20 miles. At the campground, the attendant was friendly, but informed us that it was illegal to operate "Sam" in the park without a license. (Later, to our pleasure, an exception was granted.) Three tents were set up by Mom and the boys, with Dad's exasperating instructions. As soon as it looked like Mom could finish things before dark, the boys and Dad dashed off to check out the fishing spot.



Since no block-and-tackle was available, a human chain was set up to skid Dad and his wheelchair down a gully to the bank. A dead log was set to keep him from rolling into the lake. Fishing, as it turned out, was TERRIBLE! The family only snagged one fish in three days! Was it worth it? Definitely. Here's what we learned.

- Teamwork is essential
- Courage is rewarded with satisfaction
- Determination reaps results
- Ingenuity is better than strength
- Love of family, joy of living, faith in God, trust in each other, and respect for the bond of family teamwork were proved to us!

*~ Marilyn Shankster,
Silver Lake, Indiana*

Teamwork and Laughter

“To us, what matters is an individual. To get to love the person, we must come in close contact with him. We ourselves feel that what we are doing is a drop in the ocean. But if that drop was not in the ocean, I think the ocean will be less because of that missing drop.”

~ Mother Teresa



Teamwork

Teamwork can make the days easier and the work and chores more enjoyable. Some of the best times come when you are working together as a team. It has been said it is easy to get the players for a team, the tough part is getting them to play together. That can be true of your family as well!

Helping your family work together as a team is definitely a key to helping you, as the caregiver, reduce some of the stress that you are facing. A few ideas that can help your family work more effectively as a team are:

- Hold regular family meetings to discuss chores, answer questions, and solve problems
- Honestly respond to questions that your children may have about the farm, the family or the disability
- Plan work according to each person's interest and have family members help one another
- Plan for regular fun time as a family. Maybe you all love playing Crazy Eights or basketball. Find that common fun activity that fosters unity in your family

Next time you have an unpleasant chore to do, get your children singing along with you. It will make the task more pleasant and the time to go by quicker. There's an old song that goes something like this, "There's nothing better than when family works together, when family works together, and we are having fun!"

“Teamwork is essential”.

~ Marilyn Shankster

Laughter

Allow yourself the pleasure of laughing. Read happy books and spend time with happy people. Laughter is not only contagious, it's good for your health. Start a hobby that brings a smile to your face. Maybe it's having a fish tank, planting flowers, painting or learning woodworking. Choose a hobby that brings you joy. Take time to think of three simple things that you can do that will make you and your family laugh. Commit to doing at least one of these every day.

Cultivate Laughter

The first sounds that babies make when they are born are cries of fear and discomfort – not laughs or giggles. Laughter needs to be cultivated and tended just like a flower bed. Encourage your children to laugh on a regular basis even if it takes a little tickling.

Board games, hide-and-seek, pillow fights and funny faces will usually crack the stiffest face and generate those deep belly laughs that have such a healing influence.

Sources of Humor (15)

Sources of humor are as close as your local library, video store or grocery. Pick one of the following resources and get a good belly laugh this week!

“We learned about the importance of the love of family and the joy of living...”

~ Marilyn Shankster

Books

Murphy's Law – Arthur Bloch

The Grass is Always Greener Over the Septic Tank – Erma Bombeck

Dr. Burns Prescription for Happiness – George Burns

The Fourth Garfield Treasury – Jim Davis

How to Eat Like a Child and Other Lessons in Not Being a Grown-up – Delia Ephron

How to Make Yourself Miserable – Dan Greenburg

Shoot Low, Boys – They're Riding Shetland Ponies – Lewis Grizzard

Momma Get the Hammer – There is a Fly on Pappas Head – Barbara Johnson

Put a Geranium in Your Hat and Be Happy – Barbara Johnson

Mouse Breath Conformity and Other Social Ills – Jonathan Winters

Lake Wobegon Days – Garrison Keillor

Please Don't Eat the Daises – Jean Kern

Audio Cassettes

The Ambassador of Goodwill – Jerry Clower

The Best of Bill Cosby – Bill Cosby

The Best of W.C. Fields – W.C. Fields

The Works – Groucho Marx

News from Lake Wobegon – Garrison Keillor

Crackin' Up – Ray Stevens

Video

Airplane

Back to the Future

Blazing Saddles

Making Mr. Right

The Return of the Pink Panther

The Making of the Stooges

The Films of Laurel and Hardy

“A cheerful heart is good medicine, but a crushed spirit dries up the bones.”

~ King Solomon

Activities

Spring is in the Air

Desired Outcome

Teamwork and laughter are as refreshing as a cool summer shower. This activity will help you laugh and work together as a team again.

Activity

Have you ever seen a sad person square dancing? Obtain your favorite square dancing music. Clear the floor in your living room, shop or barn and bring the whole family in for a good old-fashioned square dance, a few hollers and some hand clapping. The children will love it, you will laugh together, and even though you may not be able to “dance” with your disability... make the best attempt you can or you can be the caller!

Remember singing in the rain, dancing in puddles, or whistling and singing with a carefree heart can be refreshing for the entire family.

Teamwork – A Lesson in Thinking of Others (16)

Parents, this supplemental activity is for you. You're responsible for setting the climate in your home just as a coach cultivates a winning climate for a team. As the coaches on your team, ask yourself:

- What am I doing to make a contribution?

- Do I encourage time for fun, relaxation and privacy for my family?
- Do I really need the help I am asking for? Could it wait? Is it necessary?
- Do I let my family know that I appreciate the routine tasks that help me?
- Do I take the time for simple courtesies like saying “please and thank-you”?
- Have I planned something to make my family laugh or feel special?
- Do I help every member of the family feel a part of the team?

Assignment

Over the next week assess the amount of laughter that occurs in your home. Is there enough? Would you like to hear more?

If you would like to hear more laughter, select two or three activities from the suggestions provided and see if you can make it happen. Bring back the laughter and team spirit into your home and spring into life!

Activities

Personal Thoughts

How has the impact of disability effected the way your family works as a team or laughs together? In what positive ways?



A Time To Bear Fruit - Healing Through Service



“Even though there are many things Bob can no longer do physically on our farm, his years of experience and know-how as well as his emotional support are a real asset to us.”

~ Penny Piper,
Davenport, Washington



Bob has a T1 spinal cord injury with Syringomyelia. Penny Piper, Bob's wife writes these encouraging thoughts to her husband.

As a caregiver for the past 11 years, I have written down some things that came to mind as I think about Bob, whom I assist as a wife and caregiver.

I feel bad that this has happened to us. I'm so glad that you still want to be a part of what is happening on our farm. I still want you to be part of it; you are the best parts gopher and provide the best moral support possible. Your son and I appreciate that! Even though there are many things you are no longer able to do physically on our farm, your years of experience and know-how as well as your emotional support are a real asset to us.

We'll make the best of whatever happens. We'll plan ahead when we can, we'll take one day (or hour) at a time when we have to. Both of us have good days and bad days. I'll do my best to be understanding and hope you will too. I still love you. Keep smiling – it makes us all feel good.

You are my sounding board when I am discouraged or frustrated and I love you for allowing me to vent! You are also my cheering section and are quick to praise when things are going well! Thank you for being appreciative of our help and for occasionally telling us that you appreciate all we do.

On the days that your day-to-day care begins to get to me, you seem to sense it – then pick just the right moment to say, "Thank you, honey" or "Gee, I love you." And that puts it all back into perspective for me.

We also have learned over the years when we should keep our mouths shut and not say something we might regret. Hurt feelings can take a long time to mend – sometimes they don't – but a simple "I'm sorry" will help. We've all uttered those words more than once – we've all had our moments. Those moments are behind us, but there will probably be more, we aren't perfect.

Time helps to heal many different types of wounds. Humor usually makes it all seem bearable – that and a good night's sleep! We do a lot of good natured joking, and it really helps us.

For instance, we were all dressed up, on our way to dinner to celebrate our 30th wedding anniversary. It was pouring rain, and we were driving the van down the highway about 55 mph, when the electric motor on the wheelchair lift shorted out and filled the van with smoke – we won't go into the whole story – but it was not a fun evening! Several months went by before we were able to just look at the humorous aspect of our evening – but we're okay, and are able to laugh about it now.

Our lives changed when my husband became a paraplegic. Our lives had already changed when our son died in a car accident at age 17. Other people had survived such changes, so I knew we would too – it hasn't been easy – but I feel like we've made it!

*~ Penny Piper,
Davenport, Washington*



Healing Through Service

Giving Encouragement

“One of the highest of human duties is the duty of encouragement... Many a time a word of praise or thanks or appreciation or cheer has kept a man on his feet.”

~ *William Barclay*

As you read Penny and Bob Pipers story there is a common thread of mutual encouragement to one another. Who hasn't felt better from receiving one simple compliment or encouraging word. The exciting news is that anyone can decide to become an encourager to others. Maybe this will be the way you decide to serve others and forget about yourself. You won't have to look far for someone who needs encouragement and with a little practice you may be known as the most encouraging person in your community!

“You are also my cheering section and are quick to praise when things are going well!”

~ *Penny Piper*

Serving Others

The story is told of “The Keeper of the Spring,” a quiet forest dweller who lived high in the mountains above the village. The old man had been hired to clean the streams up in the mountains that fed the beautiful cool spring flowing into the village. Year after year he faithfully and silently removed all the debris and silt

that would otherwise contaminate the mountain stream. The crystal clear waters made the village popular for vacationers who enjoyed seeing the beautiful stream, swans and the naturally irrigated farmland.

Years passed and at a town meeting the accountant decided to fire this old man who was never seen doing his job. The town council decided he was no longer needed. In only a few short weeks after the man was relieved of his duties, the sparkling stream became discolored and full of debris. The town council quickly called an emergency meeting to hire back “the keeper of the spring.” The mountain stream was restored and all the village people were happy once again. (17)

What “the keeper of the spring” meant to his village, you mean to your town or community. Even if your acts of service go unseen, your contribution helps improve your town. Just like the village that could not live without this old man doing such a small task, neither can your community be the same without you using your talents, gifts and resources.

You may not consider yourself a servant or having something to give. However, service can be as simple as taking the time to listen to another person. A sincere compassion for others or taking the time to show a special kindness or gentleness to one in need is a great way to serve. Also, taking the time to say an encouraging word can change an entire person's life.

“Love is a fruit always in season.”

~ Mother Teresa



A Decision to Serve – Thoughts from Bob Piper

Since my son died at age 17 in an auto accident I have tried to channel my thoughts to positive ways of helping others. When life's events leave you in a wheelchair, it makes you assess how you have treated people, how people have treated you, how you want to proceed, and whom you want to ask along to help you. Simplified this means – I still want to be a nice guy and treat others the best I can!

I can't physically do some farm chores, so I have used the following as positive ways to serve others.

- Talk with newly injured patients at our St. Luke's Rehabilitation Institute
- Share my common sense farm background as a board member of our Independent Living Center
- Take on projects such as making a public service clip on the ADA for local television

- Tell others what people can accomplish with a physical challenge
- Assist with the awareness that persons with physical challenges can golf
- Give advice to a local pontoon boat builder for adapting his product; he was awarded a grant!
- Help start a CAST program locally (Catch a Special Thrill) to provide a day of fishing for children
- Volunteer to give common sense ADA adaptations for our Lincoln County Mental Health, Alcohol Drug Center, and Extension office
- Volunteer to input computer information at the local Soil Conservation office
- Talk to numerous people about adapting farm operations after an injury or illness
- Assist our Governor's Committee on Disability and Education to hold local meetings
- Take a Strobe light, a fluorescent vest, and a shovel to emphasize the need for snow removal on curb cuts in my wheelchair, one winter day
- Assist a local pharmacist making his front doors easy to use from a wheelchair so he could win an insurance contract
- Assist with a slide presentation at an AgrAbility Workshop!
- Explore many ideas to maintain my physical and mental independence!
- Maintain an upbeat and active attitude to help my wife and son

Activities

A Time To Bear Fruit

Desired Outcome

This activity is designed to get your focus off yourself and onto others. Whether you are the caregiver or the care receiver, it is easy to be consumed with self-centered thoughts that lead into a negative cycle of thinking only of your own needs, hurts or pain. Begin thinking of others today.

Activity

One way to take the focus off your own needs is to start to give and serve others. There are many simple, inexpensive ways to serve. Serving others not only brings satisfaction and joy, but also it encourages the one you are serving. In addition, it will help you from wallowing in self-pity or dwelling on yourself.

Assignment

Either by yourself or with your spouse develop a list of names of people or groups who could benefit from some type of help. You can encourage your spouse as well as others! For example, you may start by sending cards and letters to others who need encouragement in your community. Start a “telephone service” to call shut-ins, children who may be home alone or others who need someone to talk to. A short phone call, a card, a bag of groceries or a flower can go a long way towards brightening someone’s day. A little paperback book titled, *How To Make Someone’s Day – 365 Ways to Show You Care*, is an inexpensive book with the purpose of helping you “scatter seeds of joy” (K. Peel, Word Publishing, 1994). Buy one this week and try some of the simple ideas to help someone else. In the space below, make a list of those you plan to serve in some way during the coming ten days.

A Time To Bear Fruit

Name	What they need	How I can help	Date
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____

Activities

Personal Thoughts

Reflect on a time when **you** have wholeheartedly served someone else. How did you feel?

Consider a time that someone wholeheartedly served you. How did you feel?



Resources - Tools for Caregivers



**“Life is not a problem to be solved,
but a gift to be enjoyed.”**

*~ Mrs. L. Faulstich,
Monterey, Indiana*



Assistive Devices

Assistive devices can be very helpful for the caregiver. Adaptive equipment, methods or modified practices do not need to be expensive! Many devices can even be homemade or constructed locally. An especially helpful book for caregivers for low-cost solutions is *Easy Things to Make... to Make Things Easy-Hundreds of "how-to" suggestions for older people who have physical limitations* (see Resource Section). Local disability organizations can also assist you in devising low-cost, practical solutions. For example:

- There are plans for constructing accessible ramps for the home that can be built by volunteers, such as Young Farmers, a Scout Troop, or an FFA Chapter
- A low-cost intercom system can be installed to save steps and energy instead of making repeated trips to the bedroom or living room to check the needs of an individual
- There are equipment loan programs administered by local disability organizations such as the Easter Seal Society, senior centers, and local community groups that can help in obtaining equipment
- Services are available such as accessible transportation or "meals on wheels" which reduce the need to travel

"The family is the most important resource in assisting an individual return to a normal lifestyle."

Caregiving can be physically and mentally draining. The demands absorb a considerable amount of your time. Adaptive devices or practices can help make a caregiver more efficient and less fatigued.

The following section provides possible assistive devices to help you in your home and work.

Transportation

Wheelchair Transport

A rear-mounted wheelchair transport lift or rack allows a scooter or wheelchair to be transported without using cargo space.

Portable Ramps

Lightweight portable ramps can make many locations accessible.

Vehicle Lifts

Powered devices which lift a wheelchair and its user into a van without the assistance of others.

Transfers and Lifting

Lifting Systems

A wide range of electrically or manually powered devices lift users and eliminate difficult transfers. Lift systems can be purchased, which allow independent lifting from bed to bathroom, wheelchair to bed, and other applications.

Transfer Boards

Wood or plastic boards used as a bridge for transferring over a distance of one to two feet. Example: wheelchair to car seat.

Stair-Climbing

Stair Transporter

Small, tracked vehicles allow a user to climb and descend stairs.

Stair Lift

A chair permanently mounted on a track which moves the user up and down stairs.

Bathroom Needs

Bathtub Lift

A lift in the bathtub facilitates transfers and operates using water pressure or a mechanical lift.

Commode Lifts

Toilet seats can elevate users to a standing position.

Twin Shower Head

An extendible arm on the shower head allows the user to position the head.

Hand-held Shower

This shower head is on a slide bar mount which the user can position at any chosen height along a vertical slide bar.

Roll-in Showers

Allows wheelchair user to roll into shower or for those who have difficulty stepping over the side of a bathtub.

Anti-Scald Monitors

Regulates water temperature in the shower.

Walk-in Bathtub

Large volume tubs with a swinging seal-tight door and grab handles allow a user to walk in for bathing or therapy.

Shower & Toilet

Combination shower and toilet compartment is good for maximum use of area and reduces transfers.

Communication Devices

Cellular Phone, CB, FM Two-way Radios, Intercoms, and Bells

Having a proper communication device and a secondary or backup system is essential to reducing the potential of risk or injury.

Speech Output Communication Aid

Devices that allow users to type words or select pictures to verbally express themselves through computerized voice output.

Page Turning Device

Automatically turns book pages through an electric switch activated by the user.

Conveniences in the Home

Door Levers

Levers replace round door handles and improve access.

Swing Away Hinges

Hinges that allow increased access width by simple hinge replacement.

Pocket Doors

Sliding doors reduce obstructions and increase access.

Swing Up Cabinet Doors

Reduce the possibility of colliding with protruding doors for persons with visual impairments.

Home Pager

A device that signals the caregiver when an individual crosses an infrared beam.

Auto Door Opener

Units are activated by remote control to open doors for easy access.

Portable Ramps

Lightweight portable ramps can make almost any room or building accessible to persons using a wheelchair.

Recliner Seat-Lift Chairs

Comfortable chairs that use a lift under the seat cushion to elevate the user to a standing position.

Reaching Aids

Trigger activated tool that allows user to pick up items that are ordinarily out of reach.

Jar & Bottle Opener

Aids that allow the easy removal of the tops of jars or bottles. Can be either powered or stationary nonpowered unit.

Home Safety

Smoke Detector

Alerts someone of smoke by producing an audible alarm or by activating a strobe light for those with a hearing impairment.

Motion Detector

Motion sensors are mounted at strategic locations to alert you by a flashing light or audible signal that someone has arrived.

Strobe Light

Activated by an alarm, doorbell, telephone or baby crying, the strobe light flashes to alert you.

Visual Notification

Utilizing a flashing lamp, bed shaker and panel of lights, this system alerts you when the telephone rings, there is a knock at the door, an alarm goes off, and when the smoke detector or other audio alarm system is activated.

Emergency Escape Plan

The value of a well thought out family escape plan in case of fire or other crisis cannot be underestimated!

First Aid Kit

Every home should be equipped with a well stocked first-aid kit.

Fire Extinguisher

ABC fire extinguishers should be located in the kitchen, laundry room, garage and furnace area.

Computers

Home Design

Software for redesign ideas. Allows user to map out changes before making permanent modifications.

Computer TT

Computer software and an internal modem transform your computer into a text telephone (TT).

Computer Scanners

Scanners transfer written and photographic materials into the computer for further processing.

Software and Devices

Hundreds of software programs and assistive devices are available. These assist both the person with the disability and the caregiver to activate a computer to be: voice activated, print large print or Braille, or serve as environmental controls.

Voice Activated

There are hardware and software packages available that read aloud or respond to voice commands.

Video Magnifiers

Electronic system that enlarges text on a computer screen for easier reading.

Companion Dog

Working Dog

Common breeds such as Border Collie, Australian Shepherd, and Red/Blue Heelers can provide assistance to a person with a disability.

Service Dog

Dogs of several breeds guide and retrieve items for owners.



Funding Options

The primary funding sources for assistive technology can usually be categorized into either medical or vocational sources. Secondary sources include private or alternative funding. A partial listing of organizations that provide funding for or assistance in obtaining assistive technology include:

Medical Sources

- Private Insurance
- Medicaid
- Medicaid Waiver Services
- Medicare
- Bureau of Developmental Disabilities

Vocational Resources

- Vocational Rehabilitation Services
- Impairment Related Work Expenses
- Plan to Achieve Self Support
- Social Security

Disability Specific Organizations

- Easter Seal Society
- Muscular Dystrophy Foundation
- United Cerebral Palsy
- Multiple Sclerosis Society
- Paralyzed Veterans of America

Local Service Organizations

Elks, Moose, Lions, Rotary, Kiwanis, American Legion, Veterans groups, Foundations, Local trust, Churches, and Corporations.

Other Organizations that Assist with Financial Concerns

Institute of Certified Financial Planners
3801 E. Florida Avenue, Suite 708
Denver, CO 80210
303-759-4900

Medicare Consumer Line
P.O. Box 5798
Timonium, MD 21094
410-252-5310

National Insurance Consumer Helpline
110 William St.
New York, NY 10038
800-942-4242



Phone Numbers*

Aids to Daily Living Catalogues

Enrichments	800-323-5547
Independent Living Aids	800-537-2118
Ingenuity Inspiring Independence	800-645-5272
Rifton	800-374-3886
Sammons-Preston	800-323-5547
Sears “Home Health Care”	800-326-1750

Hand Tools & Equipment

A.M. Leonard, Inc.	800-543-8955
Gemplers	800-332-6744
Hard-To-Find Tools Brookstone	800-846-3000
Northern Tool & Equipment	800-221-0516
Ben Meadows Company	800-241-6401

Residential Hardware

Clairson International	800-874-0008
Van Duerr Industries	800-497-2003

Patient Aid Equipment

Guardian	800-255-5022
Invacare	866-533-5319

Automatic Door Openers

Horton Automatics	800-531-3111
Power Access Corporation	800-344-0088

Ramps

Universal Ramp Systems	800-648-3696
Van Duerr-Portable Ramps	800-497-2003

Kitchen Cabinets

Merillat	800-771-2158
American Standard	800-442-1902

* Adapted from the Missouri AgrAbility project

Vertical Wheelchair Lifts

Concord Elevator	800-661-5112
Cheney/American Stairglide	800-925-3100
National Wheel-O-Vator Co., Inc.	800-551-9095

Wheelchair Stair Lifts

Garaventa Ltd.	800-663-6556
Savaria, Inc.	800-931-5655

Stair Lift Chairs

Bruno Independent Living Aids	800-882-8183
Inclinor Co. of America	717-234-8065

Communication Products

HITEC Group International	800-288-8303
Innocomp	800-382-8622

Product Information/Research Sources

ABLEDATA (Database Searches)	800-227-0216
JAN-Job Accommodation Network	800-526-7234

Other Disability Related Catalogues

JC Penney	800-222-6161
LC Technologies	800-393-4293
Shop at Home	866-366-4010
The Complete Product Guide for People with Disabilities	800-952-2248
Maxiaids	800-522-6294
Hamilton's Assistive Technology Service	800-349-2499



Programs for Caregivers



ADOPT a Farm Family of America, Inc.

P. O. Box B
Sikeston, MO 63801-0936
573-472-4673
1-800-472-4674

The Cancer Care Counseling Line

1180 Avenue of the Americas
New York, NY 10036
1-800-813-HOPE

The Compassionate Friends

P.O. Box 3696
Oak Brook, IL 60522-3696
630-990-0010
1-877-969-0010

National Alliance for Caregivers

4720 Montgomery Lane
Bethesda, MD 20814
301-718-8444

The National Association for Parents of the Visually Impaired

P.O. Box 317
Watertown, MA 02272
1-800-562-6265

National Caregivers Foundation

801 North Pitt Street, Suite 116
Alexandria, VA 22314
703-299-9300
1-800-930-1357

National Family Caregivers Association

10400 Connecticut Ave, Suite 500
Kensington, MD 20895-3104
301-942-6430

Partners Promoting Interfaith Caregiving

368 Broadway Street 105
Kingston, NY 12401-0227
914-331-0016

Rosalynn Carter Institute

600 Simmons Street
Americus, GA 31709-4693
229-928-1234



AgrAbility Projects



National AgrAbility Project

University of Wisconsin
Biological Systems Engineering Dept.
460 Henry Mall
Madison, Wisconsin 53706
(800) 259-6280 (Toll Free)
(608) 262-0613
(608) 262-1228 (FAX)
rschuler@facstaff.wisc.edu

National AgrAbility Project

National Easter Seals
700 Thirteenth Street, N.W., Suite 200
Washington, DC 20005
(800) 914-4424 (toll Free)
(202) 347-3066 or (202) 347-7385
(202) 347-0711 (FAX)
cmaus@easterseals.com



Other Resources

Books and Publications

Agricultural Tools, Equipment, Machinery & Buildings for Farmers & Ranchers with Physical Disabilities, Purdue University, 2004.

As Your Years Increase – Loving, Caring, Preparing for Life Past 65, Tim Stafford, Harper, 1989.

Backyards and Butterflies – Ways to Include Children with Disabilities in Outdoor Activities, D. Greenstein, Cornell University, 1993.

Barn Builders – A Peer Support Network for Farmers and Ranchers with Disabilities, Breaking New Ground, Purdue University, 2002.

The Best of the Stroke Connection: A Collection of Personal Stories by Stroke Survivors and Caregivers, Courage Stroke Network, 1990.

Bridging Horizons – An FFA Advisors Guide to Involvement for Members with Disabilities, Purdue University, 1996.

Building a New Dream: A Family Guide to Coping with Chronic Illness or Disability, Janet Maurer and Patricia Strasberg, 1989.

Caregivers Products, Caregivers Inc. 1077 Race Street #804 Denver, CO 80206.

Caring Families Leader's Manual: How to Lead a Group of Family Caregivers; C.D. Fernald, J.R. Cook, C.A. Gutmann; The Family Caregiver Project at UNC Charlotte, Department of Psychology,

University of North Carolina at Charlotte, Charlotte, NC 28223

Caring for Yourself When Caring for Others, Marget Hover, Twenty-Third Publications, 1994.

Children with Disabilities – A Medical Primer, M.L. Batshaw, M.D., Y. M. Perret, M.S.W., Brookes Publishing, 1986.

Coping with Caregiving, HE-455, Purdue Cooperative Extension Service Publication, 1988.

Easy Things to Make Things Easy – Hundreds of “how-to” suggestions for older people who have physical limitations, D. Greenstein, Cornell University, 1996.

Family Centered Care for Children with Special Health Care Needs, T. Shelton, E. Jeppson, and B. Johnson, 1987.

Friendship Unlimited – How You Can Help a Disabled Friend, Joni Eareckson Tada, Zondervan, 1987.

Handicapped's Only a Word (HOW), Cooperative Extension Service, Derwood, MD 20855

Helping Yourself Help Others: A Book for Caregivers, Rosalynn Carter, Times Books, 1994.

How to Make Someone's Day, 365 Ways to Show You Care, Kathy Peel, Word Publishing, 1994.

The Joy of Caring, Gary Collins, Word Books, 1980.

Love is a Decision, G. Smalley and J. Trent, Pocket Books, 1989.

The National Council on Aging, Family Caregivers Program, 600 Maryland Avenue SW, West Wing 100, Washington, DC 20024

Family Home Caregiving Guides

Idea Book on Caregiver Support Groups

Guides for Caregivers Support Groups

Caregiving Tips

Assistive Devices

Managing Medications

Respite: You Deserve a Break

Taking Care of Yourself While You Take Care of Others

Neighbor to Neighbor – A Do-It-Yourself Guide For Organizing Farm Family Support Groups, Roger Williams, University of Wisconsin, 1987.

Parkinson's Disease: A Guide for Patients and Family, Roger Duvoisin, 1984.

A Perfect Fit: 4-H Involvement, A Leaders Guide for Involving Youth with Disabilities, Purdue University, 1992.

Preparing for Emergencies. A Checklist for People with Mobility Problems. American Red Cross.

The Resourceful Caregiver. Helping Family Caregivers Help Themselves, National Family Caregivers Association, 1996.

Resources for Rehabilitation, 33 Bedford Street, Suite 19A, Lexington, MA 02173, 617-862-6455

A Man's Guide to Coping with Disability

A Woman's Guide to Coping With Disability

Resources for People with Disabilities and Chronic Conditions

The Self-Help Sourcebook. E. Madara and A. Meese, St. Clares-Riverside Medical Center, 1990.

Today's Caregiver – The Magazine for People Caring for Loved Ones, 1814 NE Miami Gardens Drive, Suite 801, North Miami Beach, FL 33179.

When Bad Things Happen to Good People, H. Kushner, Avon Books, 1981.

When You're The Caregiver and When You're Ill or Incapacitated, J. Miller, Willowgreen Publishing, Fort Wayne, IN, 1995.

Where is God When It Hurts? Coming to Terms with Tough Times in Your Life, P. Yancey, Harper Paperbacks, 1977.

Words to Live By, Jerry Wiebel, Farming Magazine, 1990.

Videotapes

The Grit and Grace of Being a Caregiver – Maintaining Balance as You Care for Others, and You Shall Overcome – Promise and Prayers for Uncertain Times, Willowgreen Publishing, P O Box 25180, Fort Wayne, IN 46802

Music

Dino Kartsonakis, *Peace Series* – classical, hymns and nature sounds for a therapeutic affect. Dino Productions, 800-775-3466.

Internet

Caregiving Online:

<http://www.caregiving.com>

National Family Caregiver Association:

<http://www.nfcacares.org>

Patient Care Technologies:

<http://www.ptct.com>

Today's Caregiver – a quarterly magazine created for Caregivers by Caregivers:

<http://caregiver.com>

Mailing List for Caregivers – this is a discussion group for caregivers:

PUBYAC@lis.pitt.edu

National AgrAbility Project:

<http://agrabilityproject.org>

National Easter Seal Society:

<http://www.easterseals.com>

Job Accommodation Network:

<http://janweb.icdi.wvu.edu>

ADA & Disability Information:

<http://disability-resource.com/ada.html>

The ARC (information on individuals with mental retardation):

<http://www.thearc.org>

Resources for Caregivers:

<http://www.makoa.org/caregiver.htm>

National Association of Home Care:

<http://www.nahc.org>

Friends Health Connection:

<http://www.48friend.com>

Self-Help Sourcebook:

<http://mentalhelp.net/selfhelp>

Parents Helping Parents:

<http://www.php.com>

Medicaid and You:

<http://medicareinfo.com>



Footnotes

- 1 Caring Families, Leader's Manual: How to Lead a Group of Family Caregivers, C. D. Fernald, J. R. Cook, and C. A. Gutman. The Urban Institute, University of North Carolina at Charlotte, Charlotte, NC 28223
- 2 One Man's Vision, M. Teetor Meyer, 1995.
- 3 Parent Care, 1987.
- 4 Paraplegia News, January, 1992.
- 5 Modern Maturity, 1987, AARP
- 6 Love is a Decision, G. Smalley and J. Trent, 1989.
- 7 The Joy of Caring, G. Collins, 1980.
- 8 Self-Help Network, September, 1995.
- 9 Kemp and Vash, 1971.
- 10 Homebuilders, Family Ministry, P.O. Box 23840, Little Rock, Arkansas 72221, 1994.
- 11 Neighbor to Neighbor – A Do-It-Yourself Guide For Organizing Farm Family Support Groups, University of Wisconsin, Roger Williams, 1987.
- 12 Love is a Decision, G. Smalley and J. Trent, 1989.
- 13 A. Johnson, Auburn Family Institute, MA.
- 14 Children's and Youth's Health Issues, May 1996, Center of Children with Chronic Illness and Disability, University of Minnesota.
- 15 The Caregivers Survival Series; Preventing Caregiving Burnout; The Magic of Humor in Caregiving; Positive Caregiving Attitudes; and Creative Caregiving, Dr. J. Sherman, Pathway Books, Golden Valley, MN, 1994.
- 16 The Caregivers Survival Series; Preventing Caregiving Burnout; The Magic of Humor in Caregiving; Positive Caregiving Attitudes; and Creative Caregiving, Dr. J. Sherman, Pathway Books, Golden Valley, MN, 1994.
- 17 Improving Your Serve, C. Swindoll, 1981.



Notes



Final Thoughts on Caregiving

Your feelings may be stronger than you expect.

There are no “right or wrong” feelings. Everyone is different, people handle stress differently. There is no gauge for pain or suffering, but perhaps you can identify with some common reactions: fear and anxiety, anger, sadness and depression.

Your feelings are designed to be expressed.

Studies show that you tend to recuperate better and heal faster when you can release your feelings regularly. Sometimes it helps to have a good cry.

You are the most important person on your medical team.

Never forget you and the care receiver are a central part of the team. It's your body, your health and your future. You are the customer and you can direct your recovery by: insisting people use language you can understand, asking questions until you understand, and seeking second and third medical opinions.

Whatever is happening to you is happening to others.

Accept that people close to you will be making their own adjustments to what has happened to you. You are not the only one suffering or making adjustments.

However hard it may be for you, this is a time to take it easy.

For a period of time it is OK to switch from keeping busy and productive to relax and be patient with yourself.

This serious time is best approached with a sense of humor.

In the midst of anguish and fear, humor can divert your attention, bring joy and cheer up your day as well as your caregiver's. Research has shown laughter produces natural pain relievers.

You have the resources to do what you have been given to do.

You have survived past crises. You possess coping skills. As a farmer/ rancher you have already overcome many barriers. You have resources, including courage, hope, and faith.

~ Revised 2004, Purdue University

* Adapted and reprinted with permission from “When You’re the Caregiver – When You’re Ill or Incapacitated,” James Miller, 1995. Willowgreen Publishing, PO Box 25180, Fort Wayne, IN 46825 219-424-7916