But You "LOOK" Good!

"Why Seeing Is Not Believing When Dealing With A Chronic Illness!"

Written By:
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What Is A Chronic Illness, Anyway?

A chronic illness is a disease or disorder that a person has to cope with on a continuous basis. Many people become so ill, they are unable to work and are forced to give up activities they have always enjoyed. Often their illness goes undiagnosed for years, leaving thousands of people frustrated, depressed and without answers to why their bodies will not cooperate with their desires.

But They "LOOK" Fine! How Can They Be Ill?

Many chronic illnesses such as: *Arthritis, Brain Injury, Crohn's Disease, CFIDS, Cystic Fibrosis, Diabetes, Fibromyalgia, Heart Disorders, IBS, Lyme Disease, Lupus, Multiple Sclerosis, RSD and many, many more cannot be seen with the naked eye, but are nevertheless persistently keeping the person from enjoying life the way they once knew.

Unfortunately, their families and friends are not often supportive and understanding, because they do not *see* a broken bone or *bleeding* head to confirm the complaints. However, do not expect to see a disease that lives below the skin, because most illnesses are not obvious from the outside! Your friend or family member *needs* you to believe what they are saying is true, *without* judgment or question.

**This is only a very small sample of the hundreds of chronic illnesses that can be disabling; it is not intended to be a complete list of all debilitating disorders.*

So, They Have "Good" & "Bad" Days, Right?

Actually, not everyone with a chronic illness has the same symptoms or degree of symptoms; yet, there are basically three stages in any chronic illness:

1) **<u>THE EARLY STAGE</u>:** This person may notice occasional symptoms or lack of energy. They start experiencing setbacks from activities that previously never took a thought. If diagnosed in this stage, which is rare, many can get help from their doctors and proper nutrition to cure or prevent further progression of the disease. *This person has mostly "good" days with occasional "bad" days.*
2) **<u>THE MIDDLE STAGE</u> (or the Relapsing/Remitting Stage):** This person may have frequent bouts of symptoms and is forced to make limitations for themselves in order to avoid extreme fatigue and relapse of illness. They reluctantly begin discovering that the simple things they used to enjoy, now must be done with care or sacrificed completely. In this stage, some can lower the frequency of relapse and progression of the disease with help from their doctors and proper nutrition. *This person has both "good" and "bad" days, depending on activity and stress.*
3) **<u>THE LATE STAGE</u> (or the Progressive Stage):** This person's disease has progressed to the point where it does not remit. They live each and every day with symptoms that feel much like having the stomach flu, complete with extreme to unimaginable fatigue, muscle aches, weakness, nausea, cognitive difficulties, dizziness and/or pain.

   When they push themselves to do what used to be easy, like dusting a piece of furniture, going to a relative's house or doing a load of laundry, they pay a high price, because their symptoms worsen to an unbearable level for days and even months. In cases like Multiple Sclerosis, the treating drugs available are effective only for persons in stages 1 and 2. *This person does not have "good" days, only "bad" days and "horrific" days.*

Well, I Still Don't Understand!

At least once in your life, you have probably experienced having to stay home from work or school, because you were too sick to go; and, I have yet to meet someone who has never had a cold or the flu, tell me they are having the time of their lives and enjoying every minute of it! Or, you may have been hurt in an accident and were *forced* to give up activities you *loved* for weeks or even months. So, you know how stressful, depressing and frustrating being *unable* to do what you *want* to do can be!

Now, when I refer to being *sick*, I am not talking about feeling just a little "under the weather" or just not "up to" going to work that day. I am talking about being so *sick* you can barely sit up or talk, having a fever that makes every muscle ache and your bones feel like they are being crushed. Then, when you try to get up to go to the bathroom, your head pounds, your body feels like it weighs a ton and you become dizzy and nauseous.

Just imagine feeling that way every single day, week after week and year after year. True, some chronic illness sufferers have a few "good days" in between, but many do not have *any* at all! So, if you see them out and smiling, does that mean they are having a "good day?" Not necessarily! Many times they cannot wait for a "good day" to get out, because they do not have them; thus, they make the sacrifice, sitting there in horrible agony and knowing they will pay dearly for it later!

Do not expect a loved one to always be content with being sick day in and day out! After all, most people become very frustrated and impatient after just a few hours of being sick. Then, if it lasts a few days, they become panicked and angry about missing work, school or other activities. Next, they become depressed and act like a week out of their busy lives is the end of the world! Yet, they often treat their loved ones as if losing months and years out of *their* lives is no big deal! So, why would you expect your loved one to be happy with losing years of *their* lives, when *you* cannot stand to even lose a few days?

It is true, you will never fully comprehend what it is like to be chronically ill, with all of the loss and pain it poses. You will never know what it is like to feel horrible every day and you will never have a grasp at what it is like to watch your lifetime dreams come crashing down forever. So, stop using the excuse that you do not have *understanding* and start focusing on whether or not you have *compassion!*

In all, your loved one just wants you see their *courage* in enduring a life of feeling sick, achy and exhausted all of the time; and, you have the capacity to know you would not want to feel this way every day yourself! You know how horrible it is to be sick and forced to put your life on hold for a while, so why don't you tell them how amazed you are at their *strength* and *perseverance*!

But, What If They "Give In" To The Illness?

When a young ice skater named, Nancy Karrigan was assaulted and suffered a leg injury, she faced the possibility of losing all of that which she had dreamed; the whole world cried with Nancy, because it could have meant the end of her skating career! Yet, when a person loses their job or is forced to give up *their* career due to *illness*, for some reason people often treat them like they are *choosing* to do so; and, they are often insensitive to the fact that the sufferer has lost all for which they have worked, planned and hoped for their future... just like Nancy.

Most people do not "give in" to illness; in fact, it is ingrained in our nature to fight to survive as hard and as long as humanly possibly. If you believe that your loved one is "giving in" to the illness, because they have given up their usual activities, this is just your perception of how they are handling their limitations.

When a person first experiences the effects of a chronic illness, they have a fantastic attitude about conquering it; they feel *strong* and *invincible* to its grip. Even if the disease progresses, they will continue to *fight* for their right to live the way they planned their lives to be; and, they will stay *persistent* in the battle until their bodies *force* them to make limitations.

Creating limitations for oneself is one of the hardest things a person can do. It goes against everything we are and everything we ever hoped to be. No one *wants* to be sick and no one ever *chooses* to give up those things in life that bring such joy. Yet, these limitations are mandatory in managing a chronic illness; so, respect their new boundaries by acknowledging their losses and supporting their need to say, "No."

It Seems like I Am Always Saying The Wrong Thing!

What can sometimes be even harder to bear than the illness itself, it is feeling alone in the daily struggle and mourning of lifelong dreams. As pieces of oneself die off bit by bit, isolation consumes them when others refuse to affirm their pain. By repeatedly trying to *"cheer them up"* and make them see the *"bright side"* you are not validating their pain, but instead saying, "I don't want to hear the truth" or "your losses don't matter." On the other hand, if you *acknowledge* their losses, they will no longer be compelled to *gain your belief* by having to explain their situation over and over again.

Resist the temptation to make a visual diagnosis by saying, *"gee, you look like you're feeling good today"* or *"hey, you must be doing well."* They may *look* like they are feeling well, because there is joy in their face from seeing you; however, your comment will only make them realise they are alone in their battle, since you are evidently unaware of their insurmountable hurdles.

In other words, by rebutting their answers with, "But you *LOOK* good," your friend really hears, *"But, I don't believe you, because you look fine to me."* Instead try*, "I am so glad to see you," "wow, I can't imagine what you go through, you are amazing!" "you look nice today,"* or *"how can I pray for you?"*

Encourage your loved one by affirming your *trust* in them, loving them and *showing* them that they are still just as *valuable* to you even if they can no longer do the things they used to do; your willingness to *acknowledge* their losses will give them the strength and positive attitude they need to fight the illness, instead of wasting their energy fighting with you to *believe*. They are not seeking your *pity* or *sympathy*, they simply want your *compassion*; some will need your help, just listen, they will tell you how.

We, as chronic illness sufferers, do not want to give up; we want to laugh, smile, look our best and enjoy life; after all, it is our incredible *courage, perseverance* and *persistence* to fight for our lives that make our painful disabilities *seem* invisible to the naked eye.

"Learn To See With Your Ears!"

I Never Know What To Say!

Tips On What Encourages & What Discourages Someone With A Chronic, Debilitating Illness!

Written By:
The Invisible Disabilities Advocate,
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It Seems Like I Can Never Get It Right!

Have you ever wanted to encourage someone with a chronic illness, but it seems like you never know what to say? And, when you finally think of something you know will make them smile, they just snap back at you with frustration?

This booklet will give you a sample of what comments are discouraging and what comments are encouraging and why people suffering from these illnesses feel that way.

I Still Do Not Understand Where They Are Coming From!

The intent of this booklet is to list some "do's" and "don'ts" and to explain how some well-meaning comments can be heart-wrenchingly painful to someone suffering from a chronic illness; you may not understand it completely, because you are not the one suffering from a debilitating disease. Yet, if you desire to encourage your loved one, rather than to discourage them - read on!

Couldn't I Just Try To "Cheer Them Up?"

They will smile when you tell them you are sorry for what they are going through, not when you tell them it is "not that bad" And, they will find strength when they can stop using their energy in attempt to gain your support, because they no longer have to fight your disbelief.

But, I Really Do Think My Suggestions Are Helpful!

The purpose of this booklet is to explain to you why some of the "answers" you have may be hurtful, destructive and actually make you seem as if you really do not care at all.

Your loved one does not need to feel as if they are fighting for your belief, respect and compassion in addition to fighting for their lives!

So, Why Do I React That Way?

There are four basic, natural emotions that occur in response to seeing a loved one become ill. All of these emotions stem from the first stage of tragedy, called denial. Although these reactions are normal, they are often followed by comments which make it apparent to the sufferer that you are not only in denial, but you are refusing to step along side to support them in what they have lost and what they are facing.

What "Discourages" A Chronically Ill Person?

Do Not Disagree With Them, Because You Can't See It:

"But, you don't look sick!" "But, you look like you feel good!" "But, you look good!" "But, you are here, so you must be doing well!" "But, you look fine to me!"

Often, someone will take the time to ask with all sincerity what it is really like to have a chronic illness and what the person is going through. This makes them feel loved and truly cared about until, after they explain their situation, you oppose what they are telling you.

When you say things like, "but, you don't look sick," you are really saying, "but, I don't care what you are telling me, because I can't see it, so I don't believe it." They are being honest with you, try to believe in them and be strong for them.

Do Not Minimize Their Situation:

"It is not that bad!" "It could be worse!" "You're lucky you don't have to work!"

Trying to act like having lifelong hopes, dreams and desires stolen away by a disease is "no big deal," is not only extremely hurtful, but ridiculous! Unless you are in their shoes, you have no right to tell someone "it is not that bad," when you are sitting there knowing you can get up the next day and reach for your goals.

Do Not Act Like You Can Relate:

"I know what you mean, I'm always tired, too." "Join the club." "Ya, I can't get anything done, either." "Hey, I would like to have a maid, too."

If you do not have a chronic illness, you do not know what it means to be sick all of the time! For some reason, people tend to think that if they do not show they can empathize, then they cannot show compassion. Yet, in this situation it backfires, because you cannot empathize!

Many sufferers' resent comments like, "join the club," because the well person does not have the right for one minute to think they are in the same boat. If a friend is exhausted at the end of the day, I will give them all of the compassion they need; but, when they try to tell me they feel the same as I do, I have to draw the line.

What "Encourages" A Chronically Ill Person?

Acknowledge Their Situation:

"What you have been through is horrible!" "I can't believe what you must go through every day!"

Often times when a person is ill, the people around them refuse to move out of denial about the situation. Instead of listening, believing and showing compassion for what they have been through and what they are facing on a daily basis, they refuse the facts and minimize the severity of the disease.

Acknowledging your loved one's situation lets them know that you are there to accept the facts and move on to practical help. They will know that you are truly there for them to help them deal with their limitations and adjustments. But most of all, they will know that you love them even in their broken state and respect them for their perseverance!

Acknowledge Their Losses:

"I am so sorry you can't work anymore!" "It must be horrible, because you can no longer..." "I can't imagine what you have been through!"

Losing the ability to participate in activities, work and enjoy hobbies is incredibly devastating.

Acknowledging their losses will show them you have compassion for what they can no longer do or enjoy. Most of all, it shows that you believe that losing their ability to do something they once had is something that is unimaginably heart-wrenching for them and not in any way something they have wilfully chosen for themselves!

Show Them You Are Listening:

"Honestly, how are you doing?" "How can I pray for you?" "So, what is really going on?"

If your loved one tells you they do not have "good" days and are instead very ill every single day, stop asking them how they are feeling if all you want to hear is that they are feeling good! - Doing this only makes them realize you are not listening, have absolutely no idea what they are going through and will not love them until they get better or lie.

Instead, why not try, "how are you doing?" This will spark an answer that addresses how they are dealing with their challenges, struggles and emotional state, which, unlike how they are "feeling" can fluctuate.

Being A Comfort In The Face Of A Tragedy

In all, you honestly mean well and truly want to be an encouragement and comfort to others - Yes, accepting what is happening to your loved one means having to deal with all of its pain, mourning and changes, but do not sell yourself short! After all, if they are *forced* to *live with it*, you can certainly *choose* to *live next to it!*

"Truly Love Me, By First Believing In Me!"

I Never Know What To Do!

Tips On How To Help Someone With A Chronic, Debilitating Illness!

Written By:
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The Balancing Act!

Many people think a person with a chronic illness has a lot of time on their hands, when nothing could be further from the truth. In fact, most chronic illness sufferers do not get the rest they need, because they are so busy spending all day trying to do the things that a "well" person can do in one hour.

Dreaded Limitations!

In order for a chronic illness sufferer to visit with a friend or attend a social gathering, even more daily sacrifices have to be made in order to prepare for the event - They do this by avoiding any other outings or projects around the house for several days, because the energy it takes to sit, smile and talk is incredible! And, by exerting themselves, they will then suffer the consequences for several days, weeks or months and end up even more behind on their daily duties.

So, should you avoid asking them to spend time with you? Absolutely not! Spending time with friends and family who care, gives incredible strength and will to keep fighting the battle! Go ahead and invite them, but allow them to say, "no" if they have to, realizing they would if they could. By showing you want to spend time with them, you will make them feel loved and important.

So, Where Do I Start?

First, it is difficult to recognize there is a need, by simply looking at someone with a chronic illness; often they appear physically able to accomplish any task set before them...

Unfortunately, most people make the mistake of overlooking what their friend or family member is telling them, because they cannot see the disability. Therefore, the first thing you must do, is to learn to listen to their needs, without discounting them with your eyes.

So, What Can I Do?

- As previously mentioned, a person with a chronic illness will tell you how you can help, if you simply listen. Often, they need rides to doctor appointments or would benefit greatly if you could run an errand for them.
- They know you are busy, overextended and do not have a lot of leisure time; they do not want to add to your pressures. The secret to getting them to accept your much needed help is to do something that is convenient for you.

You can do this by -

Another way to approach them is to -

Or try -

And, What Else Can I Do?

Something most people don't think about is - When you go to visit your friend

Another way to ease their housekeeping situation is to - you would not even have to break a sweat!

Because getting out is often too exerting, you can

In all, remember to listen, believe what you hear, allow them to say, "no" and offer specific help that is convenient for you. Do not worry about making time for hours of strenuous help; what is simple for you could save days of excruciating work for them!

"Just A Little Bit Of Your Time Can Make A Very Big Difference!"

DISABLED?
You Don't *LOOK* Disabled!

Unmasking Society's Depiction of People with Disabilities.

Written By:
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The Survival of the Fittest

In a generation of microwaves, fast food and fax machines, we are a society on the run. We fill our days with 200 things to do, even though we only have time for 100. From the time we get up to the time we go to bed, we are running around at work, at home and all over town. Between the stresses of our jobs, our family and trying to fit in the pleasures we enjoy, we simply do not have time to sit around.

When we feel a cold coming on, we cringe and yell, "I don't have TIME to get sick!" After all, we are way to busy to even think about missing a moment lying in bed, miserable. So, we call the doctor, begging for a prescription that will make it all go away and fast! We may only be down for a few hours or maybe even a few days, but we hate every moment of it! We whine and cry to those around us, moan in pain and panic as we watch the clock wasting away our precious time.

Soon, we are back on our feet and back on track, forgetting how horrible it was to have to put things aside, feel terrible and not able to do what we want to do. Yes, we are a world that is accustomed to popping some pills or vitamins and we are back in the race, feeling like our determination could defeat any viral army. After all, we did not stay sick for long because we acted, had a positive attitude and by gosh "we were not going to let any illness keep us down!"

So, when we are confronted with a person who has been sick for months or even years, we naturally think, *"hmmm... they must be lazy and unmotivated. They must not want to work. They must not be doing what their doctor is telling them to do."* Otherwise, wouldn't they just take some medicine like you did and get better, just like you did?

What an unpleasant person to be around! Who wants to spend time with someone who *enjoys* being sick? Who wants to rub elbows with a person who does not have any goals or aspirations? Who wants to be with someone who *complains* or just wants *pity?* And, who wants to catch it?

No! We want to be in the company of people who have made something out of their lives; people who have furthered their education, careers and families; people who are involved in volunteer work, successful business owners, doctors and parents of great kids. Not the people who are limited, sick or do not fit the mold of what we should all look like and make the money that we should all be making!

Dr. Jeffrey Boyd wrote:

> *If you turn on TV or open most popular magazines, you are confronted with healthy and beautiful bodies of models under the age of thirty. That is what life is supposed to be about, or so we are told. We are all supposed to enjoy our bodies, exercise aerobically, be sexy and drive glamorous new cars and remain under the age of thirty without showing any effects of age, gravity or disease. Or at least that is the "hype" (Boyd, Tribute to an American Heroine, 2001).*

Society tells us that we can measure a person's character by what they drive, the size of the house they live in and the labels on their clothing. Many people often talk about their friends as being "successful" or a “prominent figure," as if their worth as a human is elevated when they have conquered the latter to financial status.

Often people are described by their profession; like in game or talk shows, people are introduced as, "this is Joe, a teacher from California." We are obsessed with what people “do” for a living. Sure it is interesting to find out what careers people are in; but it is sad when we define ourselves by our careers and not by our character.

We get so wrapped up in "who we are" being defined by "what we do" that it is no wonder why so many who become disabled also become insecure and feel like their lives no longer have importance. Laura, a woman with Interstitial Cystitis wrote, "I was a RN, but now am nothing, worthless and useless, homebound and on Social Security" (IDA Guest book, August, 2000). How sad that our very beings, character and purpose in life are supposedly depicted by what kind of work we are in and how successful we are at it!

Now, not all people with disabilities are unable to work; contrary to popular belief, "more than three- quarters (77.4%) of Americans age 22 to 64 with [non-severe] disabilities do not receive public assistance" (U.S. Department of Commerce, Disabilities Affect One-Fifth of All Americans, 1997).

For some, their illness or impairment may mild, allowing them to continue their careers and life goals; for many, with some limitations, medications and/or assistive devices, they are able to continue their professions; for others, they may be very ill or have great limitations, so it is all they can do to get through the day, but they push themselves with great effort to stay employed.

On the other hand, only 26% of those who have severe disabilities are still able to work (U.S. Department of Commerce, Disabilities Affect One-Fifth of All Americans, 1997). Yet, most of them are not quitting or giving up, because they want to! Instead, they mourn their inability to fulfil their lifelong goals and careers.

Frequently, at a funeral you will hear of people describing their loved one as a "productive member of society." But what if the person were not very productive? What if the person were bedridden or physically disabled? How then would we measure their character and worth as a human who takes up space on this planet? Would their life be as important or impacting on others? Could they have had a meaning or purpose, even though they were unable to work?

There seems to be no room here for people who cannot pull their own weight. People work hard and they get angry to think that others are drawing taxpayers' money for doing nothing. They feel that, "if I have to work, so should you." But, they do not realize that their being *able* to work is a *privilege* and a *blessing*, not a *curse.* In fact, most people with disabilities are not *lazy;* they *want* to!

People with severe disabilities, who can no longer work, grieve the loss of being able to excel at their talents and utilise their gifts. I do not know anyone who would *choose* to be in pain, unable to do what gives them joy and have to fight for a measly check that is about 10%-20% of what they would be making if they could work!

Let us not be like the general population of this ruthless world. We all need to realise that every person is valuable, despite the fact they may not be physically able to function normally, look like everyone else or be a prominent figure. What kind of people are we if we are judging someone by their outward appearances, ability to contribute and what they can "do", in order to measure their value? Everyone has a gift, a purpose and the ability to impact other lives *despite* their physical condition.

Of course, if a person is healthy and able bodied, there is nothing wrong with expecting them to contribute, work, be a parent or even volunteer. Sitting around, doing nothing, expecting handouts and taking advantage of others when they are perfectly able to function is not upright, responsible, moral nor Biblical.

Yes, there are people in this world who try to cheat the system. Because they do not want to work, they jump through a lot of hoops to get free money, free food and free housing, all based on the lies of a lazy man. This lifestyle and attitude is appalling and abhorrent. Let us be careful not to treat everyone with an illness, injury or disability like they belong in this group of unethical, indolent frauds!

What is a Disability?

In 1991, it was determined that:

> *"Due to a variety of physical, mental, and emotional conditions, an estimated 49 million non-institutionalised Americans (about 1 in 5) have a disability. Of these persons, 24 million have a 'severe' disability." (U.S. Dept. of Commerce, Americans With Disabilities, 1994).*

When we see someone getting out of a car that is parked in the handicapped zone, we usually look to make sure that person is actually disabled? Sometimes we even wait in our cars to see if the person getting out is actually handicapped. After all, those spaces are saved for someone who has a legitimate need to park there! And, it is a good and noble thing to make sure nobody is cheating!

Consequently, when we see someone stepping out who is not using a cane or a chair, don't we get angry! Sometimes we even get so upset that we go out of our way to give them a dirty look or yell something at them! Hey, we do not want to see those spots abused, because we know they are for people who actually need them!

So, what if someone who looked fine on the outside tried to tell us they needed to park there? Wouldn’t we think they were lying or just lazy? What if they had a handicapped placard or license plate? Wouldn't we assume they must have stolen the card or borrowed the car? For goodness sakes, we can all tell who is handicapped and who is not, it is OBVIOUS! ... Or, is it?

The truth is, there are millions of people in this world who suffer from what I call, "invisible disabilities.” They may have a ruptured disk in their back, a spinal injury, brain injury or a disease that is attacking their cells, muscles and/or nervous system. They may have heart problems, lung problems, neurological disorders, severe pain and/or weakness. In other words, their debilitation is just as real, even though the damage lies under the skin.

There are many reasons why a person with an illness or injury must use a handicapped parking space: they must stay out of the heat and/or cold; they may use an electric cart once they get inside; walking through the lot, plus walking through the store is just too much; it may be all they can do to pick up a few items at the grocery store once in a great while and without that space they could not make it; some cannot remember where they parked unless their car is visible from the store; and others wear themselves out in the store so much that they need their car to be close when they leave.

> *It can be quite humiliating and frustrating to be a person who has a physical need and legal right to park in handicapped when others stare, yell and even become confrontational. Sara, a woman with Multiple Sclerosis wrote, "I had a person chase me down in the parking lot of a grocery store telling me that I should be ashamed for using a handicap parking space (I have a placard)..." (IDA Guest book, 2/2000).*

Unfortunately, this kind of reaction is all too common. These spaces are reserved for those who have many types of disabilities, whether they are visible or not to the onlooker. The fact of the matter is, if the person has a handicapped license plate or placard, it is not for you to judge if they have a need to be there, simply by they way they *look* on the outside. Therefore, let us be sensitive to those who are living with illnesses, injury and debilitating pain, for *"blessed is he who has regard for the weak; the Lord delivers him in times of trouble"* (NIV, Psalm 41:1).

On the other hand, if you know for a fact that this person is abusing the spot, by stealing or borrowing someone else's placard you can call the local sheriff's department; they can be ticketed and the placard can be removed. If they do not display a plate or placard at all and are just boldly misusing the parking place, you can tell the store manager or security officer.

There are millions of people who suffer from illnesses, injury and pain that make us feel like we are trying to climb a giant mountain with every step. To the average person, some of us may not look like we have a disability, because society thinks that "disabled" = a visibly noticeable impairment or visibly noticeable need for a wheelchair, cane, crutches or walker. Nonetheless, we often collapse in stores, parking lots and restrooms, just trying to get out and pick up a few things that we need.

In 1994-1995, the Survey of Income and Program Participation (SIPP) found that:

> *...20.6 percent of the population, about 54 million people, had some level of disability; 9.9 percent or 26 million people had a severe disability....1.8 million used a wheelchair....5.2 million used a cane, crutches, or a walker... (McNeil, Americans With Disabilities: 1994-95, 1997).*

Notably, 26 million persons were considered to have a severe disability; yet, only 7.0 million persons used a visible device for mobility; thus, 19 million people who were defined as severely disabled, did not use a wheelchair, cane, crutches or walkers. In other words, 73% of Americans with severe disabilities do not use such devices; therefore, a disability cannot be determined solely on whether or not a person uses assistive equipment.

Many experts conclude the amount of people suffering from chronic illness is increasing, because of the improvements in medicine in the past 2 centuries. The reason being, with past medical care many people with various illnesses and injuries would not have survived. Today, they are kept alive with drugs, surgeries and treatments; yet, the improvements have not been sufficient to cure them or make them well enough to live without symptoms.

Jeffrey Boyd added:

> *The fundamental issue is that contemporary medicine is often able to delay death but not restore health, so that the more "breakthroughs of modern medicine" we have, the more sick people we have. I say this without sarcasm and without cynicism (Boyd, Tribute to an American Heroine, 2001).*

So what does "disabled" mean? Let us be honest. The label, "disabled" is quite confusing! We see special interest stories all of the time on television about a disabled person who just finished a marathon or is on a ski team. They are labelled as disabled, because they are no longer able to run on their own legs. Yet, they do not like to be called DIS-abled, because they are still ABLE, active and vital to do many things. They feel that even though they may have a limitation or obstacle, they are certainly *not* unable or DIS-abled.

Work Disabled:

The Social Security Administration defines being disabled in regards to being unable to work for at least one year, thus qualifying for disability benefits:

> *Disability under Social Security is based on your inability to work. We consider you disabled under Social Security rules if you cannot do work that you did before and we decide that you cannot adjust to other work because of your medical condition(s) (Social Security, Disability Benefits, 2000).*

Because Social Security makes payments to those who are work-disabled, their definition falls under the guidelines of no longer being able to work. Thus, they do not decide if someone has a disability, instead, if they are disabled or unable to work.

Having a Disability (in the workplace):

The Supreme Court recently redefined the definition of having a disability in its relationship to limitations in the workplace for the American Disabilities Act (ADA) and the Equal Employment Opportunity Commission (EEOC):

> *This year, the Supreme Court held... that the determination of whether a person has an ADA "disability" must take into consideration whether the person is substantially limited in a major life activity when using a mitigating measure, such as medication, a prosthesis, or a hearing aid. A person who experiences no substantial limitation in any major life activity when using a mitigating measure does not meet the ADA's first definition of "disability" (a physical or mental impairment that substantially limits a major life activity) (EEOC, Instructions..., 1999).*

One example might be of a person who is legally blind without glasses, but not with glasses. They would not be considered as having a disability under these regulations, because the eyesight is no longer limiting with glasses. But, if even with glasses, their eyesight substantially limits them, then they would be considered to have a disability.

Having a Disability (in life, daily living and work):

What constitutes having a disability or a severe disability under the regulations of SIPP, according to the Census Bureau:

> *A person is considered to have a disability if he or she has difficulty performing certain functions (seeing, hearing, talking, walking, climbing stairs and lifting and carrying), or has difficulty performing activities of daily living, or has difficulty with certain social roles (doing school work for children, working at a job and around the house for adults) (U.S. Department of Commerce, Disabilities Affect One-Fifth of All Americans, 1997).*

> *Adults aged 15 and over were classified as having a severe disability if they used a wheelchair or had used another special aid for...were unable to perform one or more functional activities or needed assistance with an ADL [Activities of Daily Living] or IADL [Instrumental ADL], were prevented from working at a job or doing housework, or had a selected condition including autism, cerebral palsy, Alzheimer's disease, senility or dementia, or mental retardation (U.S. Department of Commerce, Americans With Disabilities, 1994).*

Generally, if a person has a physical limitation that limits major life activities they have a disability (or impairment). Now, that disability may not keep them from being able to work or participate in various activities with equipment to help them, some limitations or accommodations.

In fact, according to the U.S. Department of Commerce:

> *"In the prime employable years of 21 to 64, for example, 82 percent of people without a disability had a job or business compared with 77% of those with a non-severe disability..." (U.S. Department of Commerce, Disabilities Affect One-Fifth of All Americans, 1997).*

In other words, almost the same percentages of people with mild to moderate disabilities are working as people without disabilities.

On the other hand, only "26% of those with a severe disability" (U.S. Department of Commerce, Disabilities Affect One-Fifth of All Americans, 1997) are able to work, because their disability impairs them to the point of not being able to work, even with helpful devices. In all, a person can have a disability or difficulty performing certain functions; but when their disability becomes so limiting that they are unable to perform daily activities and/or work, then they are considered to be *"disabled."*

What are Visible and Invisible Disabilities?

When most people think of a disability, they picture in their minds a person with a visible, obvious limitation. However, as there are many levels of disabilities, there are also many types of disabilities. What most people do not realize is that a person can have a hindrance that comes from the inside and may not even be visible from the outside.

This person could have debilitating pain, fatigue, weakness and/or cognitive impairments from a diseased spine, organs, nervous system and/or cells that keep them from being able to function at a normal level. They may have an injury to their back, head, legs or spine that limits their ability to work or even complete daily tasks. Nonetheless, their bodies will not cooperate with their desires whether or not others can see the damage on the outside.

- **Visible Disabilities**: People with outward limitations like missing limbs, paralysis or blindness often face the challenge of overcoming society's assumptions about their disabilities. They are put into a category of being disabled, but many times they are still able to work, raise children and even participate in sports with a little assistance. They become frustrated with being treated like they are helpless and cannot be productive. They are hurt when they are treated like they are not just as valuable to others. And, they do not want to be defined by their *DIS-abilities,* but respected for their *dis-ABILITIES.*

- **Invisible Disabilities**: Limitations that are not so obvious from the outside. These invisible limitations can stem from back, brain and spinal injuries. They can also be the result of diseases, disorders, chronic infections and birth defects. These injuries and illnesses manifest themselves with pain, fatigue, dizziness, cognitive impairments, weakness and nausea ranging from mild to severe to unbearable. People often assume that because someone with invisible disabilities may look fine on the outside, that they must just be over exaggerating, making excuses or lying about their situation. Sadly, this leaves millions of people feeling isolated and alone in their suffering, as their loved ones question the validity of their limitations.
- **Visible & Invisible Disabilities**: Some people fall under both categories; they have both obvious, visible limitations that are mild to severe *and* invisible damage inside that causes such debilitating symptoms. They may need to use an assistive device, but it is not the chair, walker or cane keeping them from being as active as they would like to be, it is the disabling symptoms. In essence, for some it is the *visible* disabilities that hinder them, for others it is the *invisible* ones and for some it is *both.*

Below, I have charted some *general similarities and dis-similarities between having a disability that is visible on the outside, versus one that is not visible from the outside. The purpose is to create a better understanding of the frustrations, concerns and desires of people living with a disability that is visible and/or invisible.

	Visible Disabilities	Invisible Disabilities
General Description	Person has visible use of wheelchair, prosthesis, walker, oxygen, etc. or they may have loss of limb(s) or sight. Limitations may be minor to totally disabling.	Person sufferers from limitations that are invisible on the outside, such as debilitating fatigue, pain, neurological damage, lung deficiencies, heart problems, etc. Limitations may be minor to totally disabling.

Different Frustrations	Although the person may *LOOK* unable to complete a task, they are often perfectly able to participate, with or without limitations. People *PRESUME* they cannot do anything, even when they say they can.	Although the person may *LOOK* perfectly able to complete a task, they may have many limitations or may even be totally unable to participate at all. People *PRESUME* they can do anything, even when they say they cannot.
Similar Frustrations	People *PRESUME* they know what their abilities are by looking at them. People *DO NOT BELIEVE THEM* when they say they can do something.	People *PRESUME* they know what their abilities are by looking at them. People *DO NOT BELIEVE THEM* when they say they cannot do something.
Different Goals	Convince others that even though they *may not LOOK* fine, they are dis-ABLED or ABLE to participate in work or an activity.	Convince others that even though they *do LOOK* fine, they are DIS-abled or UN-able to participate in work or an activity.
Common Goals	*STRIVE* for Respect, Credibility, Admiration and Belief. Do not want to be *PREJUDGED* by Outer Appearance. Desire *ACCESSIBILITY*: Right to enjoy a store, restaurant, recreational area, etc., just like everyone else.	*STRIVE* for Respect, Credibility, Admiration and Belief. Do not want to be *PREJUDGED* by Outer Appearance. Desire *ACCESSIBILITY*: Right to enjoy a store, restaurant, recreational area, etc., just like everyone else.

*This chart is a "generalization" and not meant to be a description of all cases and situations!

The irony is that it is not the visible impairments that are usually the culprit in someone being disabled or unable to work. Yet, when our visible limitations do not seem that bad, people cannot understand why we are impeded; but, it is the invisible symptoms they cannot see that are keeping us from being able to function. Therefore, throughout this book, when I refer to those with "invisible disabilities," I am speaking of people who have debilitating symptoms, whether or not they also have "visible" ones."

When a person has a visible limitation, we can see that they have impairments on the outside thus, we believe them when they tell us they cannot perform a task. For example, if a friend is in a cast, we do not question them when they tell us they cannot go water-skiing. But, when a person is debilitated by symptoms that are not visible, their integrity and intentions are often questioned when they declare they cannot participate.

People with invisible disabilities are thankful and grateful for the invisibility of their impairment; yet, it can also be a great burden to bear, with its unique set of challenges. Because people cannot *see* the limitations for themselves, they often show their disbelief with a hurtful statement. This causes the person with the illness or injury to feel as if their character and honesty is being judged. Sadly, this cuts deeply, straight to the heart, when our virtue is being torn to shreds.

Debbie, a woman with APS wrote:

> *The greatest barrier I run into every day is people who think I am trying to rob the system or faking or whatever. I feel guilty when I have a rare good day and get to go out and act like a normal person, cuz then I know folds are going, 'See!! I told ya! She is fine!!' I am seriously ill, but to look at me, you would think I was young, healthy with everything going for me. I have often told my husband, at least if I had something visible…folks would not seem to treat me with such scorn and doubt (IDA E-Mail, 2001).*

Lisa Copen, the founder of Rest Ministries, wrote:

> *He or she may be young, and no one really believes that there are young ill people in our country…The invisibility of most chronic conditions makes it even more difficult to convince others that you really are in pain (Copen, Why Don't Churches Understand Chronic Illness? pg 8).*

In all, please do not make the mistake of making a visual judgment of what a person can and cannot do and do. In the book of John, he says, "do not judge by outward appearances" (NIV, John 7:24). Instead, value each person individually, because they are made in the "image of God" (NIV, Genesis 1:27). Simply talk with them and find out what their talents and needs are! Refusing to believe what you cannot see will only make others feel isolated in their struggles and as if you think they are not honorable, respectable and valuable to you.

All too often, a person with a visible impairment is presumed to be unable to complete a task or participate in an activity; this is quite aggravating and hurtful to that person, when they are perfectly able to contribute and partake in the deed. And, it is just as insidious when a person explains their debilitating illness, yet people refuse to believe them, because they look fine on the outside; the disease may have eaten away at the brain, bones, spine, muscles, nerves, cells and joints, but because others cannot see the damage for themselves, they reject the validity of their limitations.

So, do not assume that someone using a wheelchair cannot do something or that someone not using a wheelchair can. Most of the time, it is not the wheelchair that keeps people from working and enjoying activities; it is the pain, extreme fatigue, neurological symptoms and cognitive impairment.

Donna Herrell, a patient’s advocate with Lyme Disease wrote:

> *What most people do not understand is that most appearances are deceiving and do not reflect the disability caused by symptoms or disease. If someone is overly thin and looks under the weather, people may jump to the conclusion of AIDS. The person could be naturally thin with a recent case of flu. Conversely, you can look good and have cancer. We teach our kids not to judge people by their looks, but as adults, we do so every day (Herrell, Don't Judge a Disability by Its Cover, pg 1).*

In general, neither type of disabilities is worse than the other, because each person's degree of limitations is varied, despite their outer appearance. Some have visible disabilities, some have invisible ones and others fall under both categories. For some it is the visible disabilities that hinder them, for others it is the invisible ones and for others it is mutual.

Some people's symptoms/limitations are mild, some are moderate and others are severe. Some are able to work full-time, some part-time, some not at all and for others it is all they can do to make it to doctors' appointments, shower and/or come to church once a week. The key is to *listen, do not assume* and *take them at their word,* despite what you *see on the outside.*

Be mindful to value each person individually, because they are of great value to God. Whether we have a *visible* or an *invisible* disability, we are all striving for respect, understanding, accessibility and most of all... *belief.* We do not want others to prejudge us and be unwilling to hear the truth; we want people to listen and treat us like *valuable,* contributing people with *integrity, courage* and *strength.*

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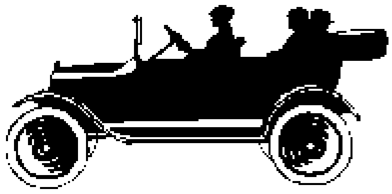
No Cast, No Cane, No Pain?

WHO Is Allowed To Park In those Handicapped Parking Spaces, Anyway?



Written By:
The Invisible Disabilities Advocate,
Sherri L. Connell, BA

Hey! They Don't LOOK Handicapped!

Have you ever seen someone get out of a car parked in a space reserved for the handicapped, who did not ***LOOK*** handicapped? Did it make you very uncomfortable or even upset? Did you let them know of your disapproval by giving them a dirty look or yelling something at them?

Well, you are not alone. Many people are very disturbed by the sight of a seemingly mobile person stealing the space of someone who is truly in need of it. After all, we want to protect the rights of people for whom these spaces are reserved!

However, in wanting to help those who deserve these parking spaces, we actually may be hurting someone who does have a legal right and a legitimate need to park there. How can this be true, you ask? Isn't it obvious who is and who is not handicapped? The answer is... ***NO***.

There are thousands of people who are forced to contend with what I call, "***invisible disabilities.***" These people are suffering from illnesses, injuries and circumstances, which have left them with mountains to climb every time they take a step.

What may seem easy to ***you***, may seem like a 14,000 foot hurdle to ***them***. Being able to park close to the entrance of a building when they need to, allows them to run an errand they otherwise would not have been able to conquer. After all, these spaces do not make life ***easy***, they make it ***possible***.

Here are just a few ***invisible*** reasons a person may be able to park in the handicapped spaces:

Arthritis, Back Injury, Brain Injury, Chronic Fatigue Syndrome, Cystic Fibrosis, Diabetes, Heart Condition, Lupus, Lyme Disease, Muscular Disorders, Multiple Sclerosis, Neurological Disorders, Osteoporosis, Organ Transplant, Oxygen Impairment, Parkinson's Disease, Difficult Pregnancy, Prosthetic, Seizure Disorder, Surgery and several others.

Wow! So, They Really Need It?

For many, the shortened distance from the parking lot allows them to: walk into a building to use an electric cart or wheelchair; avoid dangerous exposure to heat, cold and exhaust fumes; use their energy for shopping; get back to their car when they have used up all of their energy inside; or simply to remember where they parked.

As you can imagine, it is very uncomfortable when people stare, because they think you do not ***look*** like you need to park in a handicapped or disabled parking space; as a result, most people with these circumstances are left feeling afraid to use the very spaces that were intended to help them with their needs!

How do you know who can park there and who cannot? Look for a temporary or permanent Handicapped Placard in the front window or a license plate with the handicapped symbol. These items are received through an application form in which a patient's doctor must fill out for them, through the Department of Motor Vehicles.

The DMV has specific guidelines and requirements the person must meet in order to receive a Handicapped Placard or license plate. They take into consideration the impairments of the illness or injury, as well as their implications and aggravations. Therefore, if a person is issued a license and is displaying it, then they have the ***LEGAL, MEDICAL RIGHT TO PARK THERE***.

So, What If They DON'T Have A License To Park There?

Anyone who parks in a parking space reserved for the handicapped must display a placard or license or they can be fined. You can call the sheriff's department of that county if it is not on private property; however, the vehicle must be illegally parked when the officer arrives (do not call 911!). Or, you can notify a security guard to ticket them or the store manager to page the owner by license plate number and vehicle description.

But, what about those people who use their relative's placard, when their relative is not even with them? Well, this is definitely immoral, selfish and disrespectful as well as being illegal; there is NO excuse of this dishonest behaviour. However, unless you know them and know without a doubt is not their placard, it is in the best interest of those of us **who suffer from invisible disabilities to just smile and assume they have a right to be there**.

These reserved spaces are designed to help those in need of them for a number of reasons. Without these spaces, seemingly simple tasks in life would be excruciatingly painful, overwhelming, impossible or even life threatening for thousands of people. Therefore, it is honorable for you to care if these spots are being abused by those who do not need them. Just remember, as shown in this pamphlet, you cannot be the judge of who deserves to park in the handicapped spaces and who does not, just by ***looking*** at them.

Finally, if a person is displaying a license to park in a handicapped space, try offering a hand, instead of a visual judgment; after all..."the people you are graciously intending to defend, may be standing right in front of you!"

"Lend A Helpful Hand, Not A Hurtful Heart."

Visible? Invisible?
What's the Difference?

Understanding the Differences and Similarities Between Having Visible and Invisible Disabilities.

Written By:
The Invisible Disabilities Advocate,
Sherri L. Connell, BA

* * *

Visible? Invisible?
What's the Difference?

All too often, a person with a visible impairment is *presumed* to be *unable* to complete a task or participate in an activity; this is quite aggravating and hurtful to that person, when they are perfectly *able* to contribute and partake in the deed.

And, it is just as insidious when a person explains their debilitating illness, yet people refuse to *believe* them, because they *look* fine on the outside; the disease may have eaten away at the brain, bones, spine, muscles and nerves, but because others cannot *see* the damage for themselves, they *reject* the validity of their limitations.

So, do not assume that someone using a wheelchair *cannot* do something or that someone not using a wheelchair *can*. Most of the time, it is not the wheelchair that keeps people from working and enjoying activities; it is the pain, extreme fatigue and neurological symptoms.

Below, I have charted some **general* similarities and dis-similarities between having a disability that is *visible* on the outside, versus one that is *not visible* from the outside. The purpose is to create a better understanding of the frustrations, concerns and desires of people living with a disability that is visible and/or invisible.

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Different Frustrations	Although the person may *LOOK* unable to complete a task, they are often perfectly able to participate, with or without limitations. People *PRESUME* they cannot do anything, even when they say they can.	Although the person may *LOOK* perfectly able to complete a task, they may have many limitations or may even be totally unable to participate at all. People *PRESUME* they can do anything, even when they say they cannot.
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Different Goals	Convince others that even though they *may not LOOK* fine, they are dis-ABLED or ABLE to participate in work or an activity.	Convince others that even though they *do LOOK* fine, they are DIS-abled or UN-able to participate in work or an activity.
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Neither types of disabilities are worse than the other; each person's degree of limitations are varied, despite their outer appearance. And, some people fall under both categories; they may have a visible impairment as well as invisible ones. For some it is the visible disabilities that hinder them, for others it is the invisible ones and for some it is both.

Whether we have a *visible* or an *invisible* disability, we are all striving for respect, understanding, accessibility and most of all... *belief*. We do not want others to prejudge us and be unwilling to hear the truth; we want people to listen and treat us like *valuable*, contributing people with *integrity*, *courage* and *strength*.

Culture Watch

Seeing Invisible Disabilities

by Douglas Groothuis

Jesus had a way of seeing what others missed and ministering to those who were forgotten, shunned, or misunderstood. He touched and healed lepers when everyone else scurried away. He cared for those with chronic afflictions — such as congenital blindness and incurable haemorrhage — while others gave up. He bestowed hope where others scattered the ashes of despair. He was love Incarnate (John 1:14; 1 John 4:16). We need that character of divine love if we're to see and minister to the hurts of others.

America has made strides in recognizing and assisting people with disabilities. Most public facilities are now accessible to the handicapped. The pool where I swim has a lift for the disabled. The law rightly forbids discriminating against the handicapped (see Lev. 19:14, Deut. 27:18, Matt. 25:40).

In the Christian community, Joni Eareckson Tada has raised people's awareness of the needs of those who suffer from severe disabilities. She has encouraged the afflicted not to despair, but to trust God to use their broken lives for the glory of God and the good of others.

Still, many disabled people continue to suffer both chronic physical distress and misunderstanding. Their suffering is masked by a healthy appearance. They are not in wheelchairs and do not use canes. Yet their pain and debility is real and chronic. They have "invisible disabilities."

It may be the soul-sapping fatigue, environmental sensitivity, and chronic pain of fibromyalgia, or lupus, or Lyme disease, or multiple sclerosis. These souls suffer not only from their diseases, but also often from the uninformed and hurtful reactions of others.

"Those suffering from fibromyalgia, such as my wife, often ricochet from one physician to another, repeatedly encountering the impatience and defeatism that often characterize the medical community's attitude toward those whose ailments are intractable, invisible, and (usually) non-terminal." Insurance routinely refuses to cover needed treatments.

Worse yet, loved ones frequently do not understand the nature of their invisible disability and respond wrongly.

When someone looks healthy, we are tempted to tell them to "just buck up" and do what we think they should do. Those with invisible disabilities are often expected to do what is beyond them. We would never tell someone who uses a cane to run a marathon, but just going to the store may be a marathon for someone with lupus.

A seminary student of mine looks healthy, yet he suffers from such chronic and extreme back pain that he lost his medical practice. He also lost a friend who could not accept the limitations that chronic illness put on their relationship.

What can Christians do to discern people's invisible disabilities and display the love of Christ?

First, we can empathize with them, instead of lecturing or ignoring them. The Book of Hebrews tells us to remember those in prison as though we were shackled with them (13:3). Similarly, we must try to put ourselves into the prison of the chronically ill person's life. This is difficult, and almost nothing in our hedonistic culture encourages it. Nevertheless, we need empathy to be agents of love and encouragement. Jesus wept; so should we (John 11:35).

Second, we should listen to and believe what the afflicted tell us. My wife looks so healthy and fit that someone in the locker room where we swim thought she was a woman who'd been swimming at top speed for an hour. But if you listen to Rebecca's story — one of pain and frustration mixed with faith and determination — you'll find things quite different from how they appear.

Third, we can look for ways to minister to those we know with such conditions. Sherri Connell's web site, The Invisible Disabilities Advocate, *(www.InvisibleDisabilities.com)* offers a wealth of materials. Sherri, who suffers from an invisible disability, has a big heart, an indomitable spirit, and much practical and spiritual advice.

Let us seek to have the eyes of Jesus, so we may look beyond appearances and gaze deeply into the lives of those who are suffering. Then we can offer them our love, understanding, and encouragement.

The Silent
Nutra-Bomb!

Written By:

The Invisible Disabilities Advocate,
Sherri L. Connell, BA

The Silent Nutra-Bomb

Aahh! The cool, bubbly taste of a diet soda! There's nothing like it, so refreshing and thirst quenching!

But what is it that makes the soda sweet, without adding sugar? It is a substance called, aspartame (as-par-tame), or the brand names, NutraSweet, Equal, Spoonful and Equal Measure.

Many dieters know it seems too good to be true, but may be putting their health on the line every time they consume aspartame. After all, wouldn't someone ban the use of aspartame if it were dangerous? Well, let's see... remember Saccharin? Many claim it can cause cancer, others say only in mice. Yet, despite the countless studies, complaints and "red flags," it is still on the market.

Many researchers warned the US Food and Drug Administration (FDA) about Saccharin's potential dangers; yet, until there was something to replace it with, many innocent dieters were unknowingly consuming a potential cancer causing agent.

Where Did Aspartame Come From?

Aspartame was accidentally discovered by a chemist, James Schlatter, of G.D. Searle Company in 1965, when he licked his fingers after an experiment for a new drug.

Although it was approved for dry goods in 1974, objections were filed by researcher Dr. John W. Olney and Consumer attorney James Turner. The research practices of G.D. Searle were questioned, so the approval was put on hold. Of course, the parties pushing aspartame insisted it was safe and aspartame was approved for dry goods in 1981, then for carbonated drinks in 1983.

What Do Consumers Have To Say About Aspartame?

After drinking it for over a decade, do they feel it is safe? Well, aspartame accounts for 75% of the adverse reactions to food additives reported to the FDA.

As disclosed in a February 1994 Department of Health and Human Services report, 90 different symptoms have been documented the cause of aspartame. Just a few of these symptoms include: Headaches and migraines, weight gain, depression, fatigue, vision problems, hearing loss, memory loss, heart palpitations, breathing difficulties, anxiety attacks, joint pain, seizures and death.

According to a group of physicians, researchers and artificial sweetener experts studying aspartame, Mission Possible, the following chronic illnesses can be exacerbated by consuming aspartame: Alzheimer's, birth defects, brain tumours, Chronic Fatigue Syndrome, Diabetes, Epilepsy, Fibromyalgia, Lymphoma, Mental Retardation, Multiple Sclerosis and Parkinson's Disease.

Don't be quick to think you are in the clear if your chronic illness is not listed! If this substance can aggravate these problems, it may aggravate others too. And, watch out "healthy people," illnesses often develop without much warning.

What Is In It?

Aspartame is basically made up of three ingredients: 40% aspartic acid, 50% phenylalanine and 10% methanol.

40% ASPARTIC ACID: Aspartic acid is an amino acid. Sound harmless? Look again! It is what is called a "free excitatory" amino acid, which has been synthesized into a chemical. These amino acids in their natural form are necessary in controlled amounts, but in large amounts they are referred to as, "exitotoxins," because they can literally over stimulate the neural cells to death.

Generally, aspartic acid, as well as glutamic acid (99% of MSG), act as neurotransmitters in the brain by clearing the way for information to be transmitted between neurons. Too much of either of these amino acids kills certain neurons by allowing an excessive influx of calcium and free radicals.

Many documents have been written about the overuse of these amino acids, including a book by Dr. Russell L. Blaylock, a professor of Neurosurgery at the Medical University of Mississippi. Blaylock's book, "***Exitotoxins: The Taste That Kills,***" thoroughly explains the damage that is caused by eating or drinking too much aspartic acid from aspartame; and, he gives hundreds of scientific references to how excess free excitatory amino acids in our food are causing acute symptoms as well as chronic neurological disorders.

50% PHENYLALANINE: This is also an amino acid, but the most highly allergenic of them all. Furthermore, it can be fatal to people with a genetic disorder, called Phenylketornurea, (this ***caution*** is on aspartame products). Phenylalanine can grow to excess levels in the brain of anyone, and these accumulations can cause decreased serotonin levels, emotional problems, behavioural problems, schizophrenia, depression and increase susceptibility to seizures. Respectively, many vitamin manufacturers warn against the use of phenylalanine by pregnant or lactating mothers.

****Note: Amino acids are necessary for proper development and good health; however, the amino acids described above have been synthesized into chemicals, bonded to other chemicals and are not regulated by a physician. Do not stop taking the amino acids your doctor has prescribed for you!***

Caution! Poison! Harmful or Fatal If Swallowed!

10% METHANOL: Methanol?? Yes, methanol; the wood alcohol "poison" you may want to put in your car, but certainly not in your body! Non-food products with methanol have ***warnings*** and ***cautions*** not to ingest their solutions; yet, it seems the foods we eat, do not.

According to the Environmental protection Agency, methanol is considered a cumulative poison, because of its low rate of excretion once it is absorbed; also, methanol turns into two toxic substances, formic acid and formaldehyde (a deadly neurotoxin). The EPA limits the consumption of methanol to 7.8 mg in a 24-hour period; one 12-ounce can of diet soda has approximately 20 mg.

Moreover, methanol is turned into free methanol when it is heated to above 86 degrees Fahrenheit (as when it is stored, put into a 98.5 degree body or baked in an oven); alarmingly, this conversion grossly increases the absorption of the methanol and the breakdown into formaldehyde.

Decide For Yourself!

Please take these findings into consideration or do additional research, when making your own decision about what you will eat or drink. Many people do not realize they are reacting to the chemicals, until they keep a journal of what they are eating and when they have headaches or other symptoms; often a correlation can then be made.

Also, the immune system can put up a good fight, making you think you are not affected; but remember, these ingredients may accumulate over time, like a ticking bomb waiting to explode.

If you have symptoms due to the use of aspartame, they are most often alleviated when the consumption of this product is ceased. However, complete recovery time depends on how long you used the product, how much you used it, how much damage has been done and how well your immune system recovers.

Worried about your diet without aspartame? Well consider this, many people have experienced weight ***gain*** with this product and its consumption has been shown to ***increase*** the appetite for carbohydrates!

The FDA has received record numbers of reports claiming the dangers and damages of aspartame from consumers, doctors, laboratory scientists and researchers.

"Don't wait for "*THEM*" to replace it, decide for *yourself*!"

NOTE: *This article was intended for informational purposes only! Please discuss all medical concerns with your doctor! IDA does not necessarily agree with everything contained in the sites below! None of the information in this article, on this site or in these links should be taken as medical advice. Please decide for yourself.*

Further Reading:

Artificial Sweeteners Can Be a Sour Deal
www.alternativemedicine.com/whatshot/whatshot46.shtml
Aspartame is Poison *(overview of ingredients, information and links)*
www.imagin.net/~abredon/links_aspartame.htm
Aspartame (NutraSweet) Toxicity Info. Centre
www.holisticmed.com/aspartame/
AspartameKills.com *www.aspartamekills.com*
AspartameTruth.com *www.aspartametruth.com*
DORway.com *http://dorway.com*
Exitotoxins... by Russell L. Blaylock, MD
http://dorway.com/blayenn.html
What do these groups have to say?:
American Academy of Paediatrics
www.aap.org/policy/re9706.html
National Cancer Institute
http://cancer.med.upenn.edu/pdq_html/6/engl/600319.html

Pick Your Battles...

Chronic pain causes so many losses in our life; it is easy to become overwhelmed.

If pain is not treated properly, or is not treated at all, it begins to physically change the body. Nerve endings rewire and connect to other nerves that begin to fire abnormally and cause more pain. Myofascial tissue begins to harden and this causes more pain. Hormonal levels change and cause havoc in the body. Endorphin activity slows and sometimes stops completely, causing pain and depression. Digestive activity changes and can cause irritable bowel symptoms.

Understanding chronic pain will help you to decide which symptoms should be reported to your doctor, and which ones should be ignored. Chronic pain does bring change with it; there is no denying that. However, if we are to survive the trauma that living with pain causes we must be able to pick our battles and focus only on major issues that must be dealt with, and ignore symptoms that are minor inconveniences. When our viewfinder expands to include every detail and we shoot out with buckshot trying to kill all the negatives we will inevitably fail to make the target at all.

Trying to focus on too many symptoms can backfire for two reasons. First, by focusing on the problems we validate them. Obsessively looking for and validating each tiny change programs this information into our computer, the brain. Over time the brain will begin to accept this information as fact and act on it in ways that could be harmful. It may send out even more pain messages, or the stress from focusing on such a large target will make the person even more overwhelmed and tired. Remember our cognitive thinking exercises show us that dysfunctional thoughts influence our behaviour. Eventually those dysfunctional thoughts become our reality. If we continue to validate each and every change we find, those symptoms will be magnified and soon they will become a permanent part of the fabric of our condition.

Second, by drawing attention to and showing each of these tiny changes to whoever happens to be close enough to listen, the patient is inadvertently undermining his or her credibility in regard to the condition that does exist. To the people that the patient shares this information with these changes do not represent a new threat. In fact they might even share the same "symptom" and not regard it as a handicap at all. When the patient continues to focus on these changes in the body they begin to lose credibility with the person they are sharing the information with. After a short amount of time the listener begins to tune out what the patient is referring to. They also begin to judge the patient and eventually have a hard time believing anything they say. If we are looking for support this is not the way to get it.

Syndrome conditions such as Fibromyalgia do have a myriad of symptoms. None of the symptoms are life threatening. By focusing on each and every symptom we magnify them. And when we talk to others about each and every tiny symptom we push others away and they take their support with them.

My point here is that chronic pain patients must pick their battles with care. Your body will not heal properly if you continue to bombard it with thoughts about what is wrong in your life rather than what is right. This includes thoughts about the things you once were able to do and now cannot do. Your house will not fall down if it is not perfectly clean, you will not die if you have to wear that outfit that you would have ironed if you felt better. Your husband or wife will offer more support if you do not overwhelm with your symptom list.

When you find yourself listing all the problems pain has brought to your life remind yourself to FOCUS. This is the perfect time to practice your breathing exercises. Breathing deeply will release the anxiety surrounding the issue and make your body relax. Once the body is relaxed the pain messages will slow down and endorphins will be released. If you do this repeatedly each time you find yourself focusing the wide angle instead of the narrow one you will train your mind and in a short time this will be the normal thought pattern you live with. Keep reminding yourself to pick your battles and the quality of your life will improve dramatically.

'Peaceful Sleep'

Does pain give you problems with your sleep? If so, there's plenty you can do to help yourself regain blissful and peaceful sleep, leaving you refreshed to face the day. As well as plenty of suggestions, I will give you a brief introduction to the Peaceful Sleep Bedtime Routine which is explained in full on my tape and in my book, 'Peaceful Sleep'.

Bedtime is the first time of day we have without distractions and so worrying negative thoughts and pain have the opportunity to come through. To overcome this we need to approach sleep on two fronts:

1. Techniques to ease stress during the day
2. Techniques for gaining peaceful sleep at night - 'The Peaceful Sleep Bedtime Routine'.

Four Stress-relievers for the Day

1 Spend five, ten minutes or more (the longer the better) in relaxation or meditation. Relaxation is the key to pain relief and stress reduction and will be invaluable to use at night to lull you to sleep. During your relaxation session repeat the Peaceful Bedtime Routine Affirmation (more about the Peaceful Sleep Bedtime Routine in the next section): ***"Peaceful Sleep - when I say 'peaceful sleep' I fall asleep easily and sleep right through the night".*** Learn the affirmation by writing it down and then keep repeating it to yourself throughout the day.

2 Even if pain wakes you at night, it's probably negative thoughts that will help to keep you awake, such as, "I'll never get back to sleep" or "I'll feel terrible in the morning". If you concentrate on your negative thoughts they rob you of your ability to deal calmly with a situation. So always have a few phrases ready prepared to use. Make some small cards with one affirmation on each card, or write a list. Begin by ordering yourself to "STOP that!" This will stop the negative thoughts immediately. Then follow by using your favourite affirmations. One might be, "Be still, this will pass" or "I let go and relax".

3 If you possibly can, take some form of exercise in the afternoon, perhaps a walk around the block or sitting/lying down exercises for those who can't walk.

4 Daily Review. This is vital! In the early evening, note any problem areas and unfinished tasks and write down the next action to be

taken -there's no need to write everything down, just the next action to be taken. It is unfinished business like this that is the cause of most sleeplessness. Use this time as a dividing line between your day and your evening. If you start thinking about these items at night tell yourself you have dealt with them until tomorrow. Spend the last hour or so of the evening preparing for sleep. Keep all activities after the Daily Review very low key and undemanding so that you are in a relaxed and quiet mood when it is time for bed - but don't become so relaxed that you fall asleep on the sofa!

The Peaceful Sleep Bedtime Routine

Go through the 'Peaceful Sleep Bedtime Routine'. When you go to bed lie still and take two deep relaxing breaths, allowing your body to sink down into the bed. Then say to yourself the Peaceful Sleep affirmation: ***"Peaceful Sleep - when I say 'peaceful sleep' I fall asleep easily and sleep right through the night."*** (Learn the affirmation by writing it down and then keep repeating it to yourself throughout the day.) Next travel around your body giving each part the following simple instruction to go to sleep. Just allow the relaxation to happen. You say to each part: ***"Peaceful Sleep to my .... (e.g. toes)"*** Begin with the toes on your left foot, then your right foot, then your whole left foot, whole right foot. Next travel up each leg in turn, your ankle, your calf, your knee and thigh. Continue next with your abdomen, lower back, chest, upper back and all the parts of your shoulders. Then travel down each arm in turn, taking in your elbows, and hands. Then your neck and your head, going around each area of your face. Although I doubt if you will ever get this far! As you talk to each part of your body, let it feel heavy, relaxed and warm as it sinks down into the bed. Feel yourself sink further and further down as you 'visit' each part of your body. Just let yourself go. You will then feel so serene and tranquil that it is easy to drift down into a deep and peaceful sleep. (The whole of the truly relaxing Peaceful Sleep Bedtime Routine is on the tape that accompanies my book. See below for further information.)

More Tips for Peaceful Sleep

1. Your body can 'learn' what time you want it to go to sleep and wake up. This includes weekends and holidays. If you're not tired by,

say, 10.30pm get up earlier. Rising time controls bedtime. Early to bed is best as the best quality sleep is before midnight.

2. Use your bed and bedroom for sleep only. Not for reading, watching TV or as an office, then your subconscious mind will gradually accept the idea that when you go to bed it is time to go to sleep. Make sure your bed and pillow are comfortable and reasonably warm. Use small pillows and props for any part of your body that needs support.
3. NEVER try to analyse the situation during the night. If something is worrying you, write it down and shut the paper in a drawer in another room and say to yourself, "Now is the time for sleeping, not thinking. I will think about that tomorrow.
4. If lying awake, don't clock-watch. Cover or turn your clock so you can't see it.
5. If you're awake at night your mind is free to pick up on negative thoughts and feelings. Have a plan so you know what to do. If you start thinking anxious thoughts tell yourself to "STOP that" and then perhaps, "I can deal with that tomorrow, NOW is for relaxing."
6. Get up if you are still awake after 20 minutes or so and do something calming and soothing such as reading through your affirmations until you are ready to return to bed to go through the **Peaceful Sleep Bedtime Routine** again. Don't let self-pity in. Stay calm.
7. Never count the hours you think you have been asleep or awake. Remind yourself that you are always getting far more sleep than you actually realise, possibly as much as three times more.
8. Remember the 5Ps - be Persistent and Patient and Practice and Practice and Practice some more.

People and Pain

by Cecil E. Maranville

Chapter Three

THE SEARCH FOR SUPPORT

Chronic pain affects one's nerves, although doctors do not know why or how. It gouges deep emotional canyons of discouragement, depression and uncertainty. It may be the snake-in-the-grass nature of the pain cycles, coming at unexpected times, sometimes staying long, sometimes short; sometimes disabling, sometimes only hobbling, like a method of torture designed to break you down.

It could also be the long, frustrating, expensive journey of getting a diagnosis and experimenting with dozens of treatment programs, none of which is completely effective. Or it could be the interactions with family which has been rattled by the illness (see Chapter Two on "the whole family is in pain").

It could be the frustration of trying to convince insurance companies and government agencies of the validity of disability claims.

People With This Disease Need Emotional Support

Whatever the science or psychology involved, people who have fibromyalgia need emotional support! And lots of it!

There are friends who can offer support, spouses, children, extended family, support groups purposefully organized of and by people with fibromyalgia, doctors and even strangers. Also, every single one of these may not be able to, or may choose not to give support.

Confusing? Bear with me.

Picture this -- three men, one in his mid-40's, one in his late 50's, one in his early 60's, in a Toyota 4 X 4 going along a desert road hunting Gambel's quail in Arizona. One man is disabled by cluster headaches; another is disabled by chronic bronchitis. Of course, I'm the third "musketeer", disabled by fibromyalgia. We jokingly say that together we make one whole man. I breathe and think, while they walk and shoot!

These two men are dear friends and have been a critical part of my emotional support during my worst crises with fibromyalgia. I consider myself especially blessed to have this unique combination. It's hunting that brought us together, but disability makes a deeper bond. Nobody complains if one fellow's physical weakness is slowing him.

My two friends who aren't all there (physically!) treat me the same as always, whether I am in a wheelchair or up and around. They joke with me, tease me, as well as talk seriously with me.

There is no pity, no catering. But there is sympathy.

They show that by calling, writing or coming to see me when I am bedfast and house-bound. While they are here, the conversation ranges from inane to serious, as usual. (As male friends will do, we discuss and "solve" all of the world's problems!) They'll inquire how I am doing, and I answer in as much detail as they seem to want.

I also inquire about their well-being and their activities. That kind of balance enables their healthy support to continue. Were I to take a Job-like approach and give a litany of my woes, I believe they would still come to visit. But I would be forcing them into an unhealthy type of support and out of a healthy way.

There is also courtesy shown for each other. As I have helped one of them needed assistance, one of them will also push my wheelchair or make sure I have a soft seat. This is all done without fanfare.

It is a perfect level of support. What do I mean "level"? We'll get to that.

You may be surprised to learn that my doctors have given me wonderful support and encouragement -- some don't find support from their doctors. Both Dr. Kail and Dr. Daniel Remen, mentioned in Chapter One, have been kind, genuinely concerned, and sincerely happy at my progress in adjusting to fibromyalgia's "nasties". Other doctors have been kind, too, such as the psychologist who counselled me on pain management.

The medical part of my support has also been just right.

While I do not belong to an officially organized fibromyalgia support group, I have compared notes and experiences with dozens who are dealing with the illness. There is a mutual understanding immediately, and it is encouraging to have this interaction. I learn things from others, and sometimes others learn bits and pieces from me.

I have also found in these relationships exactly what I needed from them.

Levels of Support

I learned the dynamics of the different levels of support as a minister in grief counselling. One serious and sad situation clearly illustrates what I mean. The husband and father in a family was dying of cancer. One of his siblings flew into town to be with the family during the brother's final days. He was able to provide a unique level of support.

Friends and neighbours came and went with food donations, and ran errands. Some were close enough to the family to hug and cry; others were not as close emotionally, but well enough acquainted to sit and talk. Some were only casually acquainted, and lent their support in attending to dishes that needed doing, cleaning, etc. There were differing levels of support given, each special, valuable, and necessary.

A volunteer worker from the local hospice organization was also present. She was kind, considerate and caring, but not as emotionally attached as family or close friends. And she was trained in duties much more specialized than doing the dishes or walking the dog. She gave a special level of support. The family needed exactly her kind of help with personal matters, without her being too emotionally attached.

I was there as the pastor, adding yet another kind of caring and support.

Perhaps you can relate to similar situations in your own experience.

I would have been making an error if I tried to provide the support the sibling gave, or the hospice volunteer, as they would have been out of place to give the support of a casual friend or neighbour.

Unfortunately, I have often witnessed circumstances in which people did not recognize what kind of support they could, and needed to give. They attempted to force themselves into a role which wasn't theirs, and only caused discomfort.

The level at which our support is needed changes with circumstances. Sometimes you are the sibling; sometimes a Beast friend; sometimes a casual acquaintance; sometimes only a willing volunteer -- a different support role in each situation.

Every level of emotional support is essential.

When Those Who Should Support Do Not

Let's look at the flip side of the support factor and demonstrate the problems which come when we step out of our support roles.

Friends: since I started with friends, we'll begin with that category. Friends will often, unfortunately, step out of the kind of wonderfully helpful role I described of my friends, and into the role of "doctor" with fibromyalgia. Everyone who has fibromyalgia who has been given medical advice by a friend, shout "YEAH, that's right"!

Did you hear that roar?! I have wished many times that for humour’s sake I had kept a list of the remedies, rubs and recipes that have been given, pushed and offered for sale to me!

But it wasn't funny at the time I got all that advice, as I was desperately trying to find relief from whatever it was that I had -- or whatever it was that had me! People came with sincere eyes and dramatic stories, making me feel guilty for not trying their cure! (I learned a long time ago how to say, "Thanks for your concern" and to leave it at that. I stopped being a guinea pig for some home-remedy Aunt Bessie used on Uncle Fred's horse! Before you applaud my courage, I only got this nerve up after years of going along with the outlandish suggestions friends made.)

Friends should stick to giving the level of support that only friends can give. True friends cannot be quickly or easily replaced by volunteers; if they step out of their role, the one they want to help is the loser.

Doctors: consider a real absurd example for a moment. Think how ridiculous it would be for my doctor to stop giving me medical support and switching to the role of my sibling. I go to see him -- and pay him! -- and he hugs me, and asks about Mom! I try to talk about my condition and get his help, and the only thing on his mind is planning a family picnic. Friendliness in a doctor is welcomed, but this scenario just wouldn't work, would it?

Doctors usually stick to their support role, but the example illustrates the problems of abandoning a needed part of a support team.

While on the subject of doctors being doctors, it's the time and place to salute those who recognize that part of their support is a smile, a gentle touch, a kind word, and a couple of minutes to explain in clear language the reason for their choice of treatment. Hats off to you all! You only enhance your ability to treat disease.

My experience with doctors is extensive, for it goes beyond all of the appointments dealing with fibromyalgia (as you know, that's a lot!). As a pastor I interacted with hundreds of different doctors over the many years and the many cities where I ministered. Part of their professional duties is to demonstrate care. How appreciated that is by the person with fibromyalgia (and any other disease)!

Writing about the importance of giving reassurance, Dr. F. Dudley Hart says to his colleagues, "Reviewing...suggested forms of therapy, one is forced to conclude that a sympathetic and attentive physician who has the patient's confidence and gives advice of which the patient approves will probably get better results than another physician with `more powerful' prescriptions or modes of physical therapy which seldom produce a cure." ("Fibrositis: A Common Non-Entity?" © ADIS Press Limited, Drugs 35:320-327, 1988)

Family: then there is an intimate, understanding, loving support that can come only from family. But we recognize that this disease is hard on families. When family members distance themselves, as if they were only casual acquaintances, or when they, too, start "playing doctor," a needed level of support goes begging.

Spouse: of course, there is no replacing the support your spouse can give. Or is there....?

"Safe" & "Unsafe" Support

Because of the forceful, potentially destructive nature of fibromyalgia, the one who has it and the spouse need to support each other. It is ideal if each can be there for the other when that need time arrives. What happens if a time comes when you both need support, but neither can give it?

Your spouse could well "hit a wall" the same time that you are having a crisis. At such a time, it isn't a matter of his or her choosing not to give you that intimate support only a spouse can give. He **can't**. She **can't**.

A potentially devastating error is committed when a friend **of the opposite sex** takes over the role of the support a spouse should give.

There are personal thoughts normally shared with a spouse alone. They are not for a friend, child, a doctor, extended family, and certainly not strangers. But without planning it, sometimes a friend becomes more than a friend, and one begins to confide those personal thoughts, fears, frustrations, disappointments and needs.

The friend has become a substitute spouse. **And** a serious threat to the stability of your marriage and family, which, perhaps, is already under attack by fibromyalgia. We need to recognize how difficult it is to maintain an emotional bond at the spouse level with more than one person at the same time.

While you lean on your friend, you are not likely to be supporting your spouse. You might be angry that he / she is not supporting you and pull back in sort of a "tit for tat" mentality. Pulling back for the spouse will not relieve the emotional strain. Will removing the scaffolding, the framing, and the cement trucks from a construction site get the bridge built? Will withdrawing from your spouse get that emotional bridge repaired?

Emotions are confused, and judgment is poor at such a time. If your "more than a friend" is truly a friend, he / she will recognize what is developing and say, "Whoa! This is not helpful to anyone. You need to find someone else in whom to confide."

If your "more than a friend" is weak or vulnerable for some reason, you have a powder keg with a lit fuse, ready to explode into adultery. How traumatic that would be for an already traumatized marriage.

So what do you do for support when your spouse **can't** give you the attention, comfort and encouragement you need?

You must find a "safe friend".

Safe friends are most likely not to be found among the opposite sex -- unless maybe they are old enough to be your grandparent. But based upon my experience as a pastor and marriage counsellor, I'd be leery even of that, having seen some startling things over the years!

That perhaps means that you will not find an exactly suitable replacement for your spouse. But that's great, because you want to be highly motivated to renew your relationship with your spouse, when he / she is able.

Safe friends must have the unique quality of being able to listen to your deepest thoughts, never pass them on, never hold them against you, and -- importantly, never judge you or your spouse. He / she provides an escape valve, so you can "blow off steam". When you no longer need them to fulfil that special role, safe friends step back a level. Otherwise, they would begin to interfere with the marriage they helped to save.

How Do You Want to Use Support Groups?

A support beam in a house remains in place as long as the house stands. It must be a permanent fixture. By contrast, an automobile jack, also a support, remains in place only until a flat tire is replaced. If the jack stays in place permanently, your car never gets going again.

Support groups can become places for people to hide from getting on with their lives. The group becomes the kind of support to the person that the structural beam is to a building. That is unhealthy for both the one who is ill and the family. Used in such a way, the support group can actually prevent one from making necessary adjustments.

Fibromyalgia is not "you." You **have** it. Demanding though it is, it cannot and should not become your life. You need to be able to get on with living, not eat, drink, sleep and talk fibromyalgia all of the time.

If you have a support group, stop to evaluate how you are using it. Is it a jack, to support you temporarily? Do you foresee a reasonable time when you will be able to function without it? It is healthy to see a support group as temporary.

Go back to a support group when you need to, as you'd use a jack again whenever you have a flat tire to change. You don't necessarily need an officially organized group. Just "compare notes" occasionally with someone who has fibromyalgia for the help it gives and brings. Support should help you get on with your life, not become your life.

Financial Support

Hold down your cheers; I don't have any wonderful suggestions or large grants to give out! But rather, I have an appeal to make to the movers and shakers in the health-care industry. Do you want to have productivity in the work-force? Do you want a capable, trained employee to return to his job after fibromyalgia develops?

Then develop a strategy and schedule in the industry for the type of medical and psychological help needed by the person with fibromyalgia. That strategy to be the most successful needs to include some care and counselling for the family, considering how impacted it is by this disease.

Would it not be cheaper for insurance companies to support research into the care and treatment of fibromyalgia than to simply pay out the disability benefits for people who have to drop from the work-force. Not that they have to drop out; it happens for lack of the proper and timely medical care.

Dr. Don L. Goldberg in "Research in Fibromyalgia: Past, Present and Future", quoted in Chapter One, urges that: "**Granting agencies must sponsor research in this area**. There are a few nationally funded studies on fibromyal-gia in Canada and none currently in the United States." (**ibid**.) [As of this date, November, 1994, some research has recently been funded in the United States.]

For lawmakers: medical costs with fibromyalgia are high, due to the length of time it takes to determine the illness' presence, and to find successful treatment. Current federal regulations make it a punishable federal offence for doctors or hospitals to accept only insurance payments, "forgiving" the patients' co-pay on a routine basis. That forces treatment costs to stay high, and may mean treatment becomes unaffordable altogether.

We're talking about **18-20,000,000** Americans with this illness (see Chapter One), who potentially will become unproductive, and a possible burden on the social services of the nation, if the cost of diagnosis and treatment is brought down.

Support Yourself

Once again, you are the one who can help yourself the most, even in the area of emotional support. The unknown causes anxiety; since there are numerous complexities with fibromyalgia, there are a lot of unknowns. Therefore, the potential for anxiety runs high. Mistakes in medication dosages can cause problems. Waiting on your doctor to tell you what to do next -- and appointments with the doctor may be several weeks apart, causes anxiety.

But you have some control over the causes of anxiety. Take as much of the unknown out of your life as you can. Learn what you can about fibromyalgia yourself. Read about the illness; keep a personal journal. Ask questions of the doctor or the pharmacist about the purpose of prescriptions. Ask, if you think you need more or less of a certain medication.

Work **with** the doctor, rather than expecting him / her to lay out every course of action for you. If you or I were the President, or a wealthy celebrity, we'd have a private doctor whose sole duty was to see to our health. The reality is **our** doctors have hundreds of patients! It is good for **us** to see to our own health.

When discussing your illness with others, which of course you want and need to do, don't make overly much of it. We know how debilitating it is, but if you catalog all the pain over and over again, you're only adding to your anxiety. Frankly, when most people inquire about how you are, they are uncomfortable with a lengthy answer. They will ask if they want more details. A simple, "I'm managing; thanks for your concern," clearly conveys that all is not well, but that you are handling it.

Of course, high costs for treatment can cause anxiety. Initially, some is likely unavoidable, but people can learn dozens of inexpensive ways to adjust life-styles, once they have established a self-management program.

Remove the unknowns and the thinking about the negative aspects of fibromyalgia to lower anxiety as much as possible.

One More Level

There is one more level of support which I want to mention. That's the "anonymous" level. No, I don't mean you call phone numbers at random and pour out your heart!

There are two types of professionals who provide this level of support, the clergy and psychologists. What you say to either is held in strict confidence. Either can provide "safe" and meaningful listening. Beyond listening, the clergy would be able to provide more direction for spiritual peace of mind, while the psychologist can provide techniques for dealing with your pain and emotional upheaval.

With fibromyalgia, you are going to have pain. Isn't there anything that can be done to improve the quality of your life? Absolutely! Susan S. Lang wrote in "Suffer No More" in the November 1994 edition of **Good Housekeeping**, that "...some 50 to 100 million Americans suffer from pain when most could experience significant relief. Pain is the most common complaint to doctors and costs the country millions of dollars in medical bills and lost workdays."

How can I get the best results possible?

Take control. It's your responsibility to tell your doctor you're in pain, take part in planning your treatment, follow your pain management plan, ask questions, and speak up if treatment isn't working. If necessary, seek other help. Be persistent until you find what works best for you.

Set goals. Once you've found a doctor you trust, decide with your doctor on some realistic goals for things you most want to do again - for example, sleeping, working, exercising, enjoying sexual relations, etc. Begin working on the easiest goals first.

Work with your doctor or nurse to develop a pain management plan. This might include a list of medications, when to take them, and possible side effects. It might include therapies other than medication. Make sure you understand the plan and carry it out fully. If you don't, you are less likely to get relief.

Keep a pain diary. Write down information about your level of pain at different times, how you're feeling, and what activities you're able to do or not do. Keep a record of medications you're taking or any non-drug treatments. The diary will help you see what's working and measure progress. Bring your diary on visits to the doctor.

Ask your doctor or nurse about non-drug, non-surgical treatments. These could include relaxation therapy, exercise, massage, acupuncture, meditation, application of cold or heat, behavioural therapy, and other techniques.

Ask your doctor or nurse about ways to relax and cope with pain. The way you feel about your pain can actually affect the pain itself. Your pain may feel worse if you are stressed, depressed, or anxious.

If you have questions or concerns, speak up. If you're worried about medications or other treatments, ask your doctor or nurse. If your treatment is not working, insist that your pain be reassessed and new treatments offered. Be polite, but be firm.

If you're going to have surgery, ask your doctor for a complete pain management plan beforehand. Ask what medications you will receive before the operation to minimize pain later, and what will be available for pain relief afterwards.

If you're a patient in a hospital or other facility and you're in pain, speak up. Ask a doctor or nurse for help. If you don't get help right away, ask again. If you still don't get help, ask to speak to the patient advocate or representative. Most likely the doctor or nurse will respond, but be sure to insist on effective pain care without delay.

Pace yourself. Once you experience some degree of control over your pain, don't overdo it. Your body may be out of condition if you have been suffering pain for awhile. Take time to gradually build up to normal activity.

If you're not satisfied with your pain care, don't give up. Does your doctor listen to you? Is your doctor able to assess and treat your pain? Are you getting adequate care? If after a reasonable time the answer is "no," find another doctor or pain care program.

Conquering Pain

New discoveries and treatments offer hope

Pain has an element of blank;
It cannot recollect
When it began or if there were
A time when it was not.

Emily Dickinson

Laura A. McManus is just one of the 50 million Americans who are partly or totally disabled by chronic pain. The 27-year-old from Mount Sinai, N.Y., has a congenital spine dysfunction that became debilitating when she pulled her back out at age 14. Her agony has persisted through seven spinal operations and a steady stream of ever more powerful drugs. ''I've been on everything: Darvoset, Percocet, Vicodin, morphine in the pump, Dilaudid in the pump,'' she says. All of these narcotics eventually stopped working, and by 24 she had upped the dosage to the point where she was so drugged she could barely function. ''I was borderline suicidal,'' she says.

Such misery is the leitmotiv of chronic-pain sufferers. The 20th century has brought amazing breakthroughs in almost every area of medicine save the one that affects everyone--pain. In the 100-plus years since Dickinson penned her sad poem, there have been only two dismal options. Patients could take aspirin and aspirin-like non-steroidal anti-inflammatory drugs (NSAIDS) such as ibuprofen and Naproxen for mild-to-moderate pain or narcotics such as morphine and codeine for severe pain. Neither approach works for everyone or for every pain condition. Even when they do, nsaids and narcotics can have serious, even life-threatening, side effects ranging from stomach ulcers to addiction.

At last, though, chronic-pain relief is becoming more than an oxymoron. After two decades of grueling research into the complex cellular processes that trigger pain, the first drugs custom-designed to block specific pain mechanisms are emerging from the labs. These new agents promise to revolutionize the treatment of pain by allowing doctors to relieve the suffering, regardless of the underlying cause. Best of all, the new drugs promise minimal side effects.

Such breakthroughs should translate into one of the largest drug markets of the next decade (page 110). ''Let's face it: The first company that comes up with a drug for chronic pain will take off like a rocket,'' says Dr. Mitchell Max, coordinator of pain research at the National Institutes of Health. Even with the suboptimal painkillers available today, the world market for analgesics is about $7.7 billion and growing 7% a year, estimates Credit Suisse First Boston Corp. The firm figures that drugs coming on the market this year and next should add $1.5 billion to that total by 2001.

Americans alone spend some $3 billion a year on over-the-counter analgesics, and a further $750 million is doled out for narcotics prescribed for pain. The buyers include 20 million arthritis sufferers, 40 million victims of chronic recurrent headaches, 8 million Americans living with cancer, and the 15% of adults with persistent back pain.

Their need could not be more dire. For most sufferers of chronic pain--defined as persistent pain that lasts more than three months--a life free of agony is elusive. It's not just that the narcotics most commonly prescribed have a number of worrisome side effects. They don't even work for the millions who suffer from neuropathic pain arising from damage to the nerves, caused by disease, trauma, or chemotherapy. A breeze across the skin can be excruciating, and there is no pharmaceutical recourse.

Most frightening, perhaps, is that for all pain victims, the longer they suffer, the more intractable the problem becomes. Continuing pain eventually rewires the nervous system until it becomes even more sensitive to pain--and even harder to treat.

Bottom line: The American Pain Society estimates that 45% of the population seeks medical help for persistent pain at some point in their lives. Medical economists estimate that pain costs the U.S. some $100 billion every year, including 515 million workdays lost and 40 million doctor visits.

MORE FUNDING. The sufferers are beginning to be heard. In January, the Veterans Affairs Dept. announced a new effort to reduce pain for its 3.4 million patients, instructing VA doctors and nurses to assess and record a patient's pain just as they would note blood pressure, pulse, and temperature. And last year, Congress voted to allocate $102 million to the NIH for pain research in 1999, a 15% jump from 1998--and $3 million more than the White House requested.

Unfortunately, science has long lagged behind demand. The last new class of general analgesics to hit the market were NSAIDs almost 30 years ago. But in December, the logjam broke when the Food & Drug Administration approved Monsanto Co.'s (MTC) Celebrex, likely to be the first blockbuster drug for pain. It is the first of a class of arthritis drugs, known as Cox-2 inhibitors, that precisely target a key pain-triggering enzyme found around inflamed joints. The drug is no more effective at relieving pain than the commonly prescribed NSAIDs, but it's less likely to cause the stomach bleeding and ulcers experienced by about 30% of patients on the older treatments. That clearly counts for a lot: Celebrex was introduced in the U.S. on Jan. 19 with no consumer advertising, and a week later it had racked up almost 10,000 prescriptions, making its launch second only to that of Viagra, Pfizer Inc.'s (PFE) impotence treatment.

Celebrex is only the first of a wave of novel analgesics before the FDA. A similar Cox-2 treatment, Merck & Co.'s (MRK) Vioxx, is expected to win approval in May, while Algos Pharmaceutical Corp. (ALGO) in Neptune, N.J., is waiting for action on its application, filed last August, for MorphiDex, which increases the effectiveness of morphine without increasing side effects.

In November, the FDA approved a novel rheumatoid arthritis drug, Enbrel, from Immunex Corp., that boosts the body's ability to stop painful inflammation. Enbrel is also the first drug to be tested for children with juvenile rheumatoid arthritis and represents ''a dramatic advancement in treatment,'' says Dr. Daniel J. Lovell of Children's Hospital Medical Center in Cleveland. Colleen Cotter, 7, of Madison, Wis., has been transformed by the drug from a quiet to a bubbly child. ''She's doing so much better now,'' says her mother, Mary.

For something completely different, there's Ziconotide, the savior of Laura McManus. Made by Neurex Corp. in Menlo Park, Calif., the treatment is a synthetic analog of a chemical found in the paralyzing venom of Conus sea snails. Ziconotide is able to home in on receptors found only on the pain-sensing nerve cells that connect to the spinal cord, blocking their message from going any further.

Because the drug's target is so specific, side effects are minimal. McManus' doctor enrolled her in a clinical trial in January, 1998. ''One month after being on Ziconotide, it was 'Wow, I was happy,''' she says. In the following months, she started physical therapy, began walking, lost the 70 pounds she gained while the pain was at its worst, returned to college, and danced at a wedding. ''Now,'' she says, ''I can think. I can express my feelings. I can have children, finish school. I can have a life.''

For pain researchers, McManus' testimonial is proof of principle--the more tailored the drug, the more effective. Scientists have spent the past two decades ferreting out the cellular receptors, channels, and chemicals involved in different types of pain and designing drugs to block them. ''For the first time, we can dissect the pain mechanisms of different diseases,'' says Patrick W. Mantyh, director of molecular neurobiology at the Veterans Administration Medical Center in Minneapolis. ''And instead of using a general drug for all pain, [we can] come up with one specific to symptoms.''

NEW PATHS. A number of specific treatments are already in clinical trials. Abbott Laboratories (ABT) is testing ABT-594, based on a toxin found in the skin of frogs. The drug, for severe chronic pain, aims at the same cellular mechanism that is receptive to nicotine -- which smokers know can calm nerves. Although still in early human trials, ABT-594 has proved in lab animals to be 50 times as effective as morphine. In a more radical approach, CytoTherapeutics of Lincoln, R.I., is in human trials with cow adrenal cells that are implanted at the base of the spine. There, they continuously secrete natural painkilling substances, bolstering the body's own defenses.

There are several clinical trials aimed at treating neuropathic diseases of the nervous system for which there are currently no approved treatments, such as shingles, phantom limb pain, and the searing pain in the extremities that affects diabetics. Myelos Neurosciences Corp. in San Diego is in the second phase of testing Prosaptide TX14(a), a drug that regenerates the damaged nerves that cause the neuropathy. And there is increasing interest in Warner-Lambert Co.'s (WLA) epilepsy drug, Neurontin, introduced five years ago, because the nerve centers that control seizures and those that control pain are closely linked. Two new studies report that Neurontin is highly effective in the treatment of diabetic neuropathy and shingles.

Along with new treatments, a new way of thinking about pain is emerging. Researchers think pain should be treated as a disease in itself, divorced to a large degree from the underlying cause, such as cancer or a sprained back. Instead, pain would be classified by the cellular mechanisms that cause the hurt, which may be the same for different diseases--or different for the same disease. Once a pain mechanism is identified, doctors could hunt through an arsenal of highly targeted drugs for just the right treatment.

Or perhaps the body could be persuaded to stop its own hurt. One of the great mysteries of pain is the placebo effect: In almost every pain study, about 35% of patients on placebo feel relief. ''Even when patients just think they're getting treatment, there is automatically some internal release of endorphins,'' says Dr. John T. Farrar, a neurologist at the University of Pennsylvania Medical Center. ''We have to find some way to harness that ability of the mind to control pain.''

The remarkable progress in pain treatments can be traced to two important research advances in the early 1990s. Advanced imaging technologies gave scientists the ability to observe the way pain signals travel through the nervous system, while biologists developed genetically altered animal models that experience pain in the same way humans do, enabling researchers to test new compounds. Suddenly, a field that had been a scientific backwater became hot. ''In the past couple of years, there has been an exponential increase in people's interest in pain,'' says John C. Hunter, head of analgesic research at Roche BioScience in Palo Alto, Calif.

UNPREDICTABLE. That enthusiasm should speed progress, but science is still a long way from ''curing'' pain. Pain is one of the body's most complex biological functions, and it's hardly uniform. The pain response varies by gender, race, and age, making it hard to predict from one person to the next. ''The nervous system is extremely plastic,'' explains Dr. Russell K. Portenoy, chairman of pain medicine at Beth Israel Medical Center in New York. ''Once an injury occurs, the pain signals can go in any number of directions.''

Even more problematic, pain is completely subjective--each person's physical and emotional tolerance level is different. ''That's the great unknown in the study of pain,'' says Dr. Richard Payne, chief of the Pain Care Service at Memorial Sloan-Kettering Cancer Center in New York. ''How do you account for the individual variation in perception?''

Most doctors don't try. Physicians have always considered pain a byproduct of injury or disease: Treat the underlying condition, and you stop the pain. Consequently, pain itself is undertreated, and pain management is not taught at most medical schools. This lack of understanding has been almost medieval: As recently as the early 1980s, for example, it was assumed that infants could not feel or remember pain, and surgeons routinely operated on babies without anesthesia. ''Now we know that traumatic events in infancy can have long-term consequences, but that knowledge has only developed in the last 20 to 25 years,'' says Dr. Charles Berde, director of the pain treatment center at Children's Hospital in Boston.

The modern age of pain research started in the mid-1960s, thanks to a breakthrough by Ronald Melzack of Canada and Patrick D. Wall of Britain. They discovered that the pain sensation does not travel directly through the spinal cord to the brain, as had always been assumed, but is ratcheted up or down by a series of chemical gates in the spinal cord. Control the gates, they figured, and you could control the pain.

Pain starts when specific nerve fibers known as nociceptors, found throughout the body, sense a disturbance in nearby tissue. Once alerted, they release a chemical soup of pain messengers called neurotransmitters, among them potassium, prostaglandin, and substance P. If the pain is sharp and searing, these messengers rush to the spinal cord through superfast nerve conduits. Dull aches and throbbing travel along slower pathways. The chemicals collect in a part of the spinal cord called the dorsal horn until a ''gate'' opens, releasing them to the brain.

Pain isn't actually ''felt'' until the message hits the brain. The brain also prods into action the body's autonomic nervous system, which adjusts breathing, blood flow, pulse, and digestion, and the limbic system, which controls emotions. In the 1970s, researchers made an important discovery: The pain gates can be closed by chemicals that the brain sends back down the spinal cord. These pain-suppressing transmitters include adrenalin, serotonin, and most important, the endorphins, peptides similar to opium. Because receptors for these so-called endogenous opiates can be found throughout the nervous system, opium-based drugs such as morphine, codeine, and methadone are the most powerful painkillers.

But this gold standard carries a high price. Opiates can cause constipation, nausea, drowsiness, and slow breathing. In high enough doses, they can lead to addiction, though this is rare in pain treatment. To get around the side effects, Warner-Lambert and Pfizer, among others, are developing compounds that target specific opiate receptors coded only to stop pain.

BOOSTER. Meanwhile, drug companies are coming up with ways to minimize side effects by delivering narcotics directly to the site of the pain. Anesta Corp. (NSTA) in Salt Lake City is one of the first to bring this concept to market. In November, it won FDA approval for Actiq, a crystallized form of fentanyl that is the first treatment for the intense flare-ups of cancer pain that break through a patient's standard pain treatments. Patients place the lozenge against the inside of their cheek, where it is absorbed quickly into the bloodstream, avoiding the gut. ''It starts to work almost immediately,'' says William A. Ball of Harrisburg, Pa., who has bone cancer. The 74-year-old says he was immobilized by breakthrough pain before he started using Actiq. ''Now, I'm able to get out of bed easier, able to stand up easier. I even played a round of golf.''

Then there's an effort to trick the opiate receptors with dextromethorphan (DM), a common cough syrup. DM blocks a nerve receptor called NMDA from releasing secondary pain signals that prevent opiates from working. Algos combined DM with morphine to create MorphiDex, a drug that doubles the effectiveness of the narcotic without increasing the side effects--allowing patients to take half their usual dosage.

The most cutting-edge pain research avoids opiates altogether. Scientists are looking for compounds that stop pain signals before the brain gets the message, either by blocking the signal in the spinal cord or by keeping it out of the spine in the first place. Almost monthly, scientists discover potential new targets, but the bull's eyes they'd most like to hit are the neurotransmitters released at the site of the hurt.

One of the most studied is substance P, a powerful chemical whose receptors are found on 45% of the cells that respond to pain stimuli. But substance P also plays a role in depression, anxiety, and nausea, making it devilishly hard to tackle without disrupting other systems. Several compounds have already been abandoned because of their side effects.

Even so, evidence is emerging that substance P agents can stop pain. In a recently published study, an experimental Pfizer drug proved effective at easing pain caused by tooth extractions. Researcher Mantyh is experimenting in animals with a more subtle approach, using the substance P molecule as a Trojan horse. He couples it with a painkiller that it delivers to the spinal cord. ''I'm basically using [substance P] as a generic platform to get something into the cell, be it a toxin or a gene or some other agent,'' he says.

Each new discovery creates more buzz among researchers. ''There continues to be so much excitement about drugs that are receptor-targeted,'' says Dr. Michael Moskowitz, a neurology professor at Harvard University Medical School. One drug can quickly lead to better treatments, he notes--as evidenced by the rapid succession of migraine medications.

TRIPLE PLAY. For some 50 years, the best treatment for the 25 million Americans who suffer from migraines was ergotamine, which worked only some of the time and could cause nausea. Then, in 1991, Glaxo Wellcome PLC (GLX) introduced Imitrex, a fast-acting, well-tolerated drug that targets one of 15 cellular receptors for serotonin, a brain chemical that moderates mood and appetite as well as migraines. Two more drugs have since been approved, Zeneca's Zomig and Merck's Maxalt, that target the same receptor, and a third from Pfizer is in the wings. But all of them can raise blood pressure, so Eli Lilly & Co. (LLY) is in clinical trials with a drug that tries to avoid this side effect by targeting a different serotonin receptor.

Three generations of drug in one decade bodes well for pain sufferers. If such progress continues, in the 21st century, Emily Dickinson's words may finally no longer ring true: There will be a time when pain is not.

By Catherine Arnst, with Ellen Licking, in New York and Amy Barrett in Philadelphia

article

[when a friend has a chronic illness]

When a friend hurts, we gather around her. When she has surgery, we line up outside her door with meals. We send flowers, cards, and gifts. We provide childcare and, of course, prayers. Gradually she heals and is able to return to her every day life.

When a friend is diagnosed with a chronic illness the natural cycle of healing doesn't take place. What do we say? Do we encourage her to remain hopeful? Chronic illness is permanent and often degenerative, requiring her to change nearly everything about her life. The emotions that accompany these changes in her life are often more difficult to cope with than the pain itself.

What to Say   What Not to Say   How to Help

What to Say

Be honest. Say "I wish I knew the right thing to say, but I care and I am here if you need me."

Ask her if she'd like you to pray for her and ask what she wants you to pray about. Respect her request. Don't pray for healing if she wants prayer for new medications.

Remind him that coping with life's difficulties is a process and that the length of time is different for everyone. Tell him that he is coping well. Just listen. Let her share her thoughts and feelings with you and don't say, "I understand," if you haven't been there yourself.

Respect where he is with his faith. If you see him struggling, be sensitive to it and don't tell him to snap out if it, that God is still good. Pray for him silently and be patient.

Treat her as though she is still a whole person, despite her limitations. She wants to feel capable and in control. Let her make the plans.

Become somewhat educated on his illness. Ask him if he’d mind answering some of your questions. Remember, just because you’ve read a book doesn’t mean that you know how he is feeling physically or emotionally.

Don’t assume that she copes with things the same way you do. She may gain strength by alone time while being alone depresses you. Let her cope in her own way and don’t tell her she is coping in the “wrong” way.

Let him know you are thinking about him. A card or a phone call can make the difference.

What Not to Say

Avoid giving “God balm.” If you say “God will heal you” or “all things work together...” she will believe you don’t really understand and avoid sharing her feelings with you in the future.

Don’t feel compelled to share every “cure” you’ve heard of for his illness. He’s constantly bombarded with cures and he needs you to be his refuge from that.

Be aware of the fact that illness is not just a matter of attitude. Don’t say, “When are you going to get rid of that cane?” or “Did you know illness is caused by stress?”

Respect her limitations and be sensitive to them. Don’t say, “A little walk might do you some good” or “No pain, no gain!” Only she knows her limits and they will likely change from day to day depending on many factors. What she could do yesterday may not be possible today. Don’t question that.

How to Help

Offer specific ways that you can assist your friend. Say “I am going to the drug store. Can I pick something up for you?” Look around her home and see where your friend might need some help. Does the shower need scrubbed? The leaves raked? The carpet shampooed. Offer to take care of these things.

Volunteer to pick up some groceries rather than do the cooking. Many times people with illnesses have restrictive diets, so they may prefer some fresh fruits and vegetables than a casserole. Ask what meals he is eating and then freeze some of these for him to have on hand.

Accompany her to places where she may need some assistance. Get your haircut at the same time, or have the oil changed in her car while you are eating lunch. Bring an uplifting personal little gift when you come to visit: some fresh cut roses, a new book, a funny movie, some cookies for the children, a blanket, potpourri to make the house smell good.

Remember that one's spouse and children have needs too and these often concern your friend. Take the children out for awhile so s/he can get some rest. Plan something special for the children and before you drop them off at the house, pick up a small "something" that will make their parent smile like some fresh flowers.

Ask your friend what her concerns are and how you can address them. One woman who was ill said that she would like for a friend to make sure her children made it to Sunday School and church when she couldn't go.

Ask the person's spouse how you can help the family. One spouse was appreciative of gift certificates to the local fast food restaurants so that the children could occasionally have a quick meal and his wife didn't have to worry about making dinner.