

Issue 8
November 2005

*A newsletter for church leaders
and church members who live
with and without disability and
chronic illness.*

*But now, O Lord,
you are our Father;
we are the clay,
and you are our potter;
we are all the
work of your hand.*
~Isaiah 64:8 (ESV)

Note from the Editor:

The information in this newsletter is not meant as medical, legal or professional advice.

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(ESV) refers to:

The Holy Bible: English Standard Version (2001), Wheaton: Good News Publishers.

Footnote numbers refer to resources in the ***End Notes*** section.

A Grace Note from Lois

“My grace is sufficient for you, for my power is made perfect in weakness.”

~ 2 Corinthians 12:9 ESV

I'm back!

I want to thank you for hanging in there with me. I greatly appreciate your prayers for me, this newsletter, and for the people seen in these pages. I feel like I am always apologizing for not producing this newsletter on a regular basis. But no matter what I plan, **God has a better idea.**

As you probably know, I live with several disabilities and chronic illnesses. My ability to do research and write depend on my health. This year has been one of the most difficult I have had in several years. Praise God with me, that I am now doing much better.

I greatly appreciate your continued prayers, not just for my health, but also for my writing; Issue 9 will be on chronic pain, the most common problem people with disabilities and chronic illness experience, but also among the most difficult to discuss. (I promise to get Issue 9 out sometime in 2006, but I can't promise anything beyond that, although, Lord willing, I do hope to be able to do more than one issue a year.)

Living with Limitations

My personal journey with limitations began in 1971, when a muscle injury developed into nerve damage. Later on other disabilities and chronic illnesses were added, each with its own particular limitations.

In those early years with my disability and limitations I struggled spiritually because it was hard to understand what God was doing. In many ways my self-image was shattered into a million pieces — I felt like Humpty Dumpty, and it took the King of Kings to put me back together again.

Today my limitations continue to increase and decrease, sometimes unpredictably. The frustrating part is not knowing from one day to the next how I will be feeling and what I will be capable of doing. I know

this is especially frustrating for my husband, Tom.

With these and other difficulties, sometimes it helps to express how we are feeling. This poem is the result of a year of severe pain and growing limitations:

This Heart of Darkness

My home,
once open and light,
is now clouded over
by aching, gnawing,
all-consuming
pain.

The windows,
once freely open to all,
now shuttered,
bound with shades
drawn by cords pulled taut.

Yet I am given a gift
of glorious Light
in this heart of darkness;
a profound Presence with
strong, encircling arms.

With tears of awe,
I feel around me
nail-pierced hands,
scarred by pain indescribable,
draw me ever closer
to my heavenly Father's Heart.

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Ask most Christians to describe a biblical view of disability, and they'll likely have a hard time coming up with one. The common view of disability has long been that it is an abnormal part of life in a normal world. We tend to assume that the world in which we live is the baseline and, therefore normal. Differences from the norm are then regarded as something other—something abnormal. It does not take much imagination to understand why people with disabilities resent being seen this way. In reaction to this historical view, some disability-rights advocates now reframe the debate, couching disability as a difference no different than hair color. Essentially, they promote disability as a "normal part of life in a normal world."

~ Stephanie Hubach¹

Fearfully and Wonderfully Made

“I praise you, for I am fearfully and wonderfully made. Wonderful are your works; my soul knows it very well.”

~ Psalm 139:14 ESV

Everything You Wanted to Know About Limitations, But Were Afraid to Ask

Definitions

Limitations set a boundary, restricting what we are capable of doing. They set a limit beyond which we either cannot or should not go. Limitations define the range on our abilities.

We live in a world of limitations, restrictions and boundaries. Sickness and injury confine and limit our world. But there are also limitations that date from birth, and may not be due to an injury or disease. For example, not all of us can do higher math, or run the quarter-mile, or learn at the same rate.

There are limitations and there are LIMITATIONS

In this issue I will be talking mostly about those limitations that are the result of disability and chronic illness. Most people can think and feel, walk and talk, see and hear. But some of us are limited in our capability to do what others take for granted. And some of us are more limited than others. Some of us cannot do one or more of these things at all. It is important to remember that the limitations from one disorder can be affected by the limitations of another disorder. And if we do not die at an early age, the passage of time will result in the ability of each of us to slowly fade away.

Those who were born with all the usual capabilities, may lose them as the result of an accident, disease and even old age. And those of us who were born with a disability may find others being added with time and age.

Types of Limitations

The following is a list of some of the limitations people may have:

1. **Mobility:** loss may require use of a cane, crutches, walker, occasional non-walking assistance with a scooter or full-time use of a wheelchair.
2. **Vision:** loss may need the use of glasses or contacts; or cataract removal; or more severe impairment may include partial blindness in one or both eyes, or removal of one or both eyes.
3. **Hearing:** loss ranges from slight to profound hearing impairment, to complete deafness. Remember that not all types of hearing loss can be helped with hearing aides. And use of a hearing aide in a room where there are many people talking is very difficult, because they cannot filter out a single voice.
4. **Mental capacity:** a developmental disability results in a reduced intelligence, requiring special education and training.
5. **Mental illness:** neurosis or psychosis result in the use of various treatments and medications; the side effects can be devastating to some people.
6. **Communication problems:** loss is due to speech impediments, facial deformity and other disorders.

Self-imposed or Excuses?

Self-imposed limitations are the result of a person's fear and anxiety. We may think of them as real or imaginary, and we may not fully know or comprehend the reasons a person may have when they say that they cannot do something.

Some of us may use our limitations as an excuse not to interact with the world, including participating in church activities. Above all, care and sensitivity is required in all of these instances.

Those “Sometimes” Limitations

Most of us know exactly how far we can go. And some of us have to discover by trial and error those activities that will result in immediate pain and limitation. And then there are those capabilities that come and go, causing even more frustration.

Then there is the pain or limitation we might “pay for later”. These are especially frustrating. It would make life easier if we knew ahead of time, when an activity would result in additional pain. But not all activity results are predictable, keeping us on our toes, so to speak.

Never Assume...

There are some things we need to keep in mind when it comes to a person’s limitations:

☛ Never assume that a person with a disability is just giving an excuse or is just being lazy. It is hard enough trying to second-guess ourselves without having someone else getting into the act.

☛ Never assume that a person has a limitation based on their particular disability. You never know what they are capable of doing.

When Tina Simon came to Tenth, we could have assumed that she would be on the receiving end, rather than on the giving end of church participation. This is because Tina is totally blind, and when she first came to us she had a seeing-eye dog, Xanadu. Instead of assuming what she could do, we let her explore her capabilities. It did not take long before she was leading Bible studies among the homeless, and cooking for the community dinner for the homeless.

At one point she thought she would like to be a deaconess, serving people in her parish. Not knowing what she could and could not do, the Board of Deaconesses took her under their wing as a deaconess-in-training. This helped Tina to discover those things she could not do. But there were some things she could do, and she didn’t have to become a deaconess to do them. As a result, every Sunday you can now see Tina standing out in the Narthex handing out the bulletin and greeting people as they come in.

Xanadu has since passed away, but Tina now has people in the church who will take her where she needs to go. Most importantly, Tina has become a wonderful friend to me and other people in Grace Ministry. And today she actually **leads** Grace Ministry. She also helps care for the infants in the nursery and she has a passion for prayer in the church. We praise God that Tina has taught us never to assume what a person with a disability or chronic illness can and cannot do.

Summary

For many of us, life is made harder by our limitations. We often feel like we are left sitting on the sidelines while everyone else is going about their usual business. We especially appreciate your understanding when we talk about a limitation we may have. And give us the opportunity to explore our capabilities whenever possible. Like Tina, we may surprise you.

~lad



**Deepen Your
Relationship
With God**

One Body...Many Members

“Now you are the body of Christ and individually members of it.”

~ 1 Corinthians 12:27 ESV

Limitations & Values

Limitations frighten the daylights out of us because we realize that we no longer have control over what is happening to us. Limitations are... that’s it. We have capabilities that we can lose, and there is no guarantee that we will be able to keep them for the rest of our lives.

When we value people by what they are capable of doing for us, we are in danger of no longer valuing them when their capabilities are taken away. And many of us value ourselves as long as we are able to contribute to meeting the needs of others.

A History Lesson

In 1933 the Nazis began widespread and compulsory sterilization of the disabled. They took the Darwinian concept of “*survival of the fittest*” to heart, using it to promote their idea of the “*master race*.” They argued that allowing disabled people to live and have children led to the “*unfit*” reproducing more quickly than the fit. In the 1920s and early 1930s the Nazis blamed their social and economic problems on “*the weakening of the population created by an unfair burden*.” The Nazis saw the disabled as “*useless eaters*” and lives of the disabled were not worth living. In 1939, Germany began killing people with disabilities using lethal injections and poison gas at “*ethanasia centres in Germany and Austria*.” By the end of World War II, Germany had killed 275,000 disabled people.³

A Moral Dilemma

Our medical miracles have placed us into a moral dilemma. We no longer die from the many illnesses that used to take the lives of people. Today, we see people with disabilities and chronic illnesses in public places, working and worshipping.

But when are medical interventions too much? Where are we playing God and when aren't we? When do we pull the plug and when is it right to maintain the battle to stay alive? These are all moral questions we would rather not have to deal with. These are things we would rather put off until it becomes necessary to think about them.³

ByFaith magazine has had a series of articles about the disabled and the church. In their May/June 2005 issue, Jim Tonkowich wrote an article titled, "When Is It Right to Pull the Plug?" This article highlights a number of key issues pertaining to end-of-life decisions, citing some PCA position papers. The whole article can be found among the archived articles at http://www.byfaithonline.com/partner/Article_Display_Page/.

How Are We To Value Life?

Early in 2005 I had been researching, writing and rewriting this issue when the Terri Schiavo case hit national news. As I talked to a number of people about Terri, I saw how she has challenged our views about the value of people who live with disability, chronic illness and their limitations. Terri had no idea what was to happen to her and how far her humanity would be challenged. Terri is the poster child for the many forgotten and unwanted who are seen as a drain on personal time and resources.

I began my years of life-changing limitations after a back injury in 1971, when I had to re-evaluate how I valued my own life. In 1975 I lost my nursing job, and my career in nursing ended. I went through a series of losses, but losing my career in nursing was one of the most devastating, because I had defined my life by what I was capable of doing. Without nursing, who was I? I became severely depressed because of all the losses due to my pain and limitations.

How are we to value people, especially those whose lives are limited because of disability and chronic illness?

We must start our search for value at the beginning — we are each created in God's image, no matter how marred our lives may appear. In the midst of my despair, the Lord gave me the assurance that His will

for me is his very best will, not his second or third (which I later learned do not exist). I also saw that He had purposely decided to sustain my life because He saw my life as worth living. If God sees my life as worth living, then who am I to argue?

How can we help people who live with limitations to see their life as worth living?

First, each of us needs to see that Jesus displayed His value of us by dying for us. When we accept His sacrifice, and give our lives to Jesus as our Lord and Savior, we become His children. We can then tell fellow believers that because God values them, we value them.

Second, we can show people with limitations how much we value them by showing that they are worth our time and energy. When we volunteer to minister to the homeless, or to people in nursing homes, and to people with disabilities and chronic illness in our church, we need to see them as equal in God's sight. This affects our view of their value as people. It is important not to see people with disabilities as "projects."

Third, we can financially contribute to various building projects at our church to provide *equal access* for those who are disabled or chronically ill. I say "equal access" instead of "handicapped access" because people with disabilities and chronic illnesses need to be seen as equal participants in church life, and giving them equal access helps them to do just that.

How are we to see people with limitations?

When we speak to someone with a limitation, we are tempted to make little of it, or minimize it, as if it does not matter. But this tells the person that you cannot accept the limitation as a natural part of them.

My husband and I were on an Alaskan cruise in July and on board was a native-Alaskan carving a face totem. We talked at length about his art and the need to preserve his cultural heritage. As I looked at this huge head he was working on, I was bothered by a long deep crack in the wood, going straight down the middle of the face. I asked him

what he was going to do about the crack. His response? *“Nothing — it’s a natural part of the wood.”*

That is exactly what we need to do — accept a person and their disability and their limitations as a natural part of their lives. Acceptance, limitations and all, is the greatest gift you can give us.

We should not try to “fix” people. As Christians we firmly believe in the sovereignty of God in all of life, and so we need to see permanent limitations as a natural part of a person’s life — as part of God’s providence, knowing that He calls us to live with our limitations.

~lad



*“Look at the birds of the air:
they neither sow nor reap nor
gather into barns, and yet
your heavenly Father feeds
them. Are you not of more
value than they?”*

~Matthew 6:26 (ESV)

Equipping the Saints

“For the ministry of this service is not only supplying the needs of the saints, but is also overflowing in many thanksgivings to God.”

~ 2 Corinthians 9:12 ESV

Making End-of-Life Decisions

Leslie Burk is a man in Britain with a frightening problem. He has cerebellar ataxia, a degenerative brain condition that will progressively result in the loss of his normal physical abilities. He is especially concerned about the time when he will no longer be able to swallow and will need a feeding tube for nutrition and hydration. As he loses more and more physical abilities, he fears that the government-run health system will remove the tube in order to hasten his death.³

Mr. Burk’s story is not dissimilar to the story of every severely disabled person in the United States. We know this because Terri Schiavo also lost her legal battle to stay alive by artificial nutrition and hydration.

With the death of Terri Schiavo there was a mass panic in the disability community in the US as people with severe disabilities went to their attorneys to find out how they could make their end-of-life wishes known and followed without question.

Since each state and country has their own laws pertaining to end-of-life decisions, I am unable to give you specifics. I have heard that Advance Directives are being preferred over Living Wills, but this is something you should discuss with your attorney. The *Caring Connection* provides the following planning advice:

Keys to Receiving Quality End-of-Life Care

- ☛ Get information on the types of life-sustaining treatments that are available.
- ☛ Decide what types of treatment you would want or would not want.
- ☛ If you have an illness, get information on how your disease will progress.
- ☛ Discuss with your doctor what your treatments are expected to

accomplish and what the risks of these treatments are.

☛ Share with your family members and friends your personal values. Your spiritual values and beliefs make up who you are and may determine which procedures you want – or do not want.

☛ If you need a place to start, download and read the “Questions and Answers” booklets on the Caring Info site. Share what “quality of life” and “dying with dignity” means to you.

☛ Use advance directives to put into writing what types of treatments you would want if you are no longer able to speak for yourself. You can download free, state-specific Advance Directives at <http://www.caringinfo.org>.⁵

~lad



**The
Sovereign LORD
is my strength ...
He enables
me to go on
the heights ...**

Habakkuk 3:19

End Notes

¹ Hubach, Stephanie. *ByFaith Online*. "Those With Disabilities Help to Make Us Whole" April 2005.

² Cook, Ian. *Ouch!...it's a disability thing* (A BBS online magazine). "The Holocaust and disabled people." BBC. <http://www.bbc.co.uk/ouch/>.

³ Church Council of the Evangelical Lutheran Church in America. *End of Life Statement*. 1992.

⁴ Rozenberg, Joshua, Legal Editor. *Telegraph.co.uk*. "Dying man loses legal battle over right to be fed." July 2005.

⁵ National Hospice and Palliative Care Organization. *Caring Connections*. <http://www.caringinfo.org>.

The Grace in Winter Blog is up and running!

Go to: <http://graceinwinter.blogspot.com>

As I work on each issue of *Jars of Clay*,

I'll be posting portions on of the newsletter on this blog.

I'll also give some inside information on other writing jobs I'm working on. You will be able to comment.

If you would like to participate in *Jars of Clay*, and would like to write about your experience as a person with a chronic illness and disability, please limit it to 700 words and submit to me at the address on the next page.

You could write a story about your day, how you live, or tell about your specific condition/disease, etc.

Fill in below and forward to:

Lois A. Denier, 236 Drexel Ave., Lansdowne, PA 19050.

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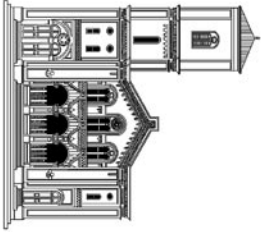
Grace grows best in winter

~ Samuel Rutherford

JARS OF CLAY is part of the writing ministry of
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Any questions, comments, problems,
or feedback are greatly appreciated!

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