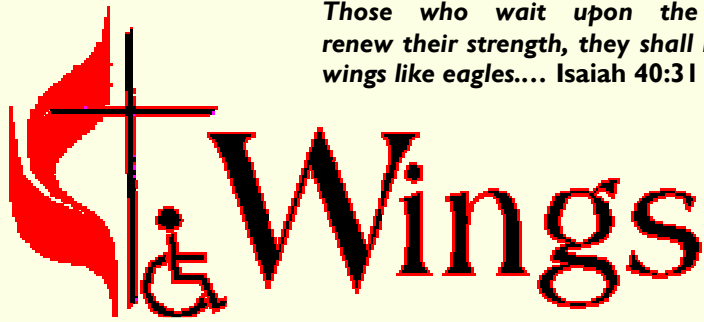


Those who wait upon the LORD shall renew their strength, they shall mount up with wings like eagles.... Isaiah 40:31 (NRSV)



A FAITHLETTER FOR UNITED METHODISTS WITH
DISABILITIES AND THOSE WHO CARE ABOUT THEM
FALL 2005 — Vol. 16 Issue 2 No. 62



FROM WHERE I SIT: DISABILITY AND TRAGEDY

By Jo D'Archangelis

The following is a slightly revised rerun of a column that first appeared in the Summer 1995 issue of *Wings*.—Editor

A few weeks ago an aunt of mine in Indiana wrote to tell us about one of her grandchildren, an infant girl who had been diagnosed with Spinal Muscular Atrophy (a condition that I too have had since infancy). She said that her granddaughter had died of pneumonia at the age of eight months. Her heart and lungs just gave out, my aunt wrote, and then she added that they would “all miss her.”

I shared the sadness in her simple words, but at the same time I noticed with some relief what she did *not* say. She did not say that what had happened was “for the best” or that the baby was now “better off” or that it was “better” for everyone that the child should have been taken “this way.” But certainly people, both disabled and nondisabled, have often said—or thought—these kinds of things in similar circumstances.

Such words are intended to be comforting for they say that God in his infinite love and wisdom takes some human beings “before their time,” so to speak, in order to forestall a greater tragedy. Un-

fortunately, in the minds of many the “greater tragedy” in these circumstances would have been having to raise or having to be a disabled child.

From my own experience, I know that dealing with severe long-term disability

If disability is a tragedy in any sense whatsoever, it is not in the disability itself but in how badly some of us deal with it.

from childhood on can be a particularly difficult situation, difficult for the family as well as for the disabled child. It can bring more than its share of medical, psychological, and social problems. But is it such a tragedy that one can make the wholesale judgment that the disabled child would be better off dead or perhaps not even born at all? It is disturbing how too many people can look at a disabled child, or adult for that matter, and automatically conclude that his or her life is not worth living, least of all nurturing and caring for.

I'm thankful that my parents and my grandparents didn't have that attitude (and this was in the “dark ages” when not that many supportive services were available). Whatever normal feelings

they may have had on their “bad days”—anger, guilt, shame, doubt, helplessness—they never gave me the idea that I was a useless thing better off dead.

I'm also grateful that they didn't pack me off to some institution. The possibility of that even happening didn't occur to me until I was about 12 or 13. My father's boss offered to pay for keeping me at the Shriners Hospital or Home for Crippled Children in Chicago (I believe it was). I would be well cared for and could even continue my education there. My parents felt that I was old enough to decide for myself what I wanted to do and so they just presented it to me without trying to persuade me one way or another. At first I agreed, thinking everyone would be “better off” without me. But nobility soon gave way to reality, and I tearfully blubbered that no way did I want to leave here and go there! The subject was never brought up again.

Is my life a tragedy? Definitely not. Is my disability a tragedy? I have not yet gotten to the point where I find disability a blessing as some have done, but I don't consider it a curse either. It's just something that happened over which I had no control, and if I had had a choice, I probably would have said, thanks but no thanks—life is hard enough without viewing it from belt-buckle height.

If disability is a tragedy in any sense whatsoever, it is not in the disability itself but in how badly some of us deal with it. If parents look at their disabled children

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CHRONIC ILLNESS AND THE FAITH COMMUNITY

By Mary Jane Steinhagen

We need to be inclusive in our faith communities, reaching out and welcoming all who wish to participate. People with chronic but non-life-threatening illnesses are often able to attend services only occasionally or sometimes not at all. If we don't make intentional efforts to help them maintain their membership, those with chronic illnesses fall into the "out of sight, out of mind" syndrome.

...I've had several conversations with people about this issue. These people encouraged me to write about their needs in hopes that faith community leaders would take note of them.

The needs we discussed seemed to fall into three broad categories: practices, connections, and attitudes. What follows are the suggestions made to me. (For

ease in understanding this, I have kept the first-person voice used by those to whom I talked.)

Practices

- ◆ I appreciate receiving taped or printed copies of the sermons.
- ◆ Include me in the prayers and periodically remind me of that prayerful support.
- ◆ Make sure that I also receive the seasonal symbols such as ashes and palms.
- ◆ When you are planning a shopping trip, call and ask what my needs are.

Connections

- ◆ Befrienders or Stephen Ministers are there to encourage outreach rather than to replace the faith community.
- ◆ Call me; ask and value my opinion on matters relating to our community.

◆ I need and value my long-term relationships with members, especially since most of the staff I knew from my active days have moved on. These enduring friendships have become my faith community.

Attitudes

- ◆ My spirit hurts when I am referred to as a 'former member' or 'someone who used to be active.'
- ◆ I am more than a box of envelopes for contributions.
- ◆ It's difficult to be someone's Sunday school project.
- ◆ Think twice about offering me advice about the latest cure for my illness; if it's in my best interest, my doctor and I have already made a decision based on my needs.

These suggestions will help us be more supportive of those who live with chronic illnesses.

Steinhagen is a Catholic Charities disability advocate in Minneapolis, Minn.



A non-official, non-profit quarterly newsletter published for, by, and about United Methodist adults with disabling conditions

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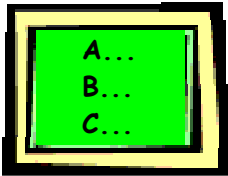
(*FWIS continued from page 1*)



only as wasted potential and disabled children look at themselves in the same way, then we have tragedy in the making.

The greatest tragedy that can befall a person is not that of disability but that of a wasted life. A child who dies young; someone unable to give or receive love; someone enslaved in self-destructive behavior; someone who sees him or herself as totally alienated from the love of God in Jesus Christ—these are the *real* tragedies, and they can happen to the disabled and non-disabled alike.

Nonetheless, as Christians we are not left utterly overwhelmed by these real tragedies any more than we are left overwhelmed by the pseudo-tragedy of disability. We believe that God can pull the wasted life up by the scruff of its neck; shake it free from its grief, disillusion, and self-absorption; and fling it headfirst into what Jesus called the "abundant life." And abundance, I might add, is by no means the prerogative of the able-bodied.



THE VOICE WITHIN

By Gary Warth

His hands can't hold a pen, his fingers can't work a keyboard, his mouth can't form the sentences he wants to speak. But inside a body frail with cerebral palsy is a spiritual heart and a lucid, albeit mechanically articulated, voice with a message of love and faith.

"You are worthy and to be praised, my Eternal God and Lord, pre-existing all Your Creation," begins Vista [Calif.] resident Rick Hohn's 108-page book, *Psalms of Praises to the Gospel of St. John* (\$10.99, Selah Publishing Group), which he wrote by pecking at a monitor with a stylus strapped to his head.

"I started writing letters to Jesus, so one day I wanted to write a devotional about the book of John," [Hohn] said in an interview through an electronic device that converts typed letters to speech. "All of the praises to God that I can give are a mist of what he truly deserves," Hohn said about his inspiration and endurance.

Hohn's words are spoken in a mechanical voice projected from a monitor attached to his electronic wheelchair. Touching a lettered key on the monitor opens a screen with a choice of words that begin with that letter, a shortcut that eliminates the need to type out every word. Once a sentence is put together, Hohn touches the screen with a stylus, and a mechanical voice reads what he has written.

In the preface to his book, Hohn, 58, recalls looking at himself in a full-length mirror at age 36 and being shocked to see his condition for the first time in years. "I said to myself, 'What a freak! Is that really me? No wonder kids have come up to me and asked if I'm from Mars!'"

But, Hohn writes, at the urging of a friend to look for something he liked about himself, he noticed that his eyes sparkled as though he were seeing the

glory of God. "This statement is certainly not to engender pity or to bring myself glory," he writes about describing his disability, "but that you would see

"I felt guilty because I knew I was dependent on my disability and my religious relatives to get me into heaven. I realized that sometimes I made my handicap an excuse." — Rick Hohn

how God's strength is perfected in weakness (2 Cor. 12-9). For in me, the Lord has done an amazing work."

Hohn attends Winds of Harvest Church in San Marcos [Calif.] and for three years was a pastor at...a substance-abuse recovery center. He still occasionally speaks at churches but spends much of his time as a consultant with DynaVox Systems, which creates devices to help people with disabilities communicate.

...His two books, including a self-published autobiography, *More Than A Watchmaker*...show Hohn [to be] an articulate writer with a gift for words and details. His candid autobiography includes episodes about his father's drinking and his own suicide attempt, but throughout the book he never loses faith and his love of God never wavers....

[He] devotes a chapter to a life-changing moment when he was 18 and watched Billy Graham on television ask

his audience whether they knew for sure they were going to heaven. "I felt as though everybody had been afraid to speak the truth to me because of my disability," Hohn writes. "So I was a glutton for more of this honesty and openness."

Graham quoted Hebrews 9:27—"It is appointed for men to die once, but after this face judgment"—and then said God treats everybody equally. "I liked what he was saying," Hohn writes. "I hated being treated differently because of my disability....I felt guilty because I knew I was dependent on my disability and my religious relatives to get me into heaven. I realized that some-

times I made my handicap an excuse." Hohn realized he had to do more, and he wept when Graham invited his viewers to take Jesus Christ into their hearts as their Lord and Savior. At the chapter's end, Hohn writes he was confident he was going to heaven....

His autobiography's title, *More Than A Watchmaker*, refers to the time a doctor told his parents that he would never be a watchmaker but there were other things he could do in life. Hohn proved him right. He studied art and has even sold some paintings. He has published two books and become a pastor and a motivational speaker and as a DynaVox consultant has traveled as far as Japan, where he was treated like a celebrity by people fascinated with the device he uses....

Contact Rick Hohn through his website, www.SpiritWheelsMinistry.com.

Abridged from North County Times (Escondido, Calif.: April 7, 2005). Warth is a staff writer for the North County Times.

I Am Disabled And...

I know that as much as anyone else's my body is your sacred temple, purchased by Christ at great price, in which your Holy Spirit dwells, and therefore I must glorify you in my body as well as in my spirit. Show me, LORD, how to glorify you with a body that has so often seemed an object of shame.

Affirmation #14 based upon 1 Cor. 3:16-17, 6:19-20 (NRSV) by Ken Tittle and Mariposa Ministry and Mariposa Online.

TRANSFORMING LOVE By Roberta Porter

God wants our lives—
not Sunday morning shiny,
but all the fragments of our failures,
shards of struggle and sin
we've gathered, hidden, on our way.
And in Jesus' transforming love,
his willing brokenness, sacrifice, rising,
our sorrow and pain become gifts
to be used for others,
our weakness the dwelling place
for the Spirit's strength,
our broken-open lives
bearers of God's grace.

From *Alive Now* (March/April 2002). Porter is a retired educator living on the coast of Oregon with her husband. She is the mother of three and the grandmother of six.



SEEING AND BEING SEEN By Rie Rainer

My assignment for photography class was to take a portrait of someone. I chose my 92-year-old grandmother, Sybil Nutt. I was visiting my family over the Thanksgiving holiday, enjoying the chance to spend time with her. She seemed pleased by my attention and interest in her, not so much because of the photographs, I sensed, but because of the time it was allowing us to spend in close contact.

From the photos that I had previously taken of her, even people who don't know her have commented that there is a sparkle or a twinkle in her blue eyes, a feistiness, a sense of strength in her face and in her hands. As I began photographing her beautiful wrinkled face it occurred to me to ask if I could photograph her back. She has osteoporosis, a condition of the bones that causes her to stand bent-over. "It's ugly," she said, meaning her curved back, the raised section of her spine. I reassured her that her back is a part of her and that all of her is both precious and beautiful to me. She said she would show her back to me and if I still wanted to take a picture, I

could. When the rest of the family was out shopping, Mama Sybil and I went up to her bedroom, where she carefully locked her door and took off the layers of clothes she wears to keep her aging body warm.

I could tell that she was uncomfortable, but I also sensed that she knew this was important to me and that she wanted to please me...She was exposing something she was ashamed of because she loved me, and I in turn was trying to show my love for her in what she found so ugly.

After several pictures I could tell that she was becoming tired and uncomfortable. I helped her put her clothes back on. As we put on each layer of clothing, I rubbed the curve in her back, thanking her. When I finally got the last layer back on, she turned to me with tears in her eyes and said, "Thank you." She said she feels that most people think that she is ugly and are reluctant to touch her, but that I had touched her without making her feel like she was ugly or disfigured. It seemed like a sacred moment. We went back downstairs and talked for a while. I

asked her if she could give me one piece of advice from her years of living. Her response was to always put God first.

My grandmother has seen six wars, lived through the Great Depression, survived a divorce when it was not socially acceptable, and raised three children on her own. Mama Sybil is very conservative, and very, very modest. (She will not say the word "pregnant" if there are men in the room.) Knowing that about her, I had never in my wildest dreams thought I would one day be standing in her bedroom taking photographs of her naked body. She was a woman of such strength I had never imagined she would allow herself to be vulnerable with me.

When I got the pictures back, I was again overwhelmed. Somehow, I had captured her vulnerability—and mine—on film. There is beauty in these images—her own beauty as a woman and as a child of God, the beauty of age and trust. For me, taking these pictures was a way to begin coming to terms with her death which, at 92, cannot be far off. I also began to come to terms with my own eventual death, and to release myself from shame about my own imperfections. I think I helped release her, too.

When someone allows herself to be truly open, God is there. One thing I recognize from this experience is that if I had not had such a meaningful, loving relationship with my grandmother, and built such trust, I could never have taken these photographs. I would have missed this experience.

I read once that all human motivation is through love or fear, and I have tried to make a conscious choice to allow my actions to come from love, not fear. In my own way, I am putting God first.

When we see one another in love, and allow ourselves to be seen, I believe we are somehow mirroring the vision of God. God sees us as we are, in our age and infirmity, in our innocence and our pain. Living a faithful life is the daily trust that God's gaze on us is always one of tenderness and love.

From *Alive Now* (May/June 2004). Rainer lives in Nashville, Tenn.,

THE "GOD SQUAD"

By Josie Byzek

Rabbis, priests, pastors and imams call Ginny Thornburgh from all over the nation for tips on how to make their congregations more accessible, and she always knows just what to say—and what not to say. First and most importantly, "I make a point of not laying a guilt trip on them. People don't need any more guilt trips," says Thornburgh, director of the National Organization on Disability's Religion and Disability Program. Instead, she finds out where the congregation is access-wise and works with the religious leader from there.

For example, let's say Thornburgh is talking to a religious leader who excitedly shares news of his congregation's brand new ramp. "I'll say, 'That's wonderful! Now tell me about your parking area.' In a loving way, I'm trying to nudge the con-

gregation from wherever they are, that's my goal."

But ramps and parking spaces aren't enough, says Thornburgh. "In fact, identifying and removing architectural barriers is easy because it's done with money. You commit [the funds], you start identifying and removing the architectural barriers, it's that simple. But how do we convince the congregation that you and I have amazing gifts and talents to bring to the church? How do we convince the synagogues and churches of America that removing the stumbling block of inaccessibility is transforming for everyone?" she asks.

Fortunately for Thornburgh, she's not in it alone—she has the capable help of Lorraine Thal, who spearheads NOD's successful Accessible Congregations

Campaign, which began in 1998. "Our slogan was, '2,000 in the year 2000,'" says Thal. "We're now up to 2,142," which means 2,142 congregations have committed to NOD in writing to remove as many barriers as possible, both architectural and attitudinal.

Thal says NOD's new major impetus is its "Seminaries: Open and Welcome" campaign, a broader approach to access advocacy. "We're trying to raise awareness that seminaries of all faiths around the country should be more accessible to students, staff and faculty." She says there are not enough faculty or students with disabilities at seminaries. "People with disabilities are interested, but not encouraged."

NOD's seminary project hopes to help seminary leaders become aware of what students, disabled and nondisabled, may face when they leave seminary and hold a pulpit. For example, students need to know not only who to call about installing a ramp, but how to talk to the new mom whose baby has spina bifida, and even how to preach a meaningful sermon on healing passages that won't turn off the wheelchair user in the first row.

Thal is also excited by the growing list of religious leaders who allow NOD to publish both their names and their disabilities. "We have between 60 and 65 right now. There aren't too many around who want to come forward and say that they do have a disability, because it's public information once you're on the Web site. But the list helps show that it doesn't discount the importance of a religious leader just because they're deaf or blind or have MS."

Both the new seminary project and NOD's ongoing religion projects lead toward one goal, says Thornburgh: "To make the congregations of the nation more welcome to all people, including people with disabilities."

Both Ginny Thornburgh and Lorraine Thal can be contacted through the National Organization on Disability, 910 Sixteenth Street, N.W., Suite 600, Washington, DC 20006, 202/293-5960; www.nod.org/ability@nod.org.

From *New Mobility* (Dec. 2002), www.newmobility.com.



ALL GOD'S CREATURES

By Rev. Dee Brauning

If you have not considered calling a pastor who happens to have a disability, you might be missing quite a bit. The first communion by intinction that Bob and I offered at our Burwell parish was also a first for Leader Dog Treasure to observe, but not to worry. I could trust him to stay in his don't-move-a-muscle-during-church position beside my chancel chair until hearing my "Come" after the benediction.

All went well as Bob and I proceeded to the base of the steps with the elements. Then Bob issued the invitation to the congregation, "Come, for all things are ready." One by one the people came through the line. There Treasure was among them ready to partake, having discreetly descended the side stairs. My hands too full of communion bread, tongue too busy with communion words, and voice too microphoned to utter anything untactful, Treasure won. Of course, when we returned to the chancel, Treasure was too busy vacuuming the crumbs to follow. Is that biblical?

Then there was First Advent with the pungent evergreen next to the chancel. I was at the lectern when my dog guide again left his "Stay" position. He crossed the chancel to Bob, another first. After my quiet word, Treasure returned to his spot. I resumed my work. Treasure took off again. Again, this obedient dog guide headed as discreetly as possible down the side steps. He walked directly to a friend in the congregation. "Will you please get me out of here? I can't breathe, and Bob and Dee aren't available." I immediately re-titled the children's meditation, "Integrity and Doing What You Must," and my allergic dog spent the rest of Advent in comfort at the rear of the sanctuary beside a delighted church member.

All three of us, each with a unique ministry, have been accepted for who we are "inside" in this new parish. My heart rejoices in this gift from a generous God to be sent to this particular congregation for God's particular reasons.

From "Reading The Signs: A Can-Do Forum About Accessibility For The Whole Church Family," *The Nebraska Herald* (Jan. 2004). Brauning and her husband Bob co-pastor the United Church of Christ in Burwell, Neb.

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PARAPHRASE ON PSALM 23 By Anne Gall

The Spirit of Goodness is my Comforter.
 I shall not want for peace of mind.
 It helps me to lie down with a calm heart.
 It leads me into quietness.
 It restores my soul.
 It leads me in paths of righteousness.

Yes, though I walk through the valley of the shadow of death,
 and I may fear the evils of this world,
 I know You are with me.
 Your love and forgiveness, they comfort me.

By Your grace I have food, clothing and shelter,
 a life more abundant than that of many
 who may consider me to be their enemy.
 Regardless of what happens in my life,
 I will trust in Your guidance forever.

From Visions And Verses Along The Spirit's Highway

Friendship is being with the other in joy and sorrow, even when we cannot increase the joy or decrease the sorrow....

— Henri Nouwen —

From Bread For The Journey (Harper: San Francisco, 1997).

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