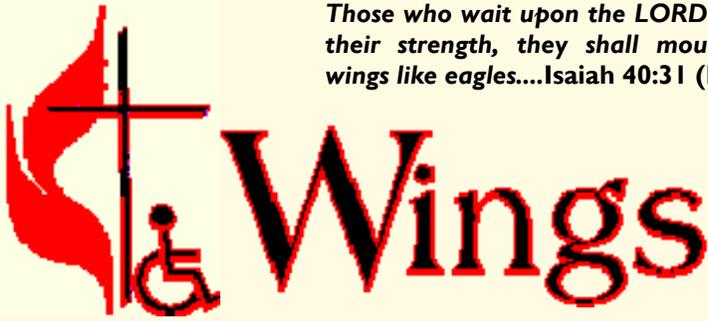


Those who wait upon the LORD shall renew their strength, they shall mount up with wings like eagles....Isaiah 40:31 (NRSV)



A FAITHLETTER FOR UNITED METHODISTS WITH DISABILITIES AND THOSE WHO CARE ABOUT THEM
Summer 2007 — Vol. 18 Issue 1 No. 69



FROM WHERE I SIT: THE ASHLEY TREATMENT

By Jo D'Archangelis

Ashley X was a young girl of 6 when she began to undergo what has come to be known as the “Ashley Treatment.” First, her healthy uterus and breast buds were surgically removed. Then for two years she was injected with high doses of estrogen to gradually shut down bone growth until she was left permanently at the size of a nine-year-old. For unknown reasons Ashley had been born with severe disabilities, and at the time these procedures were initiated she had the mental and physical capacity of an infant.

Did these procedures take place in Nazi Germany in the 30's? Or Mississippi in the 50's? No. According to the October 2006 issue of *Archives of Pediatric & Adolescent Medicine*, the “Ashley Treatment” took place at the Seattle Children's Hospital beginning in 2004.

In their online blog, Ashley's parents cite several reasons for having the procedures done, among them: to make it easier to lift, carry, and care for Ashley as she grows older (they stress that this was more for Ashley's benefit than for their own); to keep Ashley from experiencing the “discomfort” of menstrua-

tion and large, heavy breasts; and to keep Ashley from being “sexualized” (their term) and becoming the sexual prey of, e. g., male health care workers.

Needless to say, there has been quite an uproar about this in the disability community. Most of the criticism has been aimed at the medical profession rather than at Ashley's parents. After all, the parents seem to love Ashley very much—they refer to her as their “Pillow Angel”—and they want to keep Ashley at home with her family rather than consign her to some institution.

But are surgery and high-dose hormone injections to stunt “normal” sexual and physical growth in a human being, least of all a human being unable to give informed consent to medical procedures that involve health risks and irreversible results, the best or even the most sensible way to go under the circumstances?

What about medical devices and equipment such as invalid lifts which are designed to help caregivers handle even large adults? What about hiring part-time in-home healthcare workers

to assist the parents (the parents somewhat disingenuously insist they can't find workers that are “capable, trustworthy, and affordable”). What about administering low-dose hormonal contraceptives to eliminate menstrual periods and cramping? And, I'm no expert in psychosexual behavior, but it seems to me that a lack of breasts wouldn't be much of a deterrent to rapists and pedophiles.

Although I understand the parents' need for help in caring for Ashley, I don't quite understand the necessity of cutting, chopping, and injecting in order to change a somewhat messy female human being into a more manageable little toy doll for the rest of her life. Is it just me or is this whole “frozen in time” business kind of creepy?

Creepiness aside, however, the “Ashley Treatment” has brought to light the difficulties that family caregivers of people with disabilities often face in this society. Exhausted and frustrated, family caregivers are often forced to look for help wherever they believe they can find it.

But as many disability activists, ethicists, and even medical professionals have pointed out in the debate surrounding this issue—social problems such as caring for physically and/or mentally disabled persons should not, and cannot, be “fixed” by extreme medical procedures, especially when those procedures are inflicted on someone with-

(FWIS continued on page 2)

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out their knowledge or consent. Is there anything we as Methodists, disabled and non-disabled, can do to keep medical procedures like the “Ashley Treatment” from being used in the care of persons with severe physical and/or mental disabilities?

For one thing, we can call on federal, state, and local lawmakers to provide greater community-based support and resources for family caregivers—including low-cost, in-home health workers; low-cost or subsidized medical/rehabilitative equipment such as wheelchairs, hospital beds, and invalid lifts; and counseling services.

For another thing, we can encourage local churches to develop respite programs staffed by volunteers who can “fill

in” for an occasional hour or two for people caring for family members with long-term sickness or disability so they can find a bit of rest and relaxation.

Finally, we can put together and submit resolutions to our Annual Conferences, and to the 2008 General Conference, calling for viable, ethical alternatives to the use of extreme medical procedures to solve social problems involving disability and caregiving.

Hopefully, these actions and others will keep the Ashleys of the world from having to endure such “treatments” in the future.

For background info, Ashley’s parents’ blog, media stories, and statements from disability groups about the “Ashley Treatment”, go to www.katrinadisability.info/ashley.html.

GRANT AWARDED TO DEVELOP INTERFAITH BOOKLET ON AUTISM



The University of Medicine and Dentistry of New Jersey (UMDNJ)-Robert Wood Johnson Medical School announced earlier this year that The Elizabeth M. Boggs Center on Developmental Disabilities, Department of Pediatrics, has received a \$15,199 grant from The Daniel Jordan Fiddle Foundation to support the development and production of an interfaith resource booklet on autism....

The resource booklet will specifically address the integration of individuals with autism throughout their lifespan and their families in faith communities....

Said the Rev. Bill Gaventa, associate professor of pediatrics and director of community and congregational supports at The Boggs Center, “For many families, their faith community is a crucial source of support for spiritual, educational, social, and recreational needs and interests.

“For many others, clergy and congregations have been uncertain or unwilling to include people with autism. We hope that this resource booklet will be a useful starting guide for clergy, laity, and families as they work together to recognize, celebrate, and nurture the gifts of every child and adult.”

The Autism and Faith Task Force at the Center anticipates completion of the booklet by the summer of 2007....

For more information, contact Rev. Bill Gaventa (732-235-9304, billgaventa@umdnj.edu) or Rev. Alice Walsh (732-235-9314, lpboggs03@umdnj.edu). Rev. Walsh is the research assistant working directly on the booklet and also is the parent of a son with autism....

Excerpted from a UMDNJ-Robert Wood Johnson Medical School press release (March 22, 2007).



A non-official, non-profit quarterly newsletter for United Methodists with disabling conditions and all others interested in the issues of disability, accessibility, and the church

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E-WINGS Two e-mail versions of *Wings* are available for those with vision impairments and computer “reading” devices; those who have difficulty handling paper and print pages; those who live outside the USA; and/or those who just prefer computer viewing: (1.) A document version in partially formatted text without graphics available to those able to open attached files in Microsoft Word Document 2000, and (2.) A newsletter-formatted version with color graphics available to those able to open attached files in Microsoft Publisher 2000. E-mail Jo D’Archangelis at jodarlis@aol.com to request one, or both, of these versions.

DONATIONS Most of the funding for *Wings*’ publication and mailing comes from reader donations. There are no subscription fees. If you think *Wings* is worth it, please make a check or money order payable to the “Fallbrook United Methodist Church” (or “FUMC”) and mark it “Wings Newsletter.” Mail it to the church address below:

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GIFTS OF GRACE: TWO STORIES

GRANDMA'S LEGACY

By Jayne E. Korljan



My grandmother had a debilitating stroke when I was only ten years old. In a moment she was changed from a vibrantly active woman to a complete invalid.

On summer afternoons I pedaled my bike to the nursing home where she lived. There I pushed her wheelchair up and down the long corridors of the home or sat quietly with her outside in the shade of a towering oak tree.

I had no idea that during our visits Grandma was teaching me a valuable lesson. After all, her entire right side was paralyzed. She couldn't talk. All I knew was that I wanted what my friends had. Their grandmothers taught them how to sew dresses and bake cakes.

But looking back, I realize what it was that my grandmother taught me. It is a lesson that I learned from no one else. She taught me how to live in the face of suffering.

Years after her stroke, when I was nineteen and full of excitement with all that life held for me, I was diagnosed with rheumatoid arthritis. Suddenly my goals and dreams were trampled under the iron foot of pain and deformity. What good would sewing or cooking lessons be to one who could not use her fingers?

I became despondent and in my hopelessness turned to my grandmother. I found rest in her quiet empathy. She gently held my swollen hands in her good hand and looked at me with tears in her eyes. Although she could not say it, I knew that she understood. Her patient endurance and childlike trust in her Lord gave me comfort and hope.

How could my grandmother have known that her suffering would teach me the lesson of trust in Christ that I was to need so badly? Without words she gently guided me to the foot of the

cross. It was there that I found peace. I realized that my life was in the hands of the One who had felt the piercing of the nails. I knew that although I didn't understand, I could trust Christ.

Grandma gave me something during those visits so many years ago. She gave me an example to follow. I am left to carry on her legacy: to be one who, with my own broken body, leads others who are suffering to Christ.

From *Alive Now* (Sept./Oct. 1997)

ABIDING IN THE HOLY

By Jean M. Blomquist



Across the bottom of the laboratory test results, my doctor had written in large block letters: NORMAL. I was elated. After ten years of illness and a very slow return to

health, the lab tests confirmed what I'd already suspected: my lupus* had gone into remission.

Each day I celebrated the simple and extraordinary graces of health: energy to work and play, painfree joints, napless days, and freedom to visit friends, take on work, make future commitments. When one has been sick for an extended period of time as I have been, the return to health is a miracle. I cannot and will not ever take my health for granted again. It is too precious.

And yet I live in a state of constant tension. In the midst of these grace-filled, health-filled days, I am always aware that tomorrow the lupus could return. My health and my energy could vanish. Remission, though it can occur for extended periods of time, is not cure. The day-to-day uncertainty of

(*ABIDING continued on page 4*)

*Systemic lupus erythematosus is a chronic autoimmune disease for which there is no known cure.

CALIFORNIA UMC TRANSFORMS COURTYARD AREA INTO ACCESSIBLE URBAN OASIS

The La Mesa (Calif.) First United Methodist Church Lemon/Palm Corner Beautification Project embodied a new vision for the historic corner courtyard and adjoining street parking strips of the more than 110-year-old church. The area, located on the corner of Lemon and Palm Streets in downtown La Mesa, has been transformed into an urban oasis with street landscaping embracing a courtyard garden for reflection and meditation or simply for peaceful relaxation in a busy world. Inside the garden, visitors will discover an old spiritual tool, the labyrinth, awaiting. The area is surrounded with plantings and is further sheltered from the outside traffic by grilles and ambient water sounds from the fountain. Seating allows lingering and repose, and church officials made note of the fact that "the courtyard is accessible and usable by the physically challenged." Hours when the courtyard is open to the community are Monday-Friday 9 a.m. until dusk and Sunday 8 a.m. to noon. For more information and/or directions, call 619-466-4163.

Adapted from "La Mesa UMC Transforms Courtyard Area into Meditative Urban Oasis", *Circuit West*, the newspaper of the California-Pacific Conference of the United Methodist Church (Jan. 2006).

(ABIDING continued from page 3)



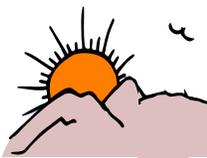
health or illness is a tension I would rather not live with, but it is the reality of my life.

Yet I've finally come to realize that this tension has always been part of my life. Even before I became ill with lupus, I had no guarantee that the health I experienced one day would be there the next. I simply assumed it would be.

The spiritual challenge of remission, then, is not unlike the spiritual challenge of illness, health, or ongoing daily life: to abide in the Holy and to savor the gifts and graces of the moment, whether they be great or small. This challenge reminds me of Christ's words: "Consider the lilies of the field, how they grow....[I]f God so clothes the grass of the field...will he not much more clothe you—you of little faith? Therefore do not worry...." (Matt. 6:28, 30-31).

These words are so beautiful, so simple—and for me, so hard to follow. I do worry—about my health, the future, and many other things. Yet Christ invites me to let go of those worries so I may fully receive the gift of life. He continually calls me, whether in sickness, in health, or somewhere in between, to trust in the goodness of God, to abide moment by moment in the embrace of the Holy.

From *Alive Now* (Sept./Oct. 1997)



WARMTH ON WHEELS: IN MEMORY OF CHERYL ROSSI

By Clarence Schadegg

Rabbi Harold Kushner once wrote a book about why bad things happen to good people.* A bad thing happened to two good people one evening last January when Cheryl Rossi was accidentally struck and killed by a vehicle as she was rolling down the side of a road in her wheelchair. The driver never saw her.

All the people of Minnesota have suffered a tremendous loss with Cheryl's passing. Her grace and spirit first touched us when senseless tragedy struck her twenty-five years ago. She had been found in an abandoned field, the victim of a gunshot wound to her head. She somehow survived that ordeal which included lying on snow-covered ground exposed to near zero temperatures for three days before she was found. She also dealt with the resulting amputation of both her legs and one arm.

I met Cheryl when she came to us at the Sister Kenny Institute in Minneapolis for rehabilitation services and instruction in independent living skills for people with disabilities. After that I saw her occasionally at public events or on the bus. Often we talked about stop-

**When Bad Things Happen To Good People, by Harold Kushner, originally published by Shoken Books (New York: 1981)*

ping for coffee but never did. Now I wish we had gone out for coffee too.

When I heard that Cheryl had been killed, I called my old high school friend John, one of the two police officers who had rescued her from that snow-covered field so many years before. He had already heard about her death. We shared memories of our relationship with Cheryl and how we had each drawn from her incredible strength.

The lump in my throat was followed by a chill that ran down my spine as John recited Psalm 121 the way he remembered Cheryl doing it when he found her lying nearly frozen in that field. He recalled how she had recited the Psalm in a calm and steady voice and said that he had also memorized the Psalm in part because her tremendous spirit had been passed on to him in those Old Testament words.

Cheryl's spirit also deeply touched Mary Schoelch, the coordinator of volunteers at Catholic Charities St. Joseph's Home for Children, who said, "Cheryl was a proactive advocate as well as a beacon of hope and help for children and youth who had been abused, neglected, and abandoned. She logged thousands of hours assisting St. Joe's to serve children most in need by coaching, counseling, teaching, mentoring, and providing superior leadership for kids, staff, volunteers, and the community at large."

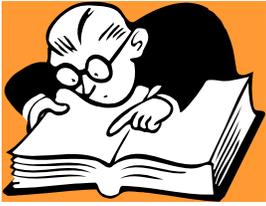
Mary further expressed Cheryl's gifts, saying that Cheryl "helped children to discover life's possibilities, an invaluable sense of self-worth, and a more positive view of the future. Her wisdom and warmth on wheels will be dearly missed by all of us at St. Joe's."

Thank you, Cheryl, for the light you helped all of us to find inside ourselves.

Adapted with permission of the author from *Access Press* (Minneapolis, Minn.: 2007)

I lift up my eyes to the hills—from where will my help come?
My help comes from the LORD, who made heaven and earth.
He will not let your foot be moved; he who keeps you will not slumber.
He who keeps Israel will neither slumber nor sleep.
The LORD is your keeper; the LORD is your shade at your right hand.
The sun shall not strike you by day, nor the moon by night.
The LORD will keep you from all evil; he will keep your life.
The LORD will keep your going out and your coming in from this time on and forevermore.

— PSALM 121 (NRSV) —



WHY DO BAD THINGS HAPPEN TO GOOD PEOPLE?: A COMMENTARY

By Richard Daggett

(Editor's Note: Richard Daggett originally presented the following commentary in 1994 to a Seekers group at the Downey [Calif.] United Methodist Church. It is based on Harold Kushner's book, *When Bad Things Happen To Good People*, and on a lecture Kushner gave after his book was published. It is also based on Daggett's own experiences and beliefs as a post-polio survivor living with severe physical limitations. Due to its length, the commentary will appear as a series of short articles over several issues of *Wings*.)

PART I: QUESTIONING GOD

Why do bad things happen to good people? If you live long enough, you'll probably be faced with this question. You see good people who are experiencing tragedy, and you see other people, good and not so good, who experience very little of it. And you may ask, "Why, if there is a God, do these things happen?" A child is killed in a house fire. A young couple is killed in an auto accident. Someone dives into a pool and breaks his/her neck and is permanently disabled. You hear and read about these things every day.

In his book, *When Bad Things Happen To Good People**, Rabbi Harold Kushner tells about his son dying of a terrible degenerative illness. All his friends, including his clergy friends, were telling him the same things that he had told others in their own times of grief. And it wasn't comforting. They would say that God was sending this to him because he was spiritually strong; he of all people could understand why this was happening and would be an inspiration to others, and besides God never burdens us with more than we can endure. But all Kushner could think of as they talked was that he wished he weren't such a religious person. He wished this tragedy had been sent to someone else.

We have often been told that you don't question God. You just bow your

head in submission to his will. But still we are full of questions. Shortly after the publication of his book, Kushner was on a talk radio show to promote it. A woman called in and asked, "Why can't you accept that God wanted this to happen because you are such a sensitive person? You will experience this tragedy and you will write a book that will inspire millions of people."

His reply to this woman was: "Do you remember the mass murderer, John Wayne Gacy? He killed several boys and buried them in his basement. Suppose his defense attorney had stood up in court and said, 'John Gacy is a hero for killing these boys. Look at all the millions of parents who can thank God that their children weren't victims. Look at all the parents who will teach their children to be more careful.'"

Kushner went on to say, "This is absurd. We wouldn't accept that from the courtroom. Why should we accept it from religion? Why would God take the life of one person just so another person would feel thankful? If I worked my way into the confidence of a person just to take their money and use it for my own aggrandizement, it would be a sin against that person and a sin against all we believe as Christians and Jews. Why would it be a sin for me but perfectly acceptable for God?"

Kushner couldn't accept the idea that tragedy strikes one person so that another can say, "Thank God, it wasn't me." And I can't accept that either. Sam Levenson, a popular humorist many years ago, used to tell the story about when he was a young boy beginning school. His mother told the teacher, "If Sammy misbehaves, hit the boy next to him. Sammy learns by example."

All of these explanations for bad things put forth by so-called "religious people" are not really intended to make us feel better or even to help us understand. They are intended to justify God. We are supposed to sit back and accept that God knows what he is doing and not to be so presumptuous as to question him. Nonetheless, human beings have always questioned God, even in the pages of the Bible.

(See **PART II: JOB'S STORY** in the Fall 2007 issue)

THORN IN THE FLESH By Carol Hamilton

Each birth brings a wail,
inrush of breath
then loud complaint.

Paul prayed for release
from pain.

We pray for exemptions.
Paul had good cause to ask,
as such a work he had to do!

Still, praise broke from his lips,
as he, like Job, saw

the heavens and the seas
and the lands
all bursting with creation,
and we held through all terrors,
gently, in our creator's hand.

From *Alive Now* (March/April 2006).

Hamilton, a Poet Laureate of Oklahoma, is a writer, educator, and storyteller and translates at a medical clinic for women and children.

*Originally published by Schocken Books (New York: 1981).

Honor Roll Of Appreciation

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Jill Halley	Rev. Ed Hoffman	Don McIntosh
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Pat Donehoo		

WHEN A BELIEVING PERSON PRAYS

By Philips Brooks

Do not pray for easy lives; pray to be stronger...

Do not pray for tasks equal to your powers; pray for powers equal to your tasks.

Then the doing of your work shall be no miracle, but you yourself shall be a miracle.

Every day you shall wonder at yourself, at the richness of life which has come to you by the grace of God.

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CAL-PAC GRANTS AVAILABLE TO MAKE CHURCH RESTROOMS ACCESSIBLE

The California-Pacific Conference of the United Methodist Church now has grant money available to help local churches construct/renovate restrooms to make them disability accessible. The total amount of \$115,000 from allocated apportionments and Jubilee Grants will be awarded in individual amounts of \$10,000-\$25,000 to those churches exhibiting the most need. Application deadline is October 1, 2007, and the church renovation/construction project must be completed by December of 2007. For more information about the application process and what conditions must be met to obtain the grant, contact Kris Hodson, Director of the Congregational Loan Committee, by phone (800-244-8622) or by e-mail (Khodson@Cal-Pac.org).

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