

Presbyterians for Disability Concerns  
A Network of the Presbyterian Health, Education & Welfare  
Association (PHEWA)

*A Variety of Gifts:  
Inclusion of People with Disabilities as We Age*



Painted by Rev. Don Milloy

**2012 Disability Inclusion Resource Packet**

*The Rev. Don Milloy, Artist*

*Don Milloy was born on May 12, 1934. After graduating from Louisville Presbyterian Theological Seminary, he was ordained and served churches in Illinois, Wisconsin, and Minnesota. He was an ardent advocate for social justice and, before his stroke, acted in a number of community theater productions.*

*Even after his stroke in January of 1993, he remained active in the Presbytery of the Twin Cities Area. He continued to paint, using his non-dominant hand. Until his death on January 5, 2012, he was an active member of the Disability Concerns Ministry of the Presbytery of the Twin Cities Area. We are grateful for Don's faithful ministry.*

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# INTRODUCTION

2012 Disability Inclusion Sunday, June 24

## **A Variety of Gifts: Inclusion of People With Disabilities As We Age**

Are people who are aging with disabilities disappearing from your congregation? Some disappear because they can no longer attend worship or other church events. Others may be “present” but disappear from active participation. Their giftedness is ignored. Must we become invisible as we age?

The Apostle Paul describes the “variety of gifts” God gives to all members of the body of Christ. He does not say that only the young or the more “abled” have gifts to share. Limitations that inevitably come with age may mean changes, even the loss of abilities that we have valued and that have defined who we are. But with age can also come new possibilities, both for the individual and for the congregation.

The goal of *A Variety of Gifts: Inclusion of People With Disabilities as We Age* is twofold. For people who are aging, the challenge is to overcome the stereotypes that devalue aging and to live with dignity and creativity. For the church, the challenges are to embrace all members of the body of Christ in the community and to affirm and welcome the gifts of persons of all ages.

But what does inclusion mean for people who are aging, with limitations? How can we include persons who can no longer attend worship or whose participation is limited by impaired mobility, sight, speech, or other losses? Perhaps the most difficult challenge is the inclusion in the life of the congregation of persons with memory loss. As contributors to these resources, we hope to offer some helpful suggestions but also to stimulate creative ideas and discussion by readers.

In addition to resources in *A Variety of Gifts*, Presbyterians for Disability Concerns has developed an excellent self-study guide for churches. [\*The Congregational Audit of Disability Accessibility and Inclusion\*](#) assists in discovering how welcoming the church is for people of all ages who live with disabilities. The audit includes the names and contact information for the PC(USA) Disability Consultants.

### The Art in *A Variety of Gifts*

The four artists whose works are featured defy any stereotypes society holds about lack of creativity by persons who are aging with disabilities. You will find a brief introduction to each of the artists. One of our contributors, the Rev. Donald Milloy, died on January 25, 2012. We are grateful to Don, Joan Scherff, Cynthia Buchanan, and Dr. Dale Propson for the beauty they have added to *A Variety of Gifts*.

### Worship Resources

The ways we include or do not include all people in worship make a powerful statement about who we are as the Church and what we believe. The prayers and litanies call us to remember that it is the whole church that joins in worship: “Help us ALL to live in your freedom, justice, and wholeness.” (Carol Brown) “An Affirmation” by the Rev. Donald Milloy affirms his own confidence that after living for many years with many limitations following a stroke, he still bears the image of God. He joins persons of all abilities in raising strong, clear voices for justice. The Rev. Thom M. Shuman joins this affirmation in his Great Prayer of Thanksgiving:

You shaped us in your image,  
promising to be with us always.

Hymn writer, Lorie Ludwig, has contributed two hymns written especially for Inclusion Sunday resources. “It’s Sad When We Exclude Them” was written for a previous Inclusion Sunday but is offered this year again because of its appropriateness for the theme. “Open Your Eyes So You Can See” is an eloquent plea for a new “vision” of older people with disabilities.

The Rev. Mary Austin calls on congregations to worship “the God who loves variety” in a variety of ways:

“... if we cannot see, we will reach out and touch.  
... when we cannot dance, we will surely sing.  
... what we do not hear, we know we will feel.”

### Models of Ministry, Personal Stories, and Information

“Look Again: A Ruse, Two Kids, and a Blessing,” by the Rev. Bebe Baldwin, is based on Genesis 27:1-46 and challenges readers to think beyond the preconceptions we bring to Bible stories about persons with disabilities. The writer asks readers this question: “Why do we assume that, because he was blind, Isaac was a fumbling old man, incapable of making good decisions?”

“Aging and Disability: Honesty, Limitations, and Hope,” by the Rev. Sue Montgomery, invites readers into a theology of gracious and wise aging. She tells a moving family story in order to urge readers to face the limitations of aging while growing into newness of life with its fresh possibilities.

“Journeying Well During Your Later Years,” by Trish Herbert, names barriers to successful aging and offers helpful suggestions for living fully and creatively throughout our lives. The writer discusses the meaning of loss for older persons and suggests ways to express our feelings of loss.

“Letting Go: A Mother’s Story,” by Roxanne Ezell, traces the writer’s own journey from being a “Mother Bear” advocate for her son to the time in life when she can begin the process of “letting go.” This intensely moving story will reverberate with many parents who are struggling with the decisions and the trust they must find as they themselves are aging.

“Who IS This Person?” by the Rev. Robin Lostetter, invites us into honest reflections on losses that come with aging. The writer, who has lived for many years with orthopedic issues, now finds a “neurological event” her “daily companion.” She writes, “I may never make peace with the increasing losses of age. But I pray that I do.”

“Later Life Decisions: Parkinson’s Disease Commands Our Attention,” by the Rev. Robert and Carolyn Cuthill, is unique because a husband and wife share in the telling of their story. Each brings her or his own perspective on the process of identifying their needs and making the needed decisions following the diagnosis.

“Even When I Forget, the Music Is Familiar,” by Lorie Ludwig, describes the benefits of music therapy for persons with memory loss. Written from the perspective of a music therapist, the article raises possibilities for parish visitors and for those who wish to plan worship that includes persons with dementia.

“Dementia and Disability,” by the Rev. Mary Austin, guides readers through the stages of dementia. The writer gives helpful suggestions for including persons with dementia while they can still attend church and later, when this is no longer possible. She assures parish visitors and family members that even in the late stages of dementia, deep and powerful connections are possible. “Even as human memory fades, God remembers us all. We are called to remember each other in God’s name and to enfold people with memory loss in community.”

“How the Parish Nurse Can Help as People Age,” by Joanie Friend, explores the ministry of the parish nurse, who is often the one who has the first contact with an individual with a disability. The writer lists ways the parish nurse serves to bring healing and wholeness, even when there is no cure. She describes the parish nurse’s biggest role as the “gift of presence to journey with patients through good times and bad.”

“Facets of Aging and Disability: A Vision for Community, Dignity, and Well Being,” by Milton Tyree, explores possibilities for “Aging Caregivers.” He addresses the social devaluation of persons who are aging and who are living with disabilities and lists helpful suggestions for living with dignity in community. He emphasizes the Apostle Paul’s words: “Now you are the body of Christ, and each one of you is a part of it.” (I Cor. 12:27)

### Resources

Carol Brown, in cooperation with other members of the PDC Leadership Team, has compiled a list of resources that we believe will be helpful for further exploration of this year’s theme. Each member of the PDC Leadership Team is knowledgeable about disability concerns, having either personal or professional experience with the issues. In addition to the listed resources, don’t miss the links suggested by Milton Tyree at the end of his article, “Facets of Aging and Disability: A Vision for Community, Dignity, and Well Being.”

### A Reminder

June 24 is the designated 2012 Disability Inclusion Sunday for the PC(USA). However, the worship resources and articles in *A Variety of Gifts* are appropriate for any time during the year. Members of Presbyterians for Disability Concerns believe that every Sunday – and every day between Sundays – should be a day for including all members of the body of Christ in the life of the community. Please join us in making this commitment!

The Rev. Bebe Baldwin, for the PDC Leadership Team

PDC Leadership Team

Carol Brown – resource coordinator

Miguel Carlin

Lynn Cox – packet coordinator

Cindy Merten – PDC Moderator, art coordinator

Sarah Nettleton

Gary Pratt

Cindy Ray – G.A. Committee on Representation liaison

Rev. David E. Young

Rev. Ernest F. Krug, III, M.D.

*A Variety of Gifts:  
Inclusion of People with Disabilities as We Age*



Painted by Joan Scherff

## Worship Resources

*Joan Scherff, Artist*

*Joan Scherff is from LeRoy, New York and discovered an art class at a senior center in 2007 when she was 66 years old. She lives in an apartment that provides support staff that assists persons who live with developmental disabilities. Her blossoming artwork has been on display at the Senior Center Art Fair, catching attention and purchase by a New York City art dealer.*

## **An Affirmation**

Rev. Donald S. Milloy

Then God said, "Let us make humankind in our image..."

Genesis 1:26a

We are those who are called "disabled." We are those who are challenged, physically or mentally. We may hobble; we may not have voice, song, sight, or sound. We may not be in control of our muscles or our minds. Yet, we join together with each other, in and with our communities, as God's daughters and sons.

We bear witness that we are made in the image of our Parent-God and capable of being God-self to the world. We raise our voices and our bodies even though we may be incapable of doing so "perfectly." We praise and proclaim the holiness of our Parent-God who has proclaimed us holy by dwelling in us.

May we get beyond the stereotypes to be who we truly are, the presence of God's Spirit in and for the world, a voice that speaks as clearly and as powerfully as any others, and a reflection of Jesus of Nazareth, the Christ.

### ***The Rev. Don Milloy***

***Don Milloy was born in 1934. After graduating from Louisville Presbyterian Theological Seminary, he was ordained and served churches in Illinois, Wisconsin, and Minnesota. He was an ardent advocate for social justice and, before his stroke, acted in a number of community theater productions.***

***Even after his stroke in January of 1993, he remained active in the Presbytery of the Twin Cities Area. Until his death on January 5, 2012, he was an active member of the Disability Concerns Ministry of the Presbytery of the Twin Cities Area. We are grateful for Don's faithful ministry.***

# Liturgical Resources

Rev. Mary Austin

## Call to Worship

Come, let us worship the God who calls us all by name.

**Let us worship the God who loves variety.**

We come to see God's face in one another,

**and if we cannot see, we will reach out with touch.**

We come to dance in God's presence

**and when we cannot dance, we will surely sing.**

We come to hear God's words of welcome,

**and what we do not hear, we know we will feel.**

We come to know God's truth: that we all belong here.

**Let us worship God, each in our own way, and all of us together.**

## Prayer of Confession

O God, you have made us all in your image,  
and in your sight we all have ability and disability.

We confess that we have failed to see our disabilities.

We have been blind to each other's needs,  
clumsy in our walk to help each other,  
deaf to another's pain.

We confess that we have failed to see our abilities,  
our strength of character,  
our lively courage,  
our loving spirits.

We have ignored the gifts you gave us,  
and been ashamed of who we are.

We forget that you made us all as your reflection,  
and that all of us belong to you,  
and show the world your image.

Forgive us, O God, and claim us all again as your children. Amen.

## Prayers of the People

O God our Creator,  
we rejoice that you have made us in your image,  
younger and older,  
quicker and slower,

wise in mind or wise in heart,  
shy or bold, silly or serious.  
We praise you that we find your image  
in each other,  
a part of you  
in each one of us.

Seeing each other, we see your patience,  
or strength,  
or peacefulness.  
Hearing each other,  
we hear your giggle,  
or your soothing voice,  
or your words of challenge.  
Touching each other,  
we touch you,  
and we give thanks.

We praise you that in the faces around us,  
we find your holy presence.  
We rejoice that in the voices near us,  
we also hear the music of your voice.  
We thank you that in the hands that touch us with honesty,  
we know your embrace.

O God our Redeemer,  
forgive us when we expect you to look a certain way,  
missing your presence because we look for it  
only in success, or beauty, or polish.  
Redeem us from our selfishness,  
renew our enthusiasm for community,  
bless us with patience for our own imperfections.  
Teach us the truth of our abilities,  
of mind, heart and body,  
and of our disabilities,  
of spirit, purpose and energy.

O God, Spirit of Truth,  
embrace us all again as your children,  
along with our sisters and brothers  
in Palestine and Israel,  
Haiti and Somalia,

and all around the world you have made.  
Let our prayers and our passion for you  
take us to every place  
where a grandmother is hungry,  
a person is sick,  
a child is frightened,  
where someone different is bullied,  
where a person with success feels like a fraud,  
where those who help others are out of energy,  
and make us builders of community.

We pray in the name of Jesus,  
who names us all as whole,  
and who taught us to pray saying, Our Father...

*The Rev. Mary Austin is the pastor (teaching elder) of Westminster Presbyterian Church, a church for all people, located in the city of Detroit, Michigan and is a former hospice chaplain. She can be reached at [maryaustin520@yahoo.com](mailto:maryaustin520@yahoo.com)*

# Liturgical Resources

Carol Brown

## Call to Worship

Leader: God calls us to be the Community of God in this place

**People: We are ALL God's children, part of God's kingdom**

L: Jesus calls us to invite ALL to join the Community of God

**P: We welcome ALL to join our community, in God's love**

L: The Holy Spirit helps us to include ALL in the Community of God

**P: Everything we need to welcome ALL comes from God**

L: Let us come, let us open our hearts and arms to the LORD and to ALL people

## Gathering Prayer

Precious LORD, we gather here in Your house, provided by You and for Your Glory. We bring all of our voices, old and young, strong and weak, loud and soft, wise and innocent, to praise you. We come to you as we are able, knowing You accept us as we are. Speak to us that we can hear Your voice, whether we are deaf, hard of hearing, or able to hear a pin drop. Help us hear so our faith may be renewed and we can share Your gifts for Your service. Help us to love You with ALL of our heart, soul, strength and mind. We ask in the strong name of Jesus, who is the Christ. Amen.

## Call to Confession

We are God's people. We have been called to share the gifts God has given us. God's Word teaches us to work together for God's kingdom. But we choose to work in our own way, going it alone, leaving others on the fringes. Or we feel we are not capable, filled with fear and doubt. Yet God calls us to accept and love each other. Only God can help us with this charge. Let us make our confession to God.

## Prayer of Confession

L: You call us to share our gifts

**P: But we are too busy**

L: You call ALL people to share their gifts

**P: But we won't let them**

L: You call us to love and accept one another

**P: But we don't know how, or don't want to, or aren't willing to**

L: We ask You to forgive us

**P: Forgive our busyness, our apathy, our ignorance, our fear, and help us live as Your people in Your Community for Your glory**

L: You hold out your heart to us, broken and bleeding, so we will know your love through Jesus Christ, our Lord and Savior, and come to live as Your people.

**P: Amen**

### **Assurance of God's Pardon**

L: God hears our prayers and changes our hearts and lives. God calls us with words of hope, grace, and forgiveness to live as God's people, just as we are, and share God's Good News.

**P: You are with us, You love us and You call us to join Your inclusive kingdom. Thanks be to God! Amen.**

### **Prayer for Inclusive Unity**

L: God, our Creator, calls us to include ALL people in the Community of God

**P: God created all people, God loves ALL people**

L: Jesus, our Redeemer, redeems ALL people and calls us to show mercy to ALL

**P: Jesus redeems all people, Jesus loves ALL people**

L: The Holy Spirit is our sustainer, healer, counselor, and guide

**P: The Holy Spirit sustains, heals, counsels, and guides ALL people**

L: Three in One, we praise you for your gifts that You impart to Your people. Give us understanding in how to use your gifts for Your glory.

**P: Help us ALL to live in Your freedom, justice and wholeness. Amen.**

Based on the following Scripture verses:

**Proverbs 22:2** – The rich and the poor have this in common: the LORD is the maker of them all.

**Micah 6:8** – He has told you, O mortal, what is good; and what does the LORD require of you but to do justice, and to love kindness, and to walk humbly with your God?

**Job 12:12, 13** – Is wisdom with the aged, and understanding in length of days? With God are wisdom and strength; he has counsel and understanding.

**Leviticus 26:12** – And I will walk among you, and will be your God and you shall be my people.

**I Samuel 12:22** – For the LORD will not cast away His people, for His great name's sake, because it has pleased the LORD to make you a people for Himself.

**Psalms 149:4** – For the LORD takes pleasure in His people; he adorns the humble with victory.

**Acts 2:17** – ... I will pour out my Spirit upon all flesh .....

Throughout the New Testament are many accounts of Jesus and his disciples taking time to listen to, participate with, and heal those with disabilities.

*Carol Brown is the parent of four children, two of whom have significant intellectual disabilities. She has been a strong advocate for inclusion of her children, facilitates Person Centered Plans through [The Arc of Midland](#) for many individuals, and was a founding member of [The Arc Faith Group](#). She has been ordained as a ruling elder and deacon at Chapel Lane Presbyterian Church in Midland, Michigan.*

# Liturgical Resources

Rev. Thom Schuman

## Call to Worship

Leader: As we seek to be as responsive as Sarah and Abraham  
as our years increase,

**People: may our aches and pains keep silent,  
while our lips speak of your wonder.**

L: As we sit by the window looking for you;  
as we search the corners of our hearts for our lost years,

**P: continue to call us to follow you, as we trust  
you will not leave us behind.**

L: As we seek not to be a challenge to others,  
consuming their time, energy, and resources,

**P: may we feel your hope filling our emptiness,  
may we know that you strengthen us on the journey.**

## Prayer of the Day

We look in the mirror  
and don't recognize ourselves:  
wrinkles carved into our faces,  
skin sagging around our necks,  
spots connecting on the backs of our hands, and we wonder where we went.  
But you, Ageless God, gaze at us  
and see those beloved children  
you bounced on your knees  
at our baptisms.

When our souls feel  
as brittle as our bones;  
as our arms are emptied  
of hope, friends, love;  
on those days when age  
consumes us faster than we want,  
who do we talk to about death  
if not you, Grave Shatterer?

In the regrets of  
yesterday,  
we find you healing;  
beyond the fears of  
tomorrow,

we glimpse your future;  
trying to make sense of  
today,  
we feel you grasp our hands  
never, ever letting go of us,  
Spirit in our every moment.

Abide with us in the evenings of our lives, God in Community, Holy in One, even as we pray as we have been taught, Our Father . . .

### **Call to Reconciliation**

Growing old is not for sissies, yet we find it easier to complain that no one knows what we are experiencing, to become reactionary rather than reflective, to focus only on what we have lost. But in doing so, we damage our relationships with God, and with others. Let us confess that aging has not kept us from being foolish, as we pray together, saying,

### **Unison Prayer of Confession**

**We try as best we can, Eternal God, to turn back the odometers of our lives, rather than trusting that you will continue to care for us, not trading us in for a newer model. We use our slower reflexes as excuses for not continuing to reach out to you. We let the creaking of our joints keep us from hearing you whisper to us of your grace and hope.**

**Forgive us when we long to trade in our golden years for just a few more silver ones. When we feel vulnerable, fill us with the vibrancy of your Spirit; when others treat us as if we are older than dirt, continue to make us in your image; when we fear to grow older, remind us of the promise that we will be with you forever, that promise made, and confirmed, through Jesus Christ, our Lord and Savior.**

Silence is kept

### **Assurance of Pardon**

**L:** We may be growing older, but we are not diminished in God's eyes. We are continually filled with hope, with wonder, with life, if we will only see these gifts offered to us.

**P:** **We are God's beloved children, no matter our age. We are God's joy and delight, and always will be. Thanks be to God, we are forgiven! Amen.**

### **Great Prayer of Thanksgiving**

**L:** When chaos had grown old,  
you spoke, Ageless God,  
bringing forth all that was new and fresh:  
rivers racing each other across continents,

eagles climbing higher and higher in the sky,  
the stars sparkling with your wisdom.  
You shaped us in your image,  
promising to be with us always.  
But afraid of growing old and alone,  
we listened to the lies of sin and death, who promised we would always stay the same.  
You would not let us go,  
continuing to reach out to us,  
through the prophets and their words,  
but we continued to draw away from you.  
And so, you sent Jesus, to bring us  
that new life you give to all.

So, with those of every age and from every time, with those who falter, and those who struggle with words, we sing our songs of thanksgiving to you:

**P: Holy, holy, holy are you, God of moments beyond number.  
All creation glorifies your name forever.  
Hosanna in the highest!**

L: Blessed is the One who came that we might know you forever.  
Hosanna in the highest!

You are the same yesterday, today, and forever, God of Hope, and you bless us through Jesus Christ, your Child, our Brother.  
He came as a baby,  
so we might grow old with you;  
he laughed and played as a child,  
so we might know the joy of innocence; he struggled with adolescence's questions,  
so we could bring our fears and doubts to you; he died as a young man,  
so we could move from never-ending pain  
to endless wonder in your presence;  
he rose from the grave,  
so we might have eternity with you.

So, as we remember his life, ministry, and death, as we celebrate his words and his resurrection, we sing of that mystery we call faith:

**P: Christ died, so we might not fear death;  
Christ rose, so we might welcome our own resurrection;  
Christ will come again, so we might be in glory.**

L: It is here at this Table  
that we are reminded of your promises,  
and where the Spirit is poured out  
upon all your children, of every age,

and on these sacred gifts.  
As we eat of the bread,  
remind us that growing frailer  
does not mean our faith diminishes;  
as we drink from the cup,  
may we recognize that  
while energy has moved away,  
we can find comfort in the silence  
slowness offers to us.

And when we have stopped aging,  
when all time has come to an end,  
gather us around your Wedding Table  
with our sisters and brothers of every time and place, where we will sing your praises  
forever God in Community, Holy in One. **Amen.**

(c) 2012 Thom M. Shuman

**The Rev. Thom M. Shuman is an interim pastor (teaching elder) of Immanuel Presbyterian Church, Cincinnati, Ohio and Associate Member, Iona Community. He is the author of**  
**Lectionary Worship Aids and blogs at:**  
[www.occasionalsightings.blogspot.com](http://www.occasionalsightings.blogspot.com)  
[www.prayersfortoday.blogspot.com](http://www.prayersfortoday.blogspot.com)  
[www.lectionaryliturgies.blogspot.com](http://www.lectionaryliturgies.blogspot.com)

## **It's Sad When We Exclude Them (Hymn)**

Words by Lorie Ludwig, © 2006

Biblical text: John 10:16

Tune: MUNICH (O Word Of God Incarnate)

It's sad when we exclude them,  
And keep them from their due,  
To live and work among us,  
They're just like me and you.  
We show our own true bias,  
When we shut people out,  
Because they're merely different,  
We don't want them about.

Life isn't always easy,  
For those who aren't the same,  
By birth or circumstances,  
We cannot cast our blame.  
When we call some disabled,  
We're labeling us all.  
For Christ calls us together;  
One flock that heeds Christ's call.

Our goal is full inclusion,  
To not be pushed aside;  
Not live life on the fringes,  
But move to the inside.  
Ignore the withered bodies,  
Fear not, the bleeding skin,  
But see the soul inside us  
Then healing can begin.

Let's gather at one table  
Where all can share the feast,  
Spread with the gifts we offer,  
From north, south, west, and east.  
Accepting of each other,  
Christ's teachings we uphold,  
With Jesus as our shepherd,  
Together in one fold.

*Lorie Ludwig is a board certified Music Therapist with fifteen plus years experience working with long term care, Memory Care, Assisted Living and Independent Living residents. Diagnosed with a vocal tremor in 2001, she is unable to sing. Lorie is a hymn author and active member of the Presbyterians for Disability Concerns Task Force, a committee of the Presbytery of the Twin Cities Area and is a member of Westminster Presbyterian Church, Minneapolis, Minnesota.*

## **Open Your Eyes So You Can See (Hymn)**

Tune: Open My Eyes So I Can See SCOTT 8.8.9.8. with refrain

Music by Clara H. Scott 1895

Words by Lorie Ludwig © 2012

Open your eyes so you can see, what I am worth, my dignity.  
Value I have, I'm more than you see, than just another elderly.

### **REFRAIN**

**Open your eyes so you can see,  
All that I am and want to be.  
Open your eyes, you need to see,  
The real me.**

Ignore my aches, my pains, my chair, I could use help to climb the stair.  
I wasn't always so unaware. Here are some things I'd like to share.

### **REFRAIN**

Look in my heart and see my soul, do not take over; get control.  
Great age has come, there is no parole. Live a whole life and live it full.

### **REFRAIN**

Soon I will go to meet my Lord, know that my love I have outpoured.  
Never I've sought a private reward, only to seek divine reward.

### **REFRAIN**

*Lorie Ludwig is a board certified Music Therapist with fifteen plus years experience working with long term care, Memory Care, Assisted Living and Independent Living residents. Diagnosed with a vocal tremor in 2001, she is unable to sing. Lorie is a hymn author and active member of the Presbyterians for Disability Concerns Task Force, a committee of the Presbytery of the Twin Cities Area and is a member of Westminster Presbyterian Church, Minneapolis, Minnesota.*

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Inclusion of People with Disabilities as We Age*



Painted by Cynthia Buchanan

**Models of Ministry, Personal Stories and Information**

*Artist, Cynthia Buchanan*

*Cynthia was diagnosed with Multiple Sclerosis 14 years ago. She is both a board member and artist with "Paint a Miracle" Studio in Rochester Hills, Michigan. Cynthia has an innate understanding of fundamental art concepts and values art as stress release in challenging times. Friendly and inspiring, she touches everyone she meets with her optimistic attitude toward life.*

## **Look Again: A Ruse, Two Kids, and a Blessing**

Genesis 27:1-46

Rev. Bebe L. Baldwin

If you love a good story, begin with two brothers who are racing to claim their father's inheritance. Add a crafty mother who has her own ideas about who should be the heir and an old man who doesn't appear to be able to tell the difference between his own sons. Mix in a good measure of stereotyping about aging and disability. You now have a classic tale about a son who, with the connivance of his mother, cheats his brother out of what is rightfully his.

The father, Isaac, is the most puzzling and, in many ways, the most intriguing character in the story. He is blind and is approaching death. Is he so enfeebled by age and so helpless because of his disability that he cannot tell the difference between his own sons?

Esau and Jacob are twins, but Esau is the firstborn. They are not at all alike. Esau is a skillful hunter, a man of the fields (Gen. 25:27). He is impulsive; the rabbis describe him as "fierce" and "violent." Jacob is "a quiet man, living in tents" (25:27). Although he is clever enough to take advantage of his brother, the rabbis consider him studious and settled. The two don't even look alike. Esau's skin is hairy and Jacob's is smooth.

The story we are considering in this article begins when Isaac calls Esau, "I am old; I do not know the day of my death." He instructs Esau to hunt for his favorite game, prepare it, and bring it to him so that he can eat it and bless him. Isaac's announcement of his coming death and the meal he requests are probably part of a ritual that includes passing on the blessing to the first born. The blessing includes most of the family wealth.

But Rebekah overhears Isaac's charge and launches her own plan. She instructs Jacob to go to the fields and bring back two choice kids which she will prepare for Isaac. She dresses Jacob in Esau's best garments and uses the kids' skins to cover Jacob's smooth arms.

The race for the blessing begins! Jacob goes to Isaac and says, "My father ... I am Esau your first born. I have done as you told me; now sit up and eat my game, so that you may bless me."

Isaac is not so easily convinced. "... Come near that I may feel you, my son, to know whether you are really my son Esau or not ... The voice is Jacob's voice, but the hands are the hands of Esau ... Are you really my son, Esau?"

Seeming to be fooled, Isaac tells Jacob to bring him food and wine so that he can eat. He then completes the ritual by bestowing the blessing upon him.

Too late, Esau returns with the game he has prepared. But the blessing cannot be revoked. After that, Esau looks forward to the death of his father so that he can kill Jacob.

But is Isaac really fooled? Is he as gullible as a casual reading of the story might suggest? Consider again the encounter between the father and his younger son.

Isaac is blind but he has not lost his other senses or his ability to reason. He has not lost his sense of time. When Jacob brings his meal he asks, “How is it you have found it so quickly?” He touches the hairy skin and he smells Esau’s clothing, the scent of the wild. He knows the sound of his sons’ voices. An ancient midrash asserts that Isaac knew from the time Jacob mentioned God’s name that he was not speaking to Esau. \*

If he knows, why does Isaac join in the deception? Custom dictated that the first born must inherit the blessing. Isaac cannot violate the norm even though he knows that Jacob is the son who will carry on the family tradition and use the inheritance well. Esau has, after all, traded his birthright for a batch of lentil stew (25:29-34) and he married two wives from other clans and “they made life bitter for Isaac and Rebekah” (26: 34-35). Isaac chose to join in the ruse.

But does it matter whether Isaac knows or does not know what he is doing? It does matter because we bring our own pre-conceptions, our own stereotypes, to the reading of scripture. Stories can affirm, reinforce, or challenge our understanding of ourselves and others. Why do we assume that, because he was elderly and blind, Isaac was gullible and powerless to recognize the rightful heir? Fortunately, theologians and biblical scholars are discovering new and liberating understandings of scripture from the perspective of people who live with disabilities. \*\*

Perhaps what is most significant in Isaac’s story is that neither his age nor his disability impairs his power to pass on the family blessing. In our culture, aging often brings with it invisibility. How many people are being ignored or discounted or regarded as burdens because of age, especially when age is accompanied by disability? Yet there is wisdom to pass on, grace to share. There are family stories that need to be told. As members of the body of Christ, many older people with disabilities still have “varieties of gifts” (I Cor. 12:4) to bring to those who will listen. I would like to give three examples.

Janice, a church educator and a former Associate Executive Presbyter of the Presbytery of the Twin Cities Area, left this legacy for her daughter, Karen.

*I think among the best lessons I gained from my mother were an irrepressible zest for life and love for others. Even as Mom’s life systems began to fail, she was determined to face these incapacities with “rising above them” faith.*

Margaret was blind for the last few years of her life. Yet, younger people were attracted to her as a source of wisdom. At her memorial service, a pastor said of her legacy:

*She was a dedicated biblical scholar. She loved her tradition but was always seeking new ideas. It was as though she had one foot in a tradition to which she was passionately committed but had the other foot out there, searching for a new perspective or a different way of thinking.*

Don died recently after living with disabilities for many years after his stroke. His “An Affirmation,” which was read at his memorial service, included these words:

*We bear witness that we are made in the image of our Parent-God and capable of being God-self to the world.*

Perhaps the Psalmist was thinking of older faithful people when he said, “They are like trees planted by streams of water, which yield their first fruit in its season, and their leaves do not wither.” (Ps. 1:3) Fortunate, indeed, are those who honor the gifts of older people of all abilities, those who listen, and those who receive the blessing.

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\* Cited in Plaut, W. Gunther, ed. *The Torah: A Modern Commentary*. New York: Union of American Hebrew Congregations. 1981. p. 192. For Plaut’s helpful commentary on Isaac’s story, see pages 190-192.

\*\* Avalos, Hector; Melcher, Sarah J.; Schipper, Jeremy, eds. *Theabled Body: Rethinking Disabilities in Biblical Studies*. Atlanta: Society of Biblical Literature. 2007. See “The Blindness of Isaac” by Kerry H. Wynn, pp. 93-96.

***The Rev. Bebe L. Baldwin is a retired Presbyterian Minister and a member of the Presbytery of the Twin Cities Area. She is the moderator of the [Presbytery Disability Concerns Ministry](#).***

# **Aging and Disability: Honesty, Limitations, and Hope**

Rev. Sue Montgomery

The Commonwealth of Pennsylvania has an advertising promotion to encourage drivers to use their seat belts. Using the state colors of yellow and gold, the signs read Buckle Up Next Million Miles. Seventy years ago there was a young father who drove a semi-trailer more than a million miles throughout Pennsylvania and the United States. This young father moved house trailers from factories in the east to the west coast. His entire career evolved around trucks, cars, driving, and eventually towing a camper from coast to coast. Driving was in his blood. Before he reached retirement age, he already had millions of miles under his belt. And then, age began to have an effect on his health, and his ability to drive.

Although he had faced a diagnosis of cancer with courage and strength, he'd overcome a heart attack and spinal arthritis, there was one thing that changed his life forever. That was age. Age affected his arteries, and in turn, he began to have small, intermittent strokes. One day while he was driving in a local shopping mall parking lot, he experienced a mini stroke. He came close to hitting a woman walking through the parking lot. With remarkable wisdom and courage, he pulled the car into a parking place, got out, and walked around to the passenger side. He opened the passenger door and handed the keys to his wife saying, "It's time for me to stop driving." That man of courage, wisdom, and profound strength was my father. He was a man who in his actions taught me how to grow old with grace. Was it easy for him? No. Is it easy for me? No! Yet, growing older and living with disabilities can be done with grace and dignity.

The problem is, no one likes to admit to the reality that limitations are a part of life and, as such, need to be embraced not with fear, but with honest and radical acceptance. It is often said of teenagers that they have an innocence, they believe nothing will ever happen to them, so with brazen courage--and sometimes foolishness--they do wild and crazy stunts. Parents ask, what ever happened to their brains? And yet, when age replaces our youth, do we still believe the same way? We think ---"It won't happen to me." "I'll be fine." "Just this once." Issues of safety, putting self limits on our activities, that's for someone else who is older, with real disabilities or infirmities, someone who needs more care than I--it doesn't affect me. The reality is, there isn't a person born yet who hasn't faced limitations. No one is immune from limitations. At the same time, it isn't uncommon for most people, if not everyone, to think of themselves as being limitless. We can do everything, we can do all things. Just don't let anything, especially age, get in our way!!

Yet, honesty forces everyone who looks in a mirror to admit, yes, there are limitations. And what follows that observation is usually the thought, "Just don't let anyone know!" The roots of these destructive attitudes are deep. The roots of rugged individualism and survival instincts feed our independence and sense of unlimited energy and performance.

At the same time there is the Protestant work ethic that most of us have been nurtured on from the very moment we were born, carried in the arms of our mothers, and nurtured by our fathers. Our faith nurtures that same spirit when we boldly proclaim, "I can do all things through Christ who strengthens me."

Aging and the changing realities aging brings to the human body, mind, and spirit forces us to continually create new images of ourselves and new identities. No longer young and carefree, aging makes each step slower, each decision more calculated. Aging leads us to think in new ways, one of which is the learning of how to develop a healthy understanding--or theology--of limitations. Instead of thinking, "We/I can do all things through Christ who strengthens me," a healthier way is to realize it is God who leads, guides, sustains, and provides--not us, not me. At the same time, a healthy theology of limitations embraces the hope that God still works through us, God still needs and embraces our gifts, talents, and even limited energies or abilities.

The second learning is how to define what it means to be the Body of Christ, the people of God in Christ working together. There is no shame in asking, or seeking help from others. There is no diminishing of self when help is sought. Hope and spiritual growth blossoms and wells up within shared relationships. The Body of Christ is celebrated and brought to life when our lives are in relationship with one another, relationships that embrace vulnerability, relationships that embrace love and acceptance in spite of our limitations and imperfections. It is Christ's grace that is sufficient for believers, it is Christ's power that is made perfect in weakness. It isn't about us, it is about Christ.

Now, where did I witness this wisdom and spiritual maturity in a more profound way than when my Dad placed the keys to the car into the hands of my mother, his wife? In that moment the mathematical component of marriage was made concrete, one plus one was one. Marriage was a partnership, life as a team. It took courage and it took wisdom. There were times when my Dad said, "Maybe I can drive again." Yet, he never did. The defining moment was when he exchanged his driver's license for a state issued identity card. From that day on, my mother became the driver. Although it changed my father's identity as the driver of the family, it never changed his identity as the man of strength, courage, and wisdom that he was.

My father's courage is what sustains me as I look at my aging body as it deals with disability. My house is no longer as clean as it once was. Energy levels are nothing like what they used to be, and sadly, my body's metabolism isn't anywhere near what it once was, either. So as age catches up to me, even though the mirror and the body don't lie--hope remains. Deuteronomy 31:8 lifts up these words: "It is the Lord who goes before you. He will be with you; he will not fail you or forsake you. Do not fear or be dismayed." With hope there is no need to be afraid. Limitations will come our way. Limitations are guides, they remind us of our humanness and that we aren't God. At the same time, in the presence of aging, God continues to create newness of life, new identities, and new possibilities. And who knows what surprises God has in store for those who age, in the communion of faith and in the presence of God. It might be

revolutionary and scary. Without a doubt, despite its challenges, it can be and will be exciting to people of faith who dare to buckle up for the next million miles!

*The Rev Sue S. Montgomery serves as the pastor (teaching elder) of the Nickleville Presbyterian Church, a smaller member congregation in Western Pennsylvania. For twenty-nine years she has also served as a chaplain at a residential facility for persons with developmental/intellectual disabilities. As Team Leader for the [PC\(USA\) Disability Concerns Consultants](#), she has heard many stories from people of faith who share their struggles, their joys, and their vision for a church that includes and embraces the gifts, hearts, and abilities of everyone. Sue is married to the Rev. Jay E. Montgomery and celebrates being a grandmother for the first time to Caleb, whose parents, Joel and Janis Montgomery are currently seniors at Pittsburgh Theological Seminary. Sue enjoys kayaking, hand cycling, riding roller coasters, camping, and finding good food and chocolates.*

# **The Three Ups to Journeying Well During Your Later Years;**

## **Wake Up, Show Up, Lighten Up**

Trish Herbert

**Wake Up.** The recipe for living well is much the same for us all. Wake Up to who you are now and how you can best spend your remaining precious years. Reflect on how you have changed over the years, what is most important to you now, and how to get more of it. You are still a work in progress. You can choose to focus on the “growing” part of growing old. Wake up to choices you have, the tools that are out there for you to use to help buffer the rough spots and improve your chances for living life as fully and satisfyingly as possible. We change. Our values change. What unfinished business do I have? What do I have to do to have peace of mind and to like myself the most? What’s on my bucket list of things I want to do? I can wake up to who I am now and who I want to be.

**Show Up.** You honor life by pouring yourself into it, by showing up for every moment and noticing all the little things along the way. It’s about appreciating your cup of coffee or tea in the morning, marveling at the snow load on the branches in the winter, the incredible spectrum of greens when the leaves are in all their freshness in the spring. By doing what you love, like gardening, reading, grand-parenting, creating or appreciating the arts, or being of service in some way that is satisfying, you are making the world a little better place. When you do something congruent with your values, however tiny the action may seem, you are making a difference. Showing up means continuing to learn and grow with your heart wide open. Showing up says don’t just let the world happen to you. Even if you can’t make something happen, you can set the stage for what you want to have happen, and have a much better chance of getting what you want. Get out there. Put yourself into circumstances where good things are more likely to happen to you. Be the architect of your future.

**Lighten Up.** Many of the values that come with late life do lighten us up. The ways-of-being that lead to becoming wiser like being authentic, comfortable with paradox, befriending mystery, appreciating the ordinary, being more humble, rediscovering our awe, being hopeful and flexible, reduces tension and stress and does a part in lightening us up. Learning how to balance between taking ourselves seriously, yet not too seriously, is key. Get as much playing and appreciating into your life as you can. Having seen so many weird and unexplainable things by this time in our lives has increased our sense of the absurd, and ability to laugh at ourselves. What works for one of us won’t for another. We learn not to judge ourselves so harshly. We will screw up because we are human. Our truckload of experiences has shown us that we aren’t perfect but that we are survivors. The seriousness of having to prove ourselves has dissipated. It’s time to accept who we

are, warts and all. The art of letting go of what we can't control and being able to laugh at ourselves and appreciate our strengths means we are journeying well.

**Dealing with the difficult times.** People with chronic illness or disability follow much the same path as those dealing with the difficult parts and indignities of the normal aging process. You find yourself gradually crossing off things that you can no longer do. Whatever age you experience loss, diminishment, or get a diagnosis, there are adjustments to be made. You may have to eat differently, use a prosthesis, use inhalers, have a new medication regimen, lose some independence.

**The process of grieving and dealing with loss is different for older persons than it is when younger.** For the elderly there is often a certain readiness, whether conscious or not, a predictability, a knowing, that this is the time of life that you have more losses, physical and emotional. Older adults are very aware of their finiteness, the temporariness of bodies, and are less cocky about how much control they have over things in general. They have had a lifetime of easing into the reality of endings. They have observed at the very least their change in hair color or amount of hair, new aches, other shifts and sags, and a lowering of energy levels. Younger people, disabled in some way or with a chronic illness, still have the illusion of control mightily embedded in them so the shock of feeling helpless may be more terrifying and daunting at first. This predictability of some sort of expected loss leads to less protest, less denial than loss at an earlier age, less of "why me?"

Some of the diminishments that come with late life are already in progress. Loss loses some of its ferocity. There may have been a steady stream of adjustments and acceptances. There's been a subtle or open anticipation of decline approaching for a long time by both the individual and the caregivers... more time to get ready and to finish unfinished business.

Major differences in how one grieves in this stage revolve around the unacceptability for persons in the old-old age bracket to really feel comfortable about expressing their feelings. There are still persons in this age group who believe that "crying doesn't help anything," "not complaining is a virtue," "displaying any expression of feeling is a sign of weakness," and they certainly don't want to "fall apart"... out of consideration for others. There is a belief that it is unpleasant for others to witness emotional pain. This difference is changing. The young-old are more into expressing their feelings. Denial of feelings get some through the rough times without the discomfort of openness, but this denial takes energy and takes a toll on the body. Working with and working through pain and suffering is far more healing in the long run. Working through the pain may be more difficult in later life because you may be dealing with multiple losses.

Often it is more difficult for older people to adjust and move on because it is harder for them to redefine themselves, invest energy in new relationships, etc. This is a much,

much harder task to do when you are very old yourself. There is less opportunity, time, energy, or often desire to do so. It is harder for older people to think in terms of starting anything...relationships, projects. Whereas younger persons may often desire new relationships the norm, in my experience, older people have less interest and expectation for this. Younger people hope to move on, find new relationships, etc. When illness or disability strikes a younger person, however, they may have a harder time finding support because people their age haven't had to deal with loss and often back off. There is no timeline on how long it will take someone to get through the process of mourning. Your mind and body will indicate when you are moving on. You know you are recovering when you begin noticing things that make you glad you are here to experience them. Moments of joy sneak up on you.

**Barriers to successful aging.** Natural things happen that make aging a challenging time even without disability. You lose physical capacity gradually and this accumulates. Your eyes and ears aren't what they used to be, and you usually have less resilience and energy. Your rebound capacity slows down after illness or accidents. One person said, "You know you are old when everything sags, dries up or leaks."

Society imprints us with negative expectations about late life. Ageism is alive and well in our society. It is aimed more at the old-old than the young-old. Ageism is the term used to describe a societal pattern of widely held devaluative attitudes, beliefs, and stereotypes based on chronological age. Any "-ism" is the need of one group to feel superior over another. Ageism is really the only "-ism" that is still on top of the table, not under it. The media and advertisers make it hard to feel good about how you look when the continual emphasis is on avoiding wrinkles, baldness, white hair, and so on. "What I know is that I spend a huge amount of time with my finger in the dike fending off aging." (Nora Ephron)

Older people, like any oppressed or marginalized group, are asked to accept societal standards and assimilate. Just as people of color are pressured to "look" white, gay and lesbians are more accepted if they look straight; young women are asked to adopt male rules in the business world, and old people are driven to look young and adopt standards of middle age. Able body-ism is closely related, as if people with chronic illness or disability have a choice. Most ageism stereotypes of older people are pejorative, one extreme being patronizing and infantilizing "poor dears." It is a pervasive attempt by the young and even the young-old to distance themselves from even thinking about this later, less-able stage of life.

**How Do I want to be treated?** There is a variation to the Golden Rule called the Platinum Rule: "Treat others as they want to be treated." When dealing with the old-old or persons with disabilities you need to get to know how they prefer to be treated. You must communicate to find out how one wants to be treated. You ask. You cannot assume anything. You ask how they prefer to be addressed. You look at them. If you can't

understand what the person is saying, you might ask them to spell the word...like T as in Tom. Don't pretend to understand. Stick with it. Talk directly to them, not to others in the room about them.

The Three Peaks of Life-- Physical, Productive, and Personhood. Being closer to the "whole" of our life we have most certainly passed the Physical Peak of our lives, healthy or not. Our biological decline begins at a relatively young age. Most studies say that it is downhill after the age of 30. We lose at a rate of about 1% our muscle mass, organ function, etc. Over a normal life span, such natural physiological declines are not preventable, although they may be accelerated or slowed by a variety of individual genetic factors, personal behaviors such as diet, smoking, and exercise, health care practices (e.g., screening and treatment for heart disease), and other environmental circumstances (e.g., working conditions).

We have most likely passed the Productive Peak of our lives, and have moved into the very important Spiritual or Personhood peaking time, which enables us to see the whole with a much broader lens. The best age to be is the age you are. Give some careful thought to how you can become closer to being the person you want to be... to live your last years congruent with your values-- and to have the best possible time doing it.

*Trish Herbert is a retired Psychologist/Gerontologist. Much of the above is taken from her book "Journeywell: A Guide to Quality Aging"... To learn more about the book or to order a copy, go to website: <http://www.trishherbert.com/Site/Welcome.html>*

## **Letting Go: A Mother's Story**

Roxanne Fredrickson Ezell

My parents eagerly volunteered to babysit for their first grandchild shortly after he was born. My husband and I were grateful for an evening away from home. When they arrived at our front door, I presented them with my son and a three-page list of instructions. I trusted them but couldn't resist telling them exactly what the baby and I expected. After some well-deserved teasing they promised to comply with as many items as time allowed. I like to imagine them sitting beside each other on the couch, my mother cradling David in her arms, my dad reading the list. Perhaps they heard echoes of their own parenting in my words.

A year later David was diagnosed with several conditions that would profoundly affect his life and ours. The pediatrician said our son must learn to trust people besides his parents. That part we assumed; David had already had many happy (and list-free) experiences with his grandparents and others in his first year. The doctor went on to explain that David must also learn to trust doctors, therapists, teachers, and all the other professional people who would be part of his life. We agreed.

What the doctor did not say, however, was that David's parents had to learn to trust others, too. This has been harder than I had imagined. It was one thing to trust a doctor's diagnosis. It has been another thing to gradually let go of the day-to-day responsibilities of supporting his life and to trust that others' care will replace our own.

In the early years – my 'mother bear' stage – I felt that if a situation was not acceptable for David, it was up to me to summon the knowledge and power to change it. Over time and by some power of grace, though, I have learned better ways to support David and even to gradually 'let go,' trusting others to keep him safe, healthy, and independent from us. We owe him that.

Mother Bear made her first appearance in my own mother one day when my parents joined us at an appointment with a language therapist. The therapist announced that

David, age two and a half, would never have an imagination. I suspected this wasn't true because he had recently pointed to a tin of cocoa stuck in the front corner of our grocery cart and said "car." The tin's indented circular lid was facing forward and David was pointing out one of the car's headlights. My mother didn't know this. Her claws came out. She looked at the therapist with such rage that I imagined her swiping the woman's face. Mother Bear's appearances in my life were rarely as dramatic. When David was in ninth grade, though, she stood up on her hind legs and roared.

Our son had thrived in elementary school with a combination of regular and special education classes. His middle school teachers in particular made countless accommodations to support his success. I was shocked when he was given only two options for high school: regular classes with no accommodations or a completely self-contained classroom. The room was bad enough - eight boys crammed into a green-walled cell devoid of resources, windows too high to see anything but sky - but worse was the teacher, whose idea of writing an Individualized Educational Plan (IEP) was to Xerox the table of contents from one of his textbooks. This man proudly told us that his students got real-life experience by taking turns walking to the cafeteria with a dollar bill to buy him a carton of milk for lunch. They counted out the change when they returned to his room.

David started the year in regular classes. I knew he would have trouble following lectures and had no idea how he would manage tests, but it seemed the only alternative. Sure enough, David had trouble processing much of what his teachers presented. Being a well-behaved child, he made no fuss, but when he couldn't learn the Latin names for the human bones in ninth grade science, Mother Bear had had enough.

Standing in our kitchen with a telephone in one hand and a list in the other, she read her demands to the Director of Special Education: a real IEP, regular contact with other students, and accommodations so he could succeed in academic courses as well as gym, and music; real-life skills like cooking one-handed, budgeting, socializing; work skills

like interviewing, writing a resume, being a dependable worker, and career exploration to find work that fit his talents, interests, and abilities.

The Director of Special Ed said they had been waiting for input just like this from a parent. I suspected I was being “handled” but took her at her word. I did not dwell on why it had taken so long for a parent to suggest changes that seemed so obvious and important to me because the story had a happy ending. The high school developed several hands-on courses like “bachelor survival” – cooking, mending clothes, budgeting, even a session on ballroom dancing - and supported David in other classes.

Late one night his biology teacher called, exultant because David had gotten a ‘B’ on a test. I was overcome with gratitude for everyone who had made it possible for my son to learn that extremely hot weather makes millions of lightening bugs fill a prairie night with twinkling. I realized David needed interventions far beyond my own power but I gave silent thanks to Mother Bear for her courage and a peculiar, calm certainty of purpose. It felt good to have been part of this transformation.

High school graduation brought grief for David. At the Senior Breakfast, he listened to others share memories and laugh at ‘in’ jokes he had never heard. He realized how isolated he had been from other students in spite of sitting next to them in class all these years. He heard their plans for next year. Later that day he came to me in tears.

“What will become of me?” he asked.

I hugged this beautiful young man, newly grown taller than his mother. I cried, too, weeping for both of us and the empty places in our hearts where visions of his future should have been. I told him the one true thing I knew.

“David,” I said, “Whatever happens, we’ll work it out together. We will never, ever abandon you. You will never be alone.”

Not long afterwards our family moved to a different state where David received three years of training in self-advocacy, career exploration, and training for getting and holding

a job. By the time he had graduated from this program, he had landed a part-time job as a janitor in a local nursing home. Two years later he moved into an apartment served by a group home. He lives there happily still, among friends and support staff who have gradually shaped his adult life in positive ways beyond what his parents could have done for him.

Managing these changes was not a job for Mother Bear. She gets credit for perseverance and cunning, but a different image helps me understand how my husband and I, along with many others, supported David's transition to adulthood. It also gives us a vision of a stable future for him, even when we are gone. Best of all, it is a gift of David's imagination.

When he was ten, he explained how people get to heaven.

“You bounce on a trampoline, higher and higher and higher, until you get up there, and then there's a big buffet everywhere, and you can eat whatever you want.”

Today David bounces sturdily on the strength and resilience of the trampoline that he and his family have woven over the past thirty-six years. We are humbled by our debt to the other weavers - teachers, doctors, school administrators, friends, job coaches, occupational and physical therapists, fellow church members, social workers, governors, legislators, psychologists, drivers, pharmacists, group home staff, employers, co-workers, neighbors, and everyone who pays taxes to help support David's precious independence – for sharing their expertise, insight, experience, and power so this image can be more than a metaphor.

At this point Roger and I are David's spotters. Legally we are his co-conservators, responsible for his person and his finances. We observe him bouncing, his angles and his height. We ask him whether he is happy where he lives and with the helping people in his life. Almost all of his day-to-day support, though, comes from the group home, his

employers, and the employment agency. We depend more and more on others to maintain his mat.

Many blessings flowed from this process. David became a 'neat-nick' once he had his own place. He kept his new surroundings immaculate. Instead of becoming a recluse, he made friends and began to enjoy socializing. He could ask trustworthy people about things he'd rather not discuss with his parents. We felt advantages, too. We no longer had to eat meals at exactly the same time every day to keep his medicine at a constant level in his blood. I had time to rediscover interests that I hadn't had time or emotional energy to pursue: writing, singing, yoga. Another humbling moment came when I realized that other people could sometimes handle situations better than me. The group home staff calls David's neurologist instead of an ambulance when David has a severe seizure, sparing him an unnecessary three hours in the emergency room.

As my husband and I age, it's increasingly urgent for us to back up and spot from a distance. This is still hard. Although we know it's for David's sake, and our own, the letting-go still frightens me. We have given the group home legal responsibility for maintaining his health. Simply writing the sentence awakens guilt and the beginning of panic. Much to our chagrin we have become single-issue voters. We look for fellow weavers, evaluating a candidate by his or her intent to maintain the social safety net. We still face the most daunting task of all, finding someone David's age or younger to be his conservator when we are gone. Our son will always need a spotter.

These days I let other people make the lists. I dream, instead, of a future beyond my control. I dream of research that finds cures for epilepsy and birth defects, of good people continuing to make careers in medicine and human services, of citizens who continue to believe that justice, not pity, requires ensuring a life of dignity to even the most vulnerable ones among us.

I dream of David living with people he cares about and who care about him, of the joys he will experience, his pride and sense of contribution for the work he does, and of the contributions he will continue to make to those around him.

I pray that the people in his life will love and appreciate David for his courage, his integrity, his loyalty, his sense of humor, and his generous heart. I pray that David and all people with disabilities will receive the blessings Isaiah promised God would give to the Israelites mourning in Zion: a garland instead of ashes, the oil of gladness instead of mourning, the mantle of praise instead of a faint spirit.

**They will be called oaks of righteousness,  
the planting of the Lord, to display his glory.**

**Isaiah 61:3**

*Roxanne Fredrickson Ezell is a graduate of Carleton College and holds an M.A. in Music from the University of Iowa. She teaches private music lessons and tutors part-time after retiring from work as a public school music teacher, computer programmer, and choir director. She has always loved the music in words. She lives in Orono, Minnesota with her husband Roger. Their son David lives nearby.*

## Who IS This Person?

Rev. Robin Lostetter

**Certainly the faithful love of the LORD hasn't ended;  
certainly God's compassion isn't through!  
They are renewed every morning. (*Lamentations 3:22-23, CEB*)**

I wasn't yet 60, as I recall. I bought two movie tickets, for myself and a friend, and I was charged two different rates. I asked the young man why, and he looked at me in obvious discomfort, unable even to stammer out an answer. It wasn't until a while later that I realized I had received a senior discount. Really? Where had the "I get carded even when I'm with my 16-year-old daughter" days gone??

At home, I looked in the mirror. She's still in there. She doesn't look so bad - does she? A few white hairs . . . Oh.

Last fall I ended up in the hospital. I'm familiar with hospitals. I've lived with a disability all my life, and with a few acquired ones nearly that long. But this wasn't one of those situations . . . not an occasion for an orthopaedic surgeon to measure and "correct" a bone or joint to near-perfect function. Nor was this something one could point to, see the difference in musculature and still be able to walk, run, and do most tasks of daily living. Well, at least for about 55 years.

At 55, I was enjoying the ocean . . . until I tried to fight the waves to get back to the shore. Those unevenly-muscled legs of different lengths wouldn't hold me up against the power of even shallow waves. And, frankly, I was too proud to crawl out of the ocean. A friend, a lifelong seaside-dweller, in her mid-70's, twenty years older than I, walked in and walked me out.

Last fall it was not the legs. It was not the knees. It wasn't even the lower back, stressed by those lower extremities. Last fall it was a "neurological event". Mini-stroke? TIA? VAD? Things I'd never thought applied to me . . . things I'd never heard of. Tests beyond the usual CT and MRI . . . now we're talking an MRA to rule out a VAD . . . what? And, at 63, I seem to be the youngest and healthiest person on the telemetry unit. I am young, aren't I? But both my daughters are driving into town? Good grief! (Must be serious!)

My elder sister-in-law is in Hospice. I'm now next in line to be the family matriarch, the crone. My nieces and nephews, from seekers to atheists to Baptists, come to me as the spiritual leader of the "clan." Even while I'm in the hospital. Am I up to it?

Looking in the mirror . . . did that criss-cross of wrinkles on my cheek just appear with this "event," or have they been there all along? Is that a crone looking back at me?

It's Tuesday. It's February, 2012, and we sit in a designated area of the airport, awaiting wheelchair assistance to our gate. Across from us is a younger man. Maybe 40. His

hand and his gait indicate he's experienced a stroke at an unusually early age. He's muttering angrily . . . "The rest of them can walk!! Why are they here? They can walk!!" I turn to my companion. "He must be very new to this." Disability is not always visible. Disability is not a respecter of age. Disability does not come with instructions. Disability does not make you kind or likable.

Age, also, does not come with instructions. And it does not make you kind, mellow, likable, grandmotherly, or wise. Age very often makes you aware of loss and makes you kin with those living with disability. Age can give rise to anger. "Rage, rage against the dying of the light" may be one's reaction to macular degeneration, a detached retina, a leaking blood vessel . . . the actual dying of the light.

I am a pastor who lives with a disability, and I have counseled many folk with the usual advice about accepting our limitations and enjoying our gifts and abilities. I understand loss – I experienced it decades ago with polio; I experienced it with divorce; and I experienced it with the deaths of my parents and siblings. But now the face in the mirror looks suspiciously – not like my mother's, but like my grandmother's! And the new loss is mine. And it's permanent; it's unpredictable; it's not even diagnosable. . . . And I don't like it. How do those people who frequent my office go about their days so seemingly complacent – actually happy – with their age, their increased "organ recitals," their lengthening list of medical specialists?

I understand orthopaedic issues. They're concrete. They're not necessarily age-related, either. But this . . . this "unusual," "unidentifiable" "neurological event" which has now become my daily companion with its random headaches and increased need for sleep and new medications with the side effect of increased "senior moments." This new daily companion is not concrete. It is slippery. It is unpredictable. It is a reminder of the frailty of flesh. And in the mirror, it screams back at me with criss-crossed wrinkles on one side of my face, with a "facial deficit" when eating or swallowing. No! I'm not ready!

So my years in a nursing home will not be what I envisioned. I have lost even that image with which I had made peace. It will not be the wheelchair and GI issues that I expected would concern me, but rather drooling and slurred speech, eating pulverized bland food . . . not the way I expected to go out of this life . . . me, with the penchant for Mexican food and chatter!!

It's March, now. By February, I had really pretty much made acquaintance with the new me. I'm now probably a better pastoral counselor. I've begun the conversations with one of my daughters about where I will live if my retirement is forced to be sooner than planned. And I've begun to see my mother's strong hands in my thinner typing fingers and more visible veins. ("The better to stick you, my dearie" in the ER, the ICU, the lab.)

**"Teach us to number our days, so we can have a wise heart." (Ps. 90:12, CEB)**

Every day there is something new! It may be a joy; it may be a challenge; it may even be a loss. But each day is precious. And as we grow older (not *old* . . . I'm not ready to say

that yet!), the days rush more quickly by! It is important, then, to taste them, to find the newness, to continue to seek the best medical-spiritual-physical-mental-communal support, and, yes, even to settle into the “new normal.” **For to every thing there is indeed a season, and a time for every joy under the heavens. (Eccles 3:1, adapted)**

I still need to be taught to number and relish these days. I may never achieve wisdom. I may never make peace with the increasing losses of age. But I pray that I do. Living peacefully with that woman in the mirror is more pleasant than fighting her every day. Learning to value the lessons that have formed many of the wrinkles — smile lines, crows feet — and to wear them proudly is preferable to seeking the elusive magic cover-up. Learning to live the words I’ve doled out in this office is a worthy discipline, and a way to be in solidarity with my older congregants, a model to my not-yet-older congregants, and a symbol of hope to my younger congregants. **Lord, in your mercy, hear my prayer.**



*The Rev. Robin Lostetter is Temporary Supply Pastor for First Presbyterian Church, Bordentown, NJ. She has served on the Leadership Team for PHEWA’s PDC network, she has served Monmouth Presbytery as moderator and in several other capacities, and she is a member of the ground-breaking Tri-Presbytery Commission “Tres Iglesias Presbiterianas.” She shares the manse with her cat Luna and two lop-eared rabbits.*

## **Later Life Decisions:**

### **Parkinson's Disease Commands Our Attention**

Rev. Bob and Carolyn Cuthill

Bob: In October 2004 our world was turned upside down. We were faced with Carolyn's diagnosis of Parkinson's Disease. Our full steam ahead retirement years needed a radical adjustment. No longer could we simply plan without considering what might be immediately ahead with the onslaught of Parkinson's.

Bob: Unfortunately, for almost a year we struggled to understand the immediate and long term nature of Parkinson's. Our first Neurologist gave us minimum help. After the initial diagnosis and one medication we were left on our own to sort out our future.

Bob: Fortunately, in September of 2005 we attended an annual gathering about the realities and recent medical discoveries to help treat Parkinson's hosted by the Struthers Parkinson's Center.

Bob: At the Struthers' annual event, information was given to us about a daylong evaluation that Carolyn could do at the Parkinson's Center. Carolyn jumped at the opportunity to get a better handle on her condition. What a remarkable day that was for both of us. The world of possible ways to help Carolyn and me, physically and mentally, was opened like a book of wonders. We now knew of a place where we would be offered the advice and support we both needed.

Bob: Out of the daylong evaluation several follow-up things happened. Carolyn made some adjustments in her life. We soon joined Silver Sneakers to keep us both more physically fit. This exercise class was important for both of us but critical for Carolyn. Speech therapy was added for a short time. Carolyn changed her Neurologist to one who specializes in Parkinson's.

Bob: But maybe most important of all, we joined a support group for Newly Diagnosed Parkinson's people sponsored by Struthers. The monthly meeting of this group caused us to build very meaningful friendships. The content of the meetings has given us insight and more awareness of how to live with Parkinson's.

Bob: One of the realities we discovered about Parkinson's is that there is no way to predict the speed or severity of the disease. Right here, I want to say how well Carolyn has done in living with the reality of Parkinson's. She is faithful in taking her medicine. She meets quite often with a Parkinson's friend to exercise her voice. She is diligent in her exercise program to keep her body moving.

Bob: By 2010, we both had reached our 80's. Earlier in life, we had talked about heading toward a Presbyterian retirement community sometime when we got "older."

Now, with the added dimension of Parkinson's, we knew it was time to get serious about finding a retirement community.

Carolyn: I began thinking seriously about planning for the future when working at Gideon Pond, one of the [Presbyterian Homes and Services](#) in Minnesota. As I talked with people about making a move into a retirement community with care facilities for use when needed, I began to see a definite trend. The people who seemed happiest with their lives had accepted change and learned to live with hope. Alice in Wonderland says, "There's no place like home!" She is right; however, home is wherever a person lives by enjoying when they make that residence into their own Home.

Carolyn: As I listened to the excuses for staying put, I began to think about what is most important for us in the years when we slow down and are unable to properly care for ourselves, as well as for our homes. It gets harder to keep up with the busy lifestyles we have enjoyed. What truly makes for happiness and a good quality of life as we age? People are the most important in our lives, not things. Taking such an approach, I was able to move into a condo, with my love, and let go of many un-needed things. We enjoyed sixteen years on Lake Minnetonka, living in a condo and with our sailboat just outside our door. What fun to enjoy the beauty of water and wind and not have to worry about the lawn or the house! God's creation is so beautiful and having the time to work the sails with the wind and glide through the water were very spiritual moments in our lives.

Carolyn: I have found retirement to be the time for reflecting on one's life up to now and having the ability and time to use our remaining life more fully each day.

Carolyn: As we began to age and body parts needed repair, we were less able to control our boat and we sadly realized our sailing days had come to an end. So, too, have our working, parenting, and formal education journey begun a different path. We moved into Eden Prairie to be closer to medical care and to be near the orchestra and live theater. We began to participate in community groups, along with church activities, and found great happiness in our new home.

Carolyn: There were medical problems for both of us and then I was diagnosed with Parkinson's Disease (P.D.). My body slowed down with more time needed to get up and go. And just as this was happening, our Presbyterian Board of Pensions had a seminar on retirement. It was most helpful, so we decided to get some retirement counseling. We also talked and planned with our financial planner. Our names were already on the lists of several Presbyterian Homes Communities. Our journey into a new lifestyle began by visiting various retirement communities. We wanted one with care facilities, as needed. I wanted Bob to be able to participate in life and not be tied down to just caring for me when the time came, as P.D. medicine would wear off. Our journey ended when we visited Waverly Gardens in North Oaks, Minnesota. All phases of retirement living may be found here.

Carolyn: Waverly Gardens is beautiful with lakes, walk ways and lovely buildings giving one privacy and a lovely apartment. The staff is happy, friendly, and caring for each resident. We are greeted by name and specially remembered on special days. And the icing on the cake is the residents who are our neighbors. We are a group of people with aging problems, yet having the ability to enjoy each new day

Carolyn: Our life here is: playing, working on projects, going to movies, enjoying special programs, and caring for one another. Does this sound unbelievable? Well it is real, and we feel so blessed to be in such a place as we enter our last chapters of earthly life.

Carolyn: Facing life with P.D. is bothersome but not depressing. I can count my blessings in a life made easier with an environment and people concerned with the quality of life in these years. I can keep my body going through the exercise and activities offered here. I can be concerned with helping others who have greater need than I do, who may be found here.

Bob: In addition to the basic areas of living, we were looking for a community that felt like home to us. For me, I wanted to know there would be enough males in residence for me to build some friendships. It was also important to us to have activities available that would keep us physically and mentally alert.

Bob: Fortunately, we moved to what is our ideal community in August 2010. In addition to excellent, modern, beautiful facilities and grounds, we have a professional staff that is highly competent and always considerate and caring. Residents come first in this community.

Bob: Since we are still physically able, and residents in the “independent living” section, we continue to keep our friendships outside this community as we develop new friendships inside the retirement community.

Bob: For us, the move at this time to a retirement community has brought us a support system that has reduced our household chores and increased our comfort zone. When returning to our apartment in January, after celebrating our common birthday with friends, I said to Carolyn, “We sure made the right choice for us in moving to [Waverly Gardens](#), Presbyterian Homes in North Oaks, Minnesota.”

*Carolyn Cuthill is the daughter of a Methodist Minister and grew up in the state of Virginia. After graduating with a B.S. degree from Madison State Teacher's College, she taught school in Richmond, VA. She was a Children's worker at Wesley House in Louisville, Kentucky where she met Bob. After getting married, she continued teaching in Fredericktown, Missouri and Peoria, Illinois. Later, she worked for the Minnesota Hospital and Homes Association, which led to her working for Presbyterian Homes of Minnesota.*

*The Rev. Bob Cuthill grew up in Buffalo, New York and earned the A.B. degree from Maryville College, Tennessee, M.Div. degree from Louisville Presbyterian Theological Seminary, and D.Min. from McCormick Theological Seminary. Bob was ordained in 1955 and served three pastorates in Missouri. Other positions served were: Associate Presbytery Executive in St. Louis, MO, Executive Presbyter for Great Rivers Presbytery, IL and Synod Executive for the Synod of Lakes and Prairies. Bob retired in 1955.*

*Bob and Carolyn have four children, nine grandchildren, and nine great-grandchildren.*

## **Even When I Forget, The Music Is Familiar**

Lorie Ludwig, MT-BC, NMT

You wake up at 2 a.m. The room is dark, quiet, you don't know the time, what you have to do that day, and you may not even remember where you are. Until you get that figured out, you are very anxious. That's what I imagine it's like to have dementia. Scary, isn't it? All at once, you hear a familiar song, the fear vanishes, and your day continues untroubled.

Music therapy is defined as music selected and used by a music therapist to maintain, improve, or restore the social, cognitive, emotional, physical, and spiritual well-being of individuals. Music therapy benefits older adults of all cognitive, visual, emotional, hearing, and mobility abilities using safe, non-threatening techniques. Residents do not have to have musical abilities to benefit from music therapy. This article explains how music therapy benefits the social, cognitive, emotional, physical, and spiritual functioning of older adults.

We are all social beings. When moving into a senior living facility (Retirement Center, Independent Living, Assisted Living, Memory Care, or Long Term Care), residents are living among strangers but must get along with each other in order to form a social unit. Music is the ideal medium to help residents socialize by singing the same song together, playing instruments together, dancing, sharing lyric sheets, and helping each other during music sessions. Music that is familiar helps residents get to know each other while participating in music therapy and acts as a springboard for later socialization. If residents are physically unable to participate, they still benefit from music therapy by watching positive interactions that occur.

Cognitive functioning (memory recall and neural processing) can be improved with music therapy. Music Bingo challenges all levels of intellect by putting a Bingo chip on a picture that represents a familiar tune. It's a different way of thinking. Music trivia includes naming the song title when given a line of the song, answering questions about a music topic, or naming the composer or performer of a song. Playing instruments with both hands challenges the brain to focus attention and follow directions in order to play on cue. Music therapy helps the brain make new neural connections after a stroke or other brain injury by challenging residents to answer questions about music familiar to them. Music is processed in different parts of the brain than speech so singing may be easier than speaking. Memory Care residents play music games such as Fishing For Songs. Since they cannot request a song, a familiar song title is written on a construction paper fish and they "fish" for a song. The group sings the chosen song. Familiar songs inspire spontaneous singing by all residents and are easy to retrieve from memories. Agitation is reduced when familiar songs are played for residents with memory loss, as songs even from childhood bring great comfort and a feeling of success. These and other music games keep minds active.

Music expresses the inexpressible and music therapy allows emotions to be safely conveyed during sessions. Emotions are expressed non-verbally by playing instruments

using different dynamics. Singing a song occasionally triggers memories that take residents back to the time when those memories occurred. Reminiscing about those triggered memories during a music therapy session is a safe outlet for these emotions. Patriotic feelings run strong in older adults and singing patriotic songs expresses these feelings as no other medium can. Spirituality is also very important in older adults. Singing, playing, learning about, and listening to favorite sacred music are a few ways to express these strong, emotional feelings. Answering a trivia question correctly or playing an instrument for the first time achieves success and how good it feels to be successful! It lets residents know that they are capable of learning at any age and that builds self-esteem, benefitting all areas of their lives.

Music therapy aids physical movement. Exercise provides the rhythm necessary to produce steady, smooth movements and distracts away from pain, thus increasing its benefits. Reaching for instruments or playing instruments at different angles to keep muscles stretched after stroke or some other neurological condition improves range of motion and strength. The tactile stimulation from playing instruments improves circulation, helps focus attention for longer periods of time, and provides sensory stimulation. Playing tone chimes improves coordination and strength by playing one or two tone chimes of different weights. Dancing improves strength, is fun, and retains closeness between couples. Residents who are hard of hearing can still play tone chimes by watching the music therapist and playing on cue. Residents with limited vision play tone chimes if the music therapist stands close to them or quietly says their name when it is time for them to play. If a resident can no longer dance due to wheelchair limitations, they can dance vicariously through a Limberjack. It is a 12-inch wooden toy with jointed arms and legs that is shaken in rhythm to music. [Editor's note: And then, there is wheelchair dancing!] Therapeutic singing encourages taking big breaths and singing for as long as possible before taking another full breath. Deep breaths while singing encourages coughing up secretions and improve lung function. These are but a few ways music therapy benefits the physical well-being of older adults.

Spirituality is very important for older adults. Older adults know that they are in their twilight years and spirituality becomes more important to them as they age. Music therapy complements the ministry of chaplains. Singing hymns and telling the history of hymns makes them more meaningful. Residents can suggest favorite hymns to sing during worship services, memorial services, or for enjoyment. Choir members can sing hymns during concerts or memorial services. Tone chimes can play hymns during rehearsal and concerts. The setting is important. If you create a space with rows and a center aisle, residents with memory loss will conduct themselves like they are at church and act accordingly. Discussions about worship traditions and favorite hymns played at residents' churches can be shared with the group. Hymns played during a resident's final moments bring great comfort to the resident and family. Nourishing spirituality is essential for all older adults, sick or well, regardless of age, mobility, hearing, vision, or memory loss. Nothing comforts like singing, "Jesus loves me, this I know, For the Bible tells me so." Spirituality needs to be addressed daily and spiritual music of choice helps older adults remain spiritually at peace.

These are a few ways music therapy is used to assist older adults of all abilities maintain, restore, or improve their social, cognitive, emotional, physical, and spiritual well-being. When you have that 2 a.m. sensation and don't know where you are, remember some hymns of older adults: *Jesus Loves Me*, *Amazing Grace*, *In The Garden*, *How Great Thou Art*, and *The Old Rugged Cross*. Life won't be quite so scary, after all.

*Lorie Ludwig is a board certified Music Therapist with fifteen plus years experience working with long term care, Memory Care, Assisted Living, and Independent Living residents. Diagnosed with a vocal tremor in 2001, she is unable to sing. Lorie is a hymn author and active member of the Presbyterians for Disability Concerns Task Force, a committee of the Presbytery of the Twin Cities Area. She is a member of Westminster Presbyterian Church, Minneapolis, Minnesota.*

# Dementia as Disability

Rev. Mary Austin

Dementia, with its troubling progress and ever-increasing symptoms, is generally considered an illness, rather than a disability. For the people who struggle with it, however, it functions like a disability in daily life. Like a disability, it can limit independence and activities, and require new life skills and changed relationships – both for the person who has the memory loss, and the people around him or her. Like a disability, it can be isolating, if people don't know how to react to changed capabilities. Like a disability, memory loss changes our sense of self, and brings both new challenges and new gifts.

Memory loss, or dementia, has different sources, including events like stroke or head injury, or diseases like Alzheimer's or Parkinson's. Forgetfulness is one of the early symptoms, and the one you may notice first in a friend or member of your congregation. Other symptoms develop over time, including trouble with language and finding words, altered perceptions, difficulty making decisions, and struggles with directions and finding familiar places. A person may grow irritable as the world becomes unfamiliar and frightening, or she or he may act more aggressively, seeming more paranoid at times. Other people may forget social engagements, or you may notice their personality flattening out.

In the early stages of dementia, people may still live at home, with help from family or friends, and may still attend church regularly. For these people, congregations might consider:

- ⤴ value community more than perfection. If someone talks during church, or sings the wrong verse of a hymn, be glad they're still present. Maintain a posture of hospitality, instead of dismay.
- ⤴ if the person has always done a particular job at church, allow them to keep doing it, with some added help. Serving the church by ushering, or helping with funeral luncheons, or being in the nursery, are all still possible, with some help. Singing in the choir may not sound perfect, but the community is invaluable to the person with dementia. Also, a family caregiver who is on duty all the time may benefit from a break, during the time the person with dementia is with other people.

In the middle stages of dementia, everything is shifting for the person and their family. This may be the time when the family needs to consider additional help, or finding residential care. We, as congregation members and leaders, can support them best by being non-judgmental about their choices. No one knows what it's like inside anyone else's home. None of us knows the stresses other people face, and so their choices belong

only to them. Wise friends can make observations about the need for more help, as we see things change. Also, we can offer to sit with the person who has dementia, so the family caregiver can take a break.

People may stop coming to church at this time, feeling embarrassed or ashamed about the changes they see in themselves, or a loved one. The church can reach out and strongly encourage people to come to worship on Sundays, and to church activities. Don't wait, or hesitate. People can always say no, but they don't always realize they're still welcome. People with dementia benefit from seeing friends, hearing familiar music, and being in a familiar place. The more recognizable the elements of the service, the more at home people will feel. Again, hospitality is more important than perfection.

In the last stages of dementia, people may not recognize family or friends any more, and may eventually subside into silence. Even in this chapter of life, when it seems that there's no meaningful interaction, deep and powerful connections are possible. Visitors from the church should continue to go, even if the person is no longer able to converse. When you visit:

- ✧ Sit next to the person, so you don't seem threatening.
- ✧ Use more statements than questions, so the person isn't pressured to answer.
- ✧ Take the person's hand in your hands. Touch is powerful.
- ✧ Read familiar Psalms or Bible passages, or sing familiar hymns. At this point, the quality of the singing won't matter a bit, and the music may touch a place words can't reach.
- ✧ If you visit someone in a care facility, leave a note or card so the family knows that you were there. It will mean a great deal to the family to know that the connection with the church still continues.

This is a time of great grief for the family, and it involves them in a complicated dance of mourning, grieving for the loved one who is now gone, but also still challenged by the work of attending to the person who is still present. Again, true support will come without judgment about their choices, or how often they seem to visit. It's hard to understand this kind of pain until we experience it.

Gradually, the person will forget how to speak, how to eat and eventually how to breathe, and they will slip from this world into the life to come. Until that time, we can bring the grace of God to them with our presence, prayers and hospitality. We can continue to keep them part of the community of faith, first by welcoming them to church, and then by bringing the church to them with our presence. Even as human memory fades, God

remembers us all. As followers of a loving God, we are called to remember each other in God's name, and to enfold people with memory loss in community.

*The Rev. Mary Austin is the pastor of Westminster Church, a church for all people, located in the City of Detroit, Michigan and is a former hospice chaplain. She can be reached at:*

[Maryaustin520@yahoo.com](mailto:Maryaustin520@yahoo.com)

# How the Parish Nurse Can Help as People Age

Joanie Friend

How will the aging of Baby Boomers affect you? Since the late 1940's when the first of the Baby Boomers was born, our society has had to brace itself for each stage of the Boomers' development. As they approach their senior years, we already can anticipate a few things.

Between 2010 and 2030 the older population is expected to double, growing from 35 million to 72 million and representing over 20 percent of the total U.S. population. The U.S. Census Bureau projects that the population age 85 and over could grow from 5.7 million in 2008 to 19 million by 2050. Medical advancements and new technology have contributed to this growth and it is a fact that older populations utilize significantly more healthcare resources than in the younger years. The good news is that Americans are not only living longer but also staying well longer. At the same time this "Age Wave" is occurring, families are becoming smaller and more scattered across the U.S. In addition, the economic climate has meant that both adult members of a household are often working yet are raising children and caring for or at least worrying about elderly family members – hence the term "Sandwich Generation." As we know, doctors have less and less time to spend with patients and healthcare is more fragmented than in the days of the "good old family doctor."

Little did I dream, when I became a parish nurse (with long experience in pediatric nursing), that I would spend most of my time with the elderly members of my congregation! Many people think that parish nursing is really geriatric consulting. Depending on one's church, it might be, but parish nursing is so much more!

Parish nurses, or faith community nurses as they are now called, focus on the promotion of health with healing and wholeness of body, mind, and spirit even in the absence of cure. Health is viewed as not only the absence of disease but a sense of physical, social, psychological, and spiritual well-being and of being in harmony with self, others, the environment, and with GOD. Parish nurses are in a unique position to impact the individuals within their congregations and the community and help them bring issues of faith and health together. Congregation members place a high degree of trust in the parish nurse who serves their congregation, whether he or she is a paid or unpaid staff member.

In addition to providing spiritual care, parish nurses have a high degree of variability in the services they provide. Each parish nurse practice is different according to the needs of the members and the skill set of the nurse. We may often be found:

\* Assessing the needs of an individual and helping them to formulate a plan of care

- \* Accompanying someone to a doctor's appointment as an advocate and note-taker and then, with the permission of the member, e-mailing or calling family members to keep them informed
- \* Sitting with a newly diagnosed patient to help them sort out useful information and to consider how this diagnosis will change their life
- \* Teaching a class about "Aging Gracefully," ethical end-of-life care, home modifications for better accessibility, mental health issues, or almost any other health-related/faith topic you can think of
- \* Raising awareness within the church of issues related to disability, accessibility, or hospitality and inclusion
- \* Visiting continuing care communities, assisted living facilities, or nursing/rehab facilities with families to find the one that will best meet the patient's needs
- \* Explaining hospice services to a family and helping them decide if this is an appropriate time for that kind of care
- \* Organizing items in the loan closet at church such as walkers, wheelchairs, bedside commodes, and other medical equipment available to borrow when the need arises
- \* Writing an article on a health topic for the monthly church newsletter
- \* Sitting at a bedside praying with a patient
- \* Visiting members in hospitals, nursing homes, or their own homes
- \* In consultation with the pastor, initiating a prayer chain of individuals with concerns or celebrations
- \* Obtaining and displaying health information or pamphlets such as "[Care Notes](#)" which provide health and spiritual guidance.
- \* Organizing a "flu clinic" at church so that folks of all ages have easy access to flu vaccine at the appropriate time of year
- \* Monitoring the automatic defibrillator to see that it is ready for use
- \* Filling the first aid kit in the office

The parish nurse is often the first person to come in contact with an individual with a disability. We try to anticipate how a medical condition might affect an individual and help that person prepare for the future. As a church member, you can help us help you by telling us everything you know about your particular condition. Parish nurses are familiar

with community resources and are full of practical advice such as home delivery of groceries, medical aids and where to obtain them with the least expense, and simple home modifications to make living space more appropriate.

I have been a member of an “Accessibility Committee” at my church for many years. We have had several worship services devoted to accessibility concerns and have been fortunate enough to have the Rev. Sue Montgomery, one of the [PC\(USA\) Disability Concerns Consultants](#), guide us and lead worship at our church. In addition to items of accessibility that have been addressed, we have concentrated on aids for those with visual and hearing difficulties. It takes time and perseverance to effect change in all of these areas but the parish nurse is definitely known as an advocate and educator in all of those areas. Simple things like reminding the pastors to arrange for communion to be served without walking up the chancel steps can raise awareness. It does not necessarily take a parish nurse but it does take the vigilance and awareness of the “village” to continue to bring awareness to the whole church community.

Having stated many of the very practical tasks accomplished by parish nurses, their biggest role is the gift of presence to journey with patients through good times and bad. As Baby Boomers age, the journey may have a few “bumps” in it as parish nurses and health ministers work creatively to help such a large group of people age gracefully. Very special relationships can develop to help folks throughout their lives and I’ve developed a “mutual admiration society” with many of the people I’ve journeyed with over the years.

*Joanie Friend is a Registered Nurse and has been the Parish Nurse at the Bradley Hills Presbyterian Church in Bethesda, Maryland for 13 years. She is also a Parish Nursing/Health Ministry Consultant and secretary of PHEWA’s [Presbyterian Health Network \(PHN\)](#). She can be reached at: [jfriend@pobox.com](mailto:jfriend@pobox.com)*

# Facets of Aging and Disability: A Vision for Community, Dignity, and Wellbeing

Milton Tyree

*To everything - turn, turn, turn  
There is a season - turn, turn, turn  
And a time for every purpose under heaven*

It was 1965. And thanks to the Byrds, a generation of Americans had Pete Seeger's tune stuck in their heads. And it wasn't just the tune. Whether or not the singing-along millions had ever peeled back the cover of a King James, they nonetheless could nail every word of Pete's rendition of Ecclesiastes 3:1-8. Well... even if not the entire song, any teenage pop fan worthy of his or her bell-bottoms and granny glasses could sing the chorus with conviction, ***"To everything, there is a season, and a time for every purpose under heaven"*** – appropriately inserting the requisite turn, turn, turns.

It's that pesky verse ***"and a time to every purpose under heaven"*** that causes so much grief nowadays. Aging just isn't cool anymore. Youth. Newness. Quickness. Independence. Self. These are the operational values of today's society. All too often, expectations are very low for leading a full and meaningful life in later years. Of course, it's not always been this way. Not long ago, elders were admired, their wisdom and experience valued, and the natural slowing down in life was anticipated.

In this article we're exploring positive possibilities for people with disabilities who are aging along with their parents, who are sometimes referred to as "aging caregivers." As with aging, our human construct of "disability" threatens the illusion of independence. It's often translated as a burden instead of a natural part of life. So adding "disability" to the aging equation intensifies the prejudice. Because even if social devaluation of elders is a phenomenon of modern times, devaluation of people with disabilities has been a part of societies before Jesus' days on earth and ever since.

The questions are many and weighty: What are ways of leveling the playing field for people at risk of social devaluation because of disability and/or aging? What will happen to my son or daughter after I'm gone? Where is safety to be found? The following introductory ideas are offered for consideration:

***Avoid "special"*** – Special groups, special classes, anything that begins with the adjective "special" when it relates to grouping people requires careful analysis. Despite the best of intentions and possible benefits, the risks are significant. When a socially devalued characteristic, in this instance aging and/or disability, becomes the qualifying characteristic for group membership, then it reinforces ideas like "those people" are all alike; "they" need the same things, and "they" belong together. The wounding intensifies until the devalued conditions that landed a person in the special group begin to define his or her identity and life. (Hearing about "the man who has Down syndrome and dementia" doesn't tell us much about this person, his aspirations, interests, and gifts.) And by extension, people on the outside of the special group come to believe

themselves to be fundamentally different, with nothing to offer and nothing to gain through relationships with “them.” It doesn’t have to be this way.

**Seek what's typical, valued, and fitting for the person's interests and talents** -- Devote time to know people – one person at a time. Build a community where all are welcome, each participating in meaningful ways according to personal gifts. The apostle Paul's familiar advice to the Corinthians rings true, **“Now you are the body of Christ, and each one of you is a part of it.” (1 Corinthians 12:27)** Wellbeing is rooted in relationships with trustworthy people in open settings. This is one often-overlooked way to address a loved-one’s present and future safety and security. Unknown, unconnected, and stigmatized people are more vulnerable to exploitation or abuse than are known, connected, and respected people.

**Avoid competition** -- A world that thrives on hyper-competition can cause people to lose perspective about themselves, others, and life.

**Seek contribution** -- A colleague who's assisted many people with disabilities secure fulfilling jobs taught me to look for things people have to contribute and then match these ways of contribution with employer needs. The same principle applies to other roles in life. Avoid competition. Memory, mobility, vision may fade over time. Just because people can't do everything they once did doesn't mean they can't do elements of former roles. So, let the contribution begin!

**Avoid feeding the ageism stereotypes** – Disability and age carry stereotypes about what people can and can't do. And often they're centered on *can't*.

**Seek purpose and fullness** -- At a recent presentation about supported employment to a group that included job seekers with intellectual disabilities, “Carolyn,” a 70-year-old woman who's never been employed was adamant about needing a job, her first job, at age 70. She's actively defying the idea that one who's never worked should seek a life of retirement. Go, Carolyn!

**Avoid doing it alone** – Many others have developed ways of pursuing lives centered in fullness -- not problem-free lives mind you, but lives lived well.

**Seek like-minded people and community and congregational responses** - A recently revised Mennonite publication, *“Supportive Care in the Congregation: Providing a Congregational Network of Care for Persons with Significant Disabilities,”* describes Supportive Care Groups, a radical approach of support for the entire family (<http://store.mpn.net/productdetails.cfm?PC=1752>). It also provides introductory information about managing resources and planning for the future using “special needs trusts” and “pooled trusts.” A companion book through MennoMedia, *“After We're Gone,”* provides additional information on wills, trusts, and guardianship. Easter Seals and the National Endowment for Financial Education developed an informational and planning document, *“With Open Arms,”* available for free download ([http://www.easterseals.com/site/PageServer?pagename=ntl\\_with\\_open\\_arms](http://www.easterseals.com/site/PageServer?pagename=ntl_with_open_arms)). The Aging in Place movement provides alternative ways of thinking about and responding to the impact of aging. Here's one web site as a way of introduction: <http://www.ageinplace.org/>

Build lives of belonging, understanding, and mutuality. The benefits are many for each person, for our communities, and for society. ***And a time for every purpose under heaven.***

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*Note: This brief article relies on a variety of ideas, insights, and theories related to social integration and belonging -- none of which originated with the author.*

**Milton Tyree serves as [PC\(USA\) Disability Concerns Consultant](#) in areas of Intellectual & Developmental Disabilities. He can be reached at: [PDcmtyree@me.com](mailto:PDcmtyree@me.com)**

*A Variety of Gifts:  
Inclusion of People with Disabilities as We Age*



Painted by Dr. Dale Propson

**Selected Annotated Resource List**

*Dr. Dale Propson, Artist*

*After being hit by a drunk driver over nineteen years ago, Dale suffered a traumatic brain injury and lost most of his eyesight. A former pediatric dentist, Dr. Dale enjoys making art with a variety of mediums including clay, pastels, fiber and paint. He and his wife, Annie, are founders of Paint a Miracle Studio in Rochester Hills, Michigan.*

<http://www.paintamiracle.org/story.html>

## SELECTED ANNOTATED RESOURCES

### Books

Unless otherwise noted, books are available through [www.amazon.com](http://www.amazon.com)

***Amazing Gifts: Stories of Faith, Disability, and Inclusion*** by Mark I. Pinsky, The Alban Institute: 2011  
A compilation of 64 amazing, real-life stories of people with disabilities, their family members, and their congregations. This book should be read cover to cover—even the forward and the introduction!

***The Disabled God: Toward a Liberatory Theology of Disability*** by Nancy L. Eiesland, Abingdon Press: 1994  
Nancy Eiesland offers a new social-intellectual framework for re-conceiving physical disabilities and explores its implications for Christian theology.

***Being Well When We're Ill - Wholeness and Hope in Spite of Infirmary*** by Marva J. Dawn, Augsburg Books: 2008, Minneapolis, MN.  
The author has multiple infirmities and explores the impact of disability and chronic illness from a faith and practical perspective. Many prayers and scripture passages are woven into text. It is a book worth owning and rereading.

***Losses in Later Life - A New Way of Walking with God*** by R. Scott Sullender, Haworth Pastoral Press: 1999, Binghamton, NY.  
A Presbyterian minister, licensed psychologist, and on the Pastoral Care/Pastoral Counseling Faculty of San Francisco Theological Seminary, the author focuses on seven major losses: loss of youth, loss of family, loss of parents, loss of work, loss of spouse, loss of health, and loss of identity. This timeless book helps to deal with grieving losses in a positive way to become a more spiritually mature individual and live a mentally healthy and rewarding life.

***Another Country - Navigating the Emotional Terrain of Our Elders*** by Mary Pipher, Riverhead Books: 2000, New York, New York.  
With the increase of an aging population in America, there is a disconnect between the younger and older generations. This author likens aging to living in a foreign country but gives insight and strategies that help bridge the gap. "And with her inimitable combination of respect and realism, she offers us new ways of supporting each other--new ways of sharing our time, our energy, and our love."

***10 Gospel Promises for Later Life*** by Jane Marie Thibault, Upper Room Books: 2004, Nashville, TN.  
Many older adults experience a spiritual crisis as they face what seems to be ongoing diminishment. This author, a clinical gerontologist and spiritual director, helps readers identify their fears and make the most of God's gift of longer life.

***Aging: God's Challenge to Church & Synagogue*** by Richard H. Gentzler, Jr. and Donald F. Clingan, Discipleship Resources: 2003, Nashville, TN.  
These authors help congregations provide needed ministry and enable older persons to utilize their many gifts. Richard H. Gentzler, Jr., D. Min. is the director of the center of Aging and Older Adult Ministries for the General Board of Discipleship of The United Methodist Church. The late Rev. Dr. Donald F. Clingan, an ordained minister of the Christian Church (Disciples of Christ) served as the founding president and first executive director of the National Interfaith Coalition on Aging.

***The Gift of Years: Growing Older Gracefully*** by Joan Chittister, Blubridge: 2008.  
In these topical essays on aging, Joan Chittister describes her life as a "series of new beginnings" as she explores the spiritual dimensions and wisdom that come with age.

***Dare to Care-Caring for Our Elders*** by Cheryl Carmichael, iUniverse Publishing: 2011.  
Dare to Care-Caring for our elders is a basic cookbook for new or existing adult non-professional caregivers. It is easy to read and useful as a handy reference.

***My Parents My Children: Spiritual Help for Caregivers*** by Cecil Murphey, Westminster John Knox Press: 2000, Louisville, KY. Available from amazon.com or from:

<http://www.thethoughtfulchristian.com/Products/0664222463/my-parents-my-children.aspx>

“Cecil Murphey provides reflections from his counseling experience to illuminate the challenges facing those who respond to the physical and emotional needs of both young children and aging parents. Each devotional begins with a description of a difficult or trying moment common to caregivers and ends with a prayer and a biblical reading.”

***Caring for Mother, A Daughter's Long Good-bye*** by Virginia Stem Owens, Westminster John Knox Press: 2007, Louisville, KY. Available from amazon.com or from:

<http://www.thethoughtfulchristian.com/Products/0664231527/caring-for-mother.aspx>

“Virginia Stem Owens gives a clear and realistic account of caring for an elderly loved one. Along the way, Owens notes the spiritual challenges she encountered, not the least of which included fear of her own suffering and death. This book will be a helpful companion to those who have recently assumed the role of caregiver, helping them anticipate some of the emotional turbulence they will encounter along the way.”

***Journeywell: A Guide to Quality Aging*** by Trish Herbert, Tascora Books: 2009, Minneapolis, MN. ISBN: 978-1-934690-52-9

This powerful, graceful and honest book shows practical paths to choices and surprises to quality aging. It provides a new perspective, valuable insights, tools, and a realistic optimism to enable one to make the most of the rest of their life. This planning guide is helpful to anyone on the road to old age or caring for an older person.

***Supportive Care in the Congregation: Providing a Congregational Network of Care for Persons with Significant Disabilities*** by Dean A. Preheim-Bartel, Aldred H. Neufeldt, Paul D. Leichty, Christine J. Guth; Herald Press: 2011.

This 100 page book describes Supportive Care Groups, a radical approach of support for the entire family. It also provides introductory information about managing resources and planning for the future using "special needs trusts" and "pooled trusts."

<http://store.mpn.net/productdetails.cfm?PC=1752>

***After We're Gone; A Christian perspective on estate and life planning for families that include a dependent member with a disability***, by Duane Ruth-Heffelbower, Herald Press: 2011. A companion book also available through MennoMedia, provides additional information on wills, trusts, and guardianship. After We're Gone is available from Herald Press by calling 1-800-245-7894 (U.S.A.). Price: \$8.99 USD. Also available from amazon.com

## Magazine

### ***The Grace of Aging***

Horizons: The Magazine of Presbyterian Women - November/December 2011

Several articles relating to aging as a woman of God.

<http://horizons.pcusa.org/magazines/2011/hrznspot11/aboutspot11.htm>

## PC(USA) Resources

***Offering Our Gifts.*** <http://apps.pcusa.org/ga219/home/offering-our-gifts/player.html>

PHEWA/Presbyterian Disability Concerns (2010). This PowerPoint download presentation, with pictures and audio, features the personal experiences of persons with disabilities, “Access Your Heart” by poet Sarah Nettleton, and “Beatitudes for an Inclusive Church” by Bebe Baldwin. The resource celebrates the valuable gifts people with disabilities bring to the Body of Christ and offers practical suggestions for including people with disabilities in the church’s life. This PDF Download was originally developed by the PDC Leadership Team for orientation of commissioners to the 219th General Assembly (2010). It is appropriate and recommended for all church gatherings.

**Congregational Audit of Disability Accessibility, and Inclusion.** <http://www.pcusa.org/phewa/pdc>

A comprehensive guide to help congregations discover how welcoming they are to people of all ages and abilities. The audit includes access to all areas of church life, including leadership.

**Living Into the Body of Christ; Towards Full Inclusion of People with Disabilities**

<http://www.pcusa.org/resource/living-body-christ/>

Comprehensive policy statement approved by the 217<sup>th</sup> General Assembly (2006) of the Presbyterian Church (U.S.A.); includes a study guide.

**Life Abundant: Values, Choices and Health Care — The Responsibility and Role of the Presbyterian Church (U.S.A.)**

<http://www.pcusa.org/resource/life-abundant-values-choices-and-health-care/>

“The 200th General Assembly (1988) adopted this revolutionary and far-reaching policy statement.” In pdf form, feel free to print out the sections useful to you from the PC(USA) website link.

## **Online Articles**

**Including Every Member of the Body; Welcoming God’s Children of All Abilities**

<http://www.scribd.com/doc/71335540/InPrint-November-2011>

A publication of the Presbytery of the Twin Cities Area. This issue features personal stories of people with a variety of abilities and how they participate with their congregations. The “Beatitudes for an Inclusive Church” are very insightful.

**Compound Caregivers: Overlooked and Overburdened** Florida Center for Inclusive Communities-University of South Florida [http://flfcic.fmhi.usf.edu/docs/FCIC\\_compoundcaregivers\\_070811.pdf](http://flfcic.fmhi.usf.edu/docs/FCIC_compoundcaregivers_070811.pdf)

A white paper by Elizabeth A. Perkins, PhD, RNMH, July 2011, exploring the “sandwich generation.” Often caregivers of a child with intellectual disabilities find they become caregiver for a parent, also.

**Aging in Community** New York State’s Office for People with Developmental Disabilities and New York State Office for the Aging

[http://www.opwdd.ny.gov/opwdd\\_community\\_connections/aging\\_information\\_corner/documents/brochures\\_agingincommunity](http://www.opwdd.ny.gov/opwdd_community_connections/aging_information_corner/documents/brochures_agingincommunity)

PDF document (29 pages) about helping people with developmental disabilities age with dignity through fostering relationships, having good health, and living in the home of their choice. DVD is also available:

[http://www.opwdd.ny.gov/opwdd\\_community\\_connections/aging\\_information\\_corner/aging\\_in\\_community](http://www.opwdd.ny.gov/opwdd_community_connections/aging_information_corner/aging_in_community)

**Caring in America: A Comprehensive Analysis of the Nation’s Fastest Growing Jobs: Home Health and Personal Care Aides**

Direct Care Clearing House <http://www.directcareclearinghouse.org/download/caringinamerica-20111212.pdf>

This PHI publication reports the most up-to-date data and research evidence on the state of the direct support workforce in America today. Topics include service delivery systems, training, job hazards, workforce compensation, hours worked, workforce instability and labor shortages, and the status of wage and hour protection. While this is a lengthy document at 126 pages, the later portion provides details on a state-by-state basis, which may be helpful to those looking to hire personal care aides.

**Medicaid’s Role for Women Across the Lifespan** Kaiser Family Foundation

<http://www.kff.org/womenshealth/upload/7213-03.pdf>

A Kaiser Family Foundation Issue Brief, January 2012, discusses the role of Medicaid for women and examines how changes under the health reform law will affect the program and women covered by Medicaid. The Brief explores Medicaid’s role for women across their lifespans including reproductive health services, care for chronic conditions and disabilities, and long-term care services. And it provides new state-level data on enrollment and coverage policies on services of importance to women.

### ***National Plan on Dementia and Adults with Intellectual Disabilities***

American Academy of Developmental Medicine and Dentistry <http://aadmd.org/ntg/thinker>

The National Task Group on Intellectual Disabilities and Dementia Practices has issued a plan for improving the community care of adults with intellectual disabilities affected by dementia. The Group's report, "***My Thinker's Not Working; A National Strategy for Enabling Adults with Intellectual Disabilities Affected by Dementia to Remain in Their Community and Receive Quality Supports,***" summarizes and addresses some of the challenges facing the nation due to the increasing rate of dementia found in older people with intellectual disabilities. A free download of the report is available from the link.

### ***With Open Arms; Embracing a Bright Financial Future for You and Your Child***

[http://www.easterseals.com/site/PageServer?pagename=ntl\\_with\\_open\\_arms](http://www.easterseals.com/site/PageServer?pagename=ntl_with_open_arms)

"Easter Seals and the National Endowment for Financial Education have collaborated to create a 72-page financial planning booklet for parents, caregivers, grandparents, or others involved in the care of a child with disabilities; free download at web link.

## **Agencies and Organizations**

### **University of Rochester Program in Aging and Developmental Disabilities**

<http://www.urmc.rochester.edu/childrens-hospital/developmental-disabilities/PADD/>

The University of Rochester, through the Strong Center for Developmental Disabilities, has an extensive Program on Aging and Developmental Disabilities, including knowledgeable staff, education opportunities, environmental assessments and assistance in identifying interventions.

### **The Aging in Place Movement**

<http://www.ageinplace.org/>

The Aging in Place movement provides alternative ways of thinking about and responding to the impact of aging. This is one of many websites that provide resources, collaboration, and a network of support.

### **National Center on Elder Abuse**

[http://www.ncea.aoa.gov/ncearoot/Main\\_Site/index.aspx](http://www.ncea.aoa.gov/ncearoot/Main_Site/index.aspx)

The National Center on Elder Abuse, directed by the U.S. Administration on Aging, is committed to helping national, state, and local partners in the field be fully prepared to ensure older Americans will live with dignity, integrity, independence, and without abuse, neglect or exploitation. The NCEA is a resource for policy matters, social service and healthcare practitioners, the justice system, researchers and advocates.

### **Alzheimer's Foundation of America** <http://www.alzfdn.org/>

Provides optimal care and services to individuals confronting dementia, and to their caregivers and families. They have many resources available to caregivers and other organizations helping families: books, videos, grants...

### **AARP**

Resources, caregiver workshops, information. Free Caregiver Resource Kit

[http://www.aarp.org/relationships/caregiving/info-02-2010/resources\\_available\\_to\\_help.html](http://www.aarp.org/relationships/caregiving/info-02-2010/resources_available_to_help.html)

Resources Available to Help Juggle Work, Life and Caregiving; free Caregiver Resource Kit (# D15267) available by phoning: 1-800-424-3410 or at: <http://www.aarp.org/relationships/caregiving/info-04-2010/prepare-to-care.html>

### **Easter Seals Project Action** (Transportation Information/Assistance) <http://www.projectaction.org/>

Promotes access to transportation for people with disabilities, answers questions about ADA rights and responsibilities, offers two free newsletters, and directs persons to additional resources and more.

**Presbyterian Health, Education & Welfare Association (PHEWA)**

<http://gamc.pcusa.org/ministries/phewa/>

**Presbyterians for Disability Concerns (PDC)** is one of ten grassroots volunteer ministry networks of PHEWA.

PHEWA is a community of ministries providing resources, peer support, and networking connections for Presbyterians involved in social welfare and justice ministries. PHEWA has also worked, since its creation by General Assembly action in 1956, to make the church more responsive to the needs of those too often excluded or on the margins of the church and of society. PHEWA provides a forum where these persons can make their voices heard, offering perspectives that enrich the church.

Volunteer ministry specialists, through the national networks of PHEWA provide assistance in developing strategies for effective responses to a wide variety of needs encountered in the practice of ministry, both in the congregation and in the surrounding community. Stay connected, and help to keep these ministries strong, through membership in PHEWA and any/all of the PHEWA Networks: [http://www.phewacommunity.org/images/PHEWA\\_membership\\_form.pdf](http://www.phewacommunity.org/images/PHEWA_membership_form.pdf)

The Rev. Trina Zelle serves as National Organizer and Executive Director of PHEWA. Trina spends a lot of time out in the field and in communication with congregations who either have or hope to have active ministries in the areas addressed by PHEWA Networks; as well as with presbyteries and synods (mid-councils). She helps folks make connections and gather resources that are useful and that reflect the policies of the PC(USA). She can be reached at (602) 796-7477 or at: [trinazelle6@gmail.com](mailto:trinazelle6@gmail.com)

Trina also manages PHEWA's independent resource website: <http://www.phewacommunity.org/>

*Carol Brown, in cooperation with other members of Presbyterians for Disability Concerns (PDC), has compiled this list of selected annotated resources.*