

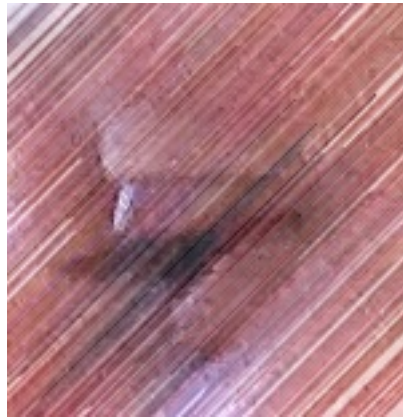


**Presbyterian Health Network**

A Network of the Presbyterian Health, Education & Welfare Association (PHEWA)

## **Caregiver Sunday 2014**

### **In the Blink of an Eye: Preparing for the Unexpected**



**“Life can change in the blink of an eye;  
but God never blinks.”**

**A Resource from the  
Presbyterian Health Network (PHN)  
A Network of the  
Presbyterian Health, Education and Welfare Association  
(PHEWA)**

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## **“In the Blink of An Eye” Caregiving As An Unexpected Role**

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## **“In the Blink of an Eye” Caregiver Sunday Introduction**

On that beautiful Hawaiian morning last May, I woke up unaware that I’d never spend a night in that house again. The phone call summoning us to our son’s hospital bedside came in late afternoon. My husband and I flew out that same evening. Two months later I returned, accompanied by our now-recovering adult son, to a new, half-moved-into home and a new life.

It’s not as if any of us gets much warning for most of the major occurrences that change our lives, but to become a caregiver as the result of an unexpected event is a unique experience. It requires that we negotiate a rapid self-identity shift while we are still responding to the crisis and absorbing its practical implications.

Eventually, things do settle down – sort of. A recovery trajectory emerges along with the routines of recovery. But during those early days, before things start to settle down, while the jury is still out on the diagnosis, a special kind of support is needed – support that combines encouragement, practicality, and humor.

There are a lot of resources out there that address long term caregiving but very little to help people through those early days of shock and disorientation. It is our hope that what we present here will encourage the development of even more resources, based on your own experiences.

Rev. Trina Zelle  
Executive Director/National Organizer  
PHEWA



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## Life can change in the Blink of an Eye but God never blinks . . .

A phone call in the middle of the night; a frightening diagnosis; a sudden fall: all of these and more can change your life and the lives of your family forever. With no preparation, you find yourself thrust into the role of caregiver – nothing you had ever seen yourself doing.

However, as former First Lady Rosalyn Carter has said, 'There are only four kinds of people in the world - those who have been caregivers, those who currently are caregivers, those who will be caregivers, and those who will need caregivers.'

### When you become a caregiver you might find yourself feeling:

- **Gratitude** for your loved one's survival.
- **Fear** of what the future will look like, both for your loved one and for you.
- **Resentment** due to the abrupt change in your own life plans, accompanied by guilt for having those feelings.
- **Exhaustion** from trying to maintain your old lifestyle, including work, while adding all of the activities associated with caring for your loved one (doctor's appointments, rehab therapy, etc.).
- **Overwhelmed** by trying to juggle it all.

## What congregations can do:

### As an immediate response to a specific crisis:

- Be there for individuals and families in crisis: initially this could include meals, transportation, care of minor children.
- As the situation resolves itself, provide respite care for caregivers.

### For the longer term:

- Stay in touch with the affected family in a systematic way; set up a volunteer schedule.
- Offer transportation to outpatient rehabilitation and doctors' appointments.
- Gather a list of local resources including support groups for caregivers. If there are no such groups, consider starting one.

### To institutionalize your congregational response in anticipation of future need:

- Create and maintain a list of volunteers;
- Develop volunteer trainings using the expertise of local and denominational professionals.
- Link your congregation's website to websites such as "Lotsa Helping Hands" ([www.lotsahelpinghands.com](http://www.lotsahelpinghands.com)) so that people can volunteer.
- Look into beginning a health ministry. You can find resources and people to talk to at our PHEWA/Presbyterian Health Network sites:  
[www.phewacommunity.org/phnhealthnetwork/congregationalresources.html](http://www.phewacommunity.org/phnhealthnetwork/congregationalresources.html)  
<http://www.pcusa.org/phewa/phn>
- Seek resources at the National Alliance for Caregiving: [www.caregiving.org/](http://www.caregiving.org/), the Family Caregiver Alliance, or the National Family Caregiver Support Program.
- If you are located near a major medical center, consider creating an emergency response team to assist out-of-town families in a crisis situation.



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## Do's and Don'ts for New Caregivers

### While the situation is still acute:

- **Do** take breaks and bring nutritious snacks from home. Intense focus on our loved one can lead to neglect our own physical needs. Hospital vending machines tend to be out of order with stale/unhealthy choices.
- **Do** be receptive to the offers of friends and colleagues of help. If they offer to bring food, or to relieve you for awhile, let them.
- **Do** avail yourself of hospital services including the Chaplain/Pastoral Care Department and the discharge caseworker. They will know what services are available including lodging/food and transportation.
- **Do** remember that you are the patient's advocate and often their only voice. Ask questions about everything; it's not necessary to be combative – usually – but make sure that you know the reasons why something is being done as well as alternatives.
- **Do** ask questions about insurance and finances, especially as it relates to discharge planning. Insurance varies in coverage and additional resources may be needed.
- **Don't** neglect your own spiritual health. If your usual disciplines feel empty, try practicing them differently – i.e. pray with your eyes open and/or while you're taking a walk.
- **Don't isolate.** Talk to someone who isn't intimately involved in the situation. It's OK to vent – in fact it's critical to your health.

### Post-hospitalization

- **Do** be patient – with yourself and with others, including your loved one; healing takes time.
- **Do** stay in the moment. It's easy to be overwhelmed at the prospect of ongoing care with no clear end date, but things often unfold in ways we don't anticipate.
- **Do** prepare your home before your loved one's discharge to make it safe and accessible for them and convenient for you. A faith community nurse (parish nurse) or occupational therapist can do a walk-through with you.
- **Don't isolate.** Again, it is easy to get caught up in the day-to-day tasks and after the initial flurry of support, people are less likely to contact you and pull you out of your routine. Don't wait to be called – reach out to others. Even a brief phone conversation with someone else can feel like a break.

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**Everyone is a potential caregiving recipient, even you!  
Here's what you can do to make things easier for the ones  
who will be caring for you:**

- **Carry a list** of medications and emergency contacts in your purse or wallet.
- **At any age**, but especially if you are a parent of young children, have a designated health care power agent and financial power of attorney along with the appropriate paperwork for your state. Make sure that you ask permission of the individuals you designate and give them copies of these documents along with your known wishes.
- **Utilize existing resources.** Local hospitals or health agencies may have a "File of Life" or "Vial of Life" to be placed on or in the refrigerator with useful information for emergency medical personnel if they are called.
- **If you live alone**, consider using a medical alert device which can be activated in the event of a sudden health event. At the very least, arrange with a neighbor or close friend to be in touch daily so that someone is aware that you need help.
- **Anyone in a hospital setting needs an advocate!** If family is not present, ask for the hospital chaplain or have someone call your church to see if your pastor, Faith Community Nurse (formerly known as Parish Nurse), or a deacon is available to be with you.
- **Keep a computerized or handwritten record** of your past medical history in the car and with you when you travel or where a family member or friend can obtain it. Continue to keep it updated after appointments and procedures.



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## **Scripture Passages for New Caregivers Advice for Preachers and Others**

As the “authoritative word of God,” we turn to scripture in many circumstances. Through “the inward persuasion of the Holy Spirit . . .” (Calvin) we find guidance and comfort. Especially, we seem to turn to scripture during those times when life’s uncontrollable mysteries confront us.

But referencing particular scripture passages in the context of offering support to someone else who is in the middle of a crisis can be a challenge. Passages that might comfort and empower at a later stage of someone’s journey into their “new normal,” could be received differently at the outset.

This is part of the challenge of creating a resource that is useful to people who suddenly find themselves in the role of caregiver. Well intentioned words of comfort, whether drawn from scripture or other sources, may not accomplish what was intended. Guilt, resentment or even an increase in a sense of isolation could result.

That doesn’t mean we shouldn’t try, but we do need to proceed carefully rather than automatically default to what we might consider to be obvious passages. This will be easier if we avoid stereotypical notions of who caregivers are, or what they might be thinking or experiencing.

Which is why the first few of these suggested scripture passages are not usually found as a caregiver resource. More traditional passages are further down the page, along with the suggestion that their words might be as applicable to the caregiver’s community as to the caregiver him or herself.

### **For caregivers in the early days:**

To become a caregiver suddenly, means that there has been a traumatic life event that has altered the future for everyone concerned, especially the person being cared for. Whether the context is a sermon, a special worship service, or a pastoral visit, that loss needs to be acknowledged

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and a space created for mourning and reflection. Scripture is full of instances where God's most faithful cry out, asking why and calling for relief.

Psalm 13:1,2:

How long, O Lord? Will you forget me for ever?  
How long will you hide your face from me?  
How long must I bear pain in my soul,  
and have sorrow in my heart all day long?

Psalm 22:1,2,19-21:

My God, my God, why have you forsaken me?  
Why are you so far from helping me, from the words of my  
groaning?  
O my God, I cry by day, but you do not answer  
and by night, but find no rest  
O Lord, do not be far away!/O my help, come quickly to  
my aid! Deliver my soul from the sword  
my life from the power of the dog!  
Save me from the mouth of the lion!

Psalm 42:1-3,5,6:

As a deer longs for flowing streams,  
so my soul longs for you, O God.  
My soul thirsts for God, for the living God.  
When shall I come and behold  
the face of God?  
My tears have been my food day and night,  
while people say to me continually,  
'Where is your God?'

**Traditional Caregiver Passages (and for those who care for the caregivers):**

The following passages offer comfort and encouragement to anyone who receives them, but they are especially important for those who find

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themselves on the third or fourth ring of care. The inner ring is, of course, the caregiver or caregivers and the person being cared for. The second ring would be family and perhaps a couple of close friends. The third ring is comprised of people who are friends whose lives intersect frequently but not every day. The fourth and fifth rings represent diminishing levels of connection, but that does not mean that scripture doesn't have something to teach.

Philippians 2:4:

Let each of you look not only to your own interest, but also to the interests of others.

John 13:34-35:

A new commandment I give to you, that you love one another: just as I have loved you, you also are to love one another. By this all people will know that you are my disciples, if you have love for one another.

1 John 3:18:

Little children, let us not love in word or talk but in deed and in truth.

Galatians 6:2:

Bear one another's burdens, and so fulfill the law of Christ.

James 2:14-17:

What good is it if someone says that they have faith but does not have works? Can that faith save him? If a brother or sister is poorly clothed and lacking in daily food, and one of you says to them, "Go in peace, be warmed and filled," without giving them the things needed for the body, what good is that? So also faith by itself, if it does not have works, is dead.

1 John 3:17:

But if anyone has the world's goods and sees their brother or sister in need, yet closes their heart against them, how does God's love abide in that one?

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## **“In the Blink of an Eye” Worship Suggestions for Caregiver Sunday**

### **Call to Worship** (From Psalms 42 and 43)

God is our refuge and strength  
A very present help in trouble.

**Therefore we will not fear, though the earth be moved,  
And though the mountains be toppled into the depths of the sea.**

Why are you so full of heaviness, O my soul?  
And why are you so disquieted within me?

**Send out your light and your truth, O God, that they may lead us,  
and bring us to your holy hill and to your dwelling.**

**Let us worship God.**

### **Prayer of Confession:**

God of healing and hope, we come before you today with full hearts and not a little anxiety. We know that you made a good creation and desire only good for your creatures. But we are a fallen people who let fear diminish our faith. Forgive us. Help us, we pray, in our current circumstances. Open our eyes to your presence and our minds to your wisdom. Protect us from despair and doubt; help us step forward in confidence and courage. We pray in the name of our Great Physician, even Jesus Christ. Amen.

### **Suggested Scripture Readings:**

- Psalm 22
- Psalm 23
- Psalm 42
- Psalm 43
- Revelation 7:9-17
- Hebrews 11:1-3

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### **Suggested Scripture Readings:**

- Matthew 5:1-12

### **Sermon Topics:**

The challenge for the preacher on "Caregiver Sunday" is one of scope. "Sudden caregivers" need acknowledgement of their current situation as well as reassurance and comfort; the congregation at large needs to understand their own call to stand with a brother or sister in need; everyone needs to identify sources of hope and healing.

### **\*Benediction**

The peace of God,  
Which passes all understanding,  
Keep your hearts and minds  
In the knowledge and love of God  
And of God's Son, Jesus Christ our Lord;  
And the blessing of God almighty, the Father, the Son, and the Holy Spirit,  
Remain with you always.

### **Alleluia! Amen!**

### **\*Suggested Hymns**

#### **Sermon Hymns:**

- "We Cannot Measure How You Heal" #797
- "As Pants the Deer for Living Streams" #778
- "O Christ the Healer" #793
- "We Come to You For Healing Lord" #796
- "When We Must Bear Persistent Pain" #807

#### **Closing Hymns**

- "Will You Let Me Be Your Servant" #727
- "Called As Partners In Christ's Service" #761
- "Abide With Me" #836

**\*Benediction and hymns can be found in "Glory to God: The Presbyterian Hymnal."** (2013, Westminster John Knox Press)

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