

**NATIONAL
FAMILY CAREGIVERS
MONTH**
November 2013



Family Caregivers - Now More Than Ever!

CAREGIVER
ACTION
NETWORK

CAN

Caregiver Action Network promotes **resourcefulness** and **respect** for the more than **90 million** family caregivers across the country.

CAN Connects Caregivers with

- ✓ Valuable Resources
- ✓ Advice from Caregiver Voices
- ✓ Peer Support
- ✓ Caregiving Information
- ✓ Educational Webinars

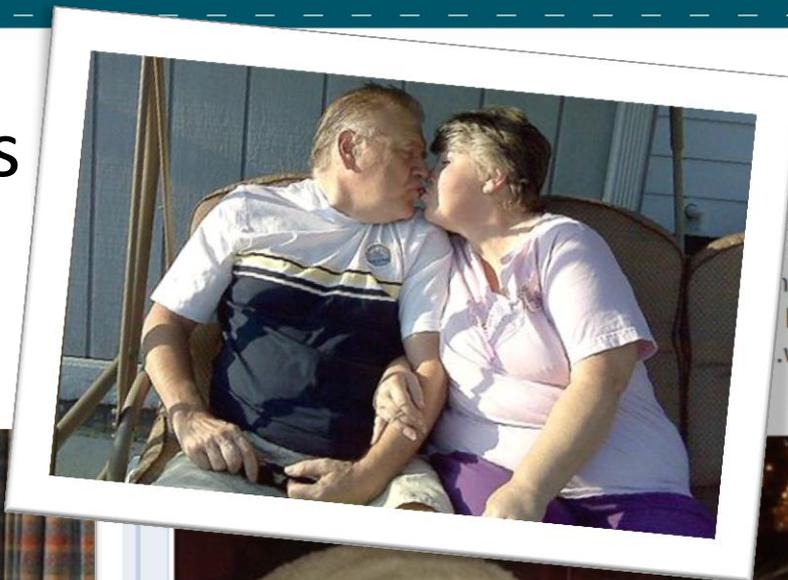
At [CaregiverAction.org](https://www.CaregiverAction.org) you can find tools to:

- ✓ Stay strong
- ✓ Ask for help
- ✓ Stay organized
- ✓ Balance demands with limits

Everyday, practical ideas from

✓ Family Caregivers

- Gloria
- Dave



and stemming
her caregiver
.we also take

Photos from www.facebook.com/CaregiverActionNetwork

Advice and resources from



Caregiving Professionals

- Kathleen Coolidge from Genzyme
- Lisa Winstel from Caregiver Action Network

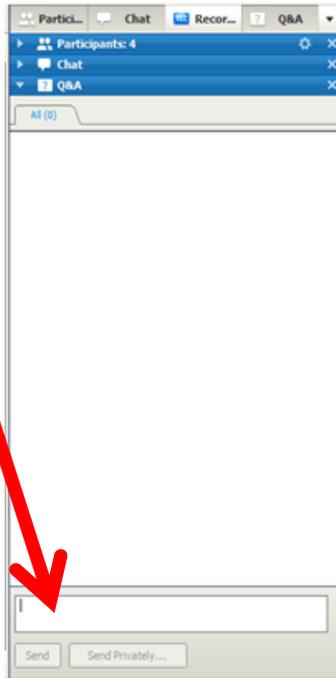


Photos from www.facebook.com/CaregiverActionNetwork

Questions from

✓ You!

Through the Q&A feature, please direct your questions to the Global Genes representative (or Host), Katie Mastro.



Why I do what I do....



Taking Care Of Yourself 101

***Two important lessons I have learned
being a primary caregiver:***



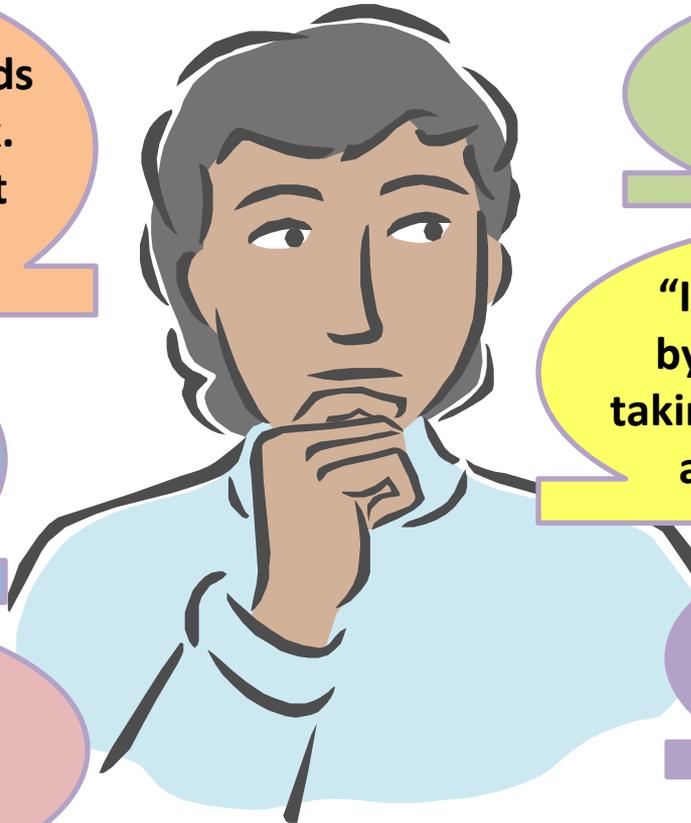
Time Management
&
Prioritizing My Needs
(without guilt)

Why Am I Last On The List?

“My child’s needs are so complex. Only I can do it all.”

“What if I am not there for an emergency?”

“As a primary caregiver, there is nobody else.”



“I can’t find time for myself.”

“I’m overwhelmed by the juggling act, taking care of everyone and everything.”

“There’s just no energy left for me.”

Sound familiar?

When I Found Time For My Needs:

- Improved health and energy
- Improved focus and sense of direction
- A new-found level of trust
- Increased involvement and independence skills for the rest of the family
- Happier me...Happier family



How Did I Learn to Take Care of Myself?

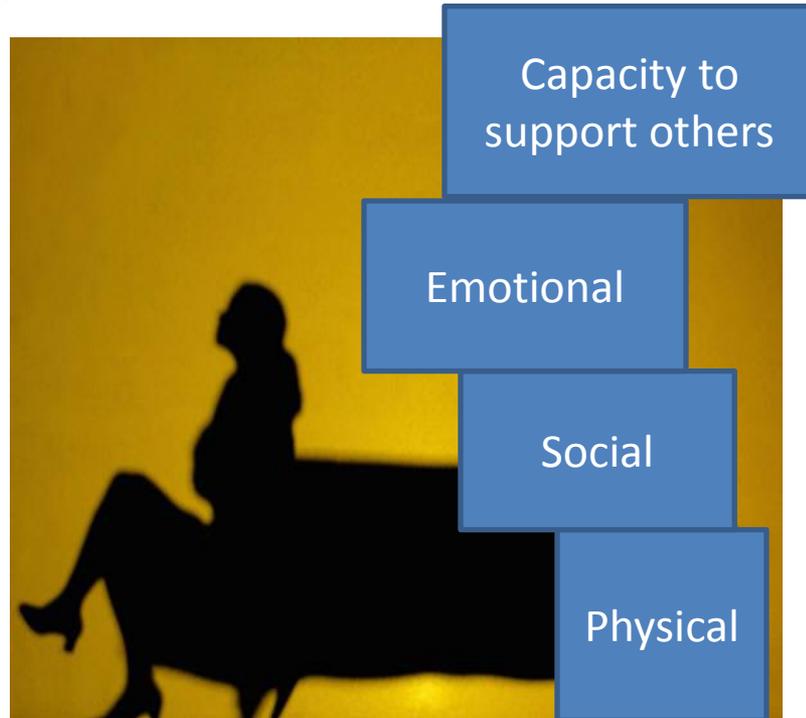
- 1. I realized my needs are important.**
- 2. I figured out what interests and activities were most important to me.**
- 3. I tackled my to-do list.**
- 4. I created a family calendar!**

Setting Up a Calendar:



Fitting This Dream Into Your Life

What might happen if you do NOT address your own personal needs?



What might happen if you get “selfish” and follow your heart, in finding time for yourself?

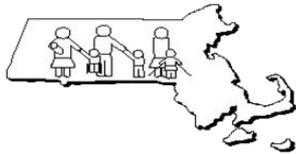


Just One More Thought

- You know how good it feels to help others?
- Give others the opportunity to help you.
 - Develop a list of activities that others can do, to support your family
 - Learn to ask for help, a true sign of strength
 - Acknowledge your appreciation for the support and assistance of others (including your family at home)



FAMILY TIES of Massachusetts



Gloria Klaesges
Statewide Parent to Parent Coordinator
Family TIES of Massachusetts

gloria@fcsn.org
www.massfamilyties.org



FEDERATION FOR CHILDREN
WITH SPECIAL NEEDS





Carol Milam & husband Dave Late Adult Onset POMPE

Carol's Late Onset POMPE Disease

Muscular Dystrophy Glycogen Storage Disorder

- Diagnosed at age 62; now 69
- Began enzyme replacement therapy ERT 5 yrs ago, now every 2 weeks— for life
- Less severe than most

MOBILITY, STRENGTH, **ENERGY**, SWALLOWING,
FALLS & UNKNOWN PROGRESSION

Gratefulness and Hope are Essential



RARE DISEASE Caregiving Begins



- UNEXPECTEDLY, in a FOREIGN LAND & CONSEQUENTIAL
- Through the journey, KAOS comes:
 - ✓ knowledge
 - ✓ attitude
 - ✓ opportunities
 - ✓ skills

AFTER 5 Years of Caregiving

- I asked respected friends “Tell me about caregiving?”
- **TAKE CARE OF YOURSELF**
 - Physically
 - Interests
 - Friends
 - Energy
- **TOUGH LOVE and BOUNDARIES**



Takeaways from Genzyme's Patient Advisory Board

- Comprised of dedicated Caregiver Advocates
- Focused on their care receiver—not themselves



When the Mother Bears were asked:

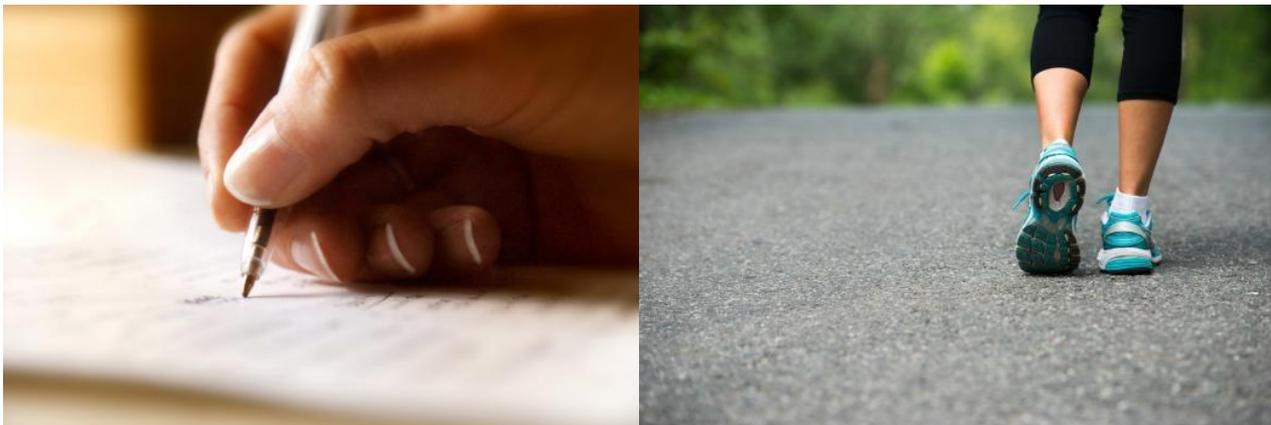
- “Where do you get your energy?”
- You could hear a pin drop! & FEEL IT



It was difficult for the Caregiver Advisory Board members to think of themselves!

Reflection...Is Valuable

- *Find a way that's best for you to reflect*



Sharing Reflections is Valuable Too

IMAGINE

*Being heard
Hearing from*

ME to We- & Me

GROWTH

A Flashback on Prior Reflections

- In the beginning as new difficulties arise, and again and again, it is difficult to share
- A story from the beginning of my cancer journey



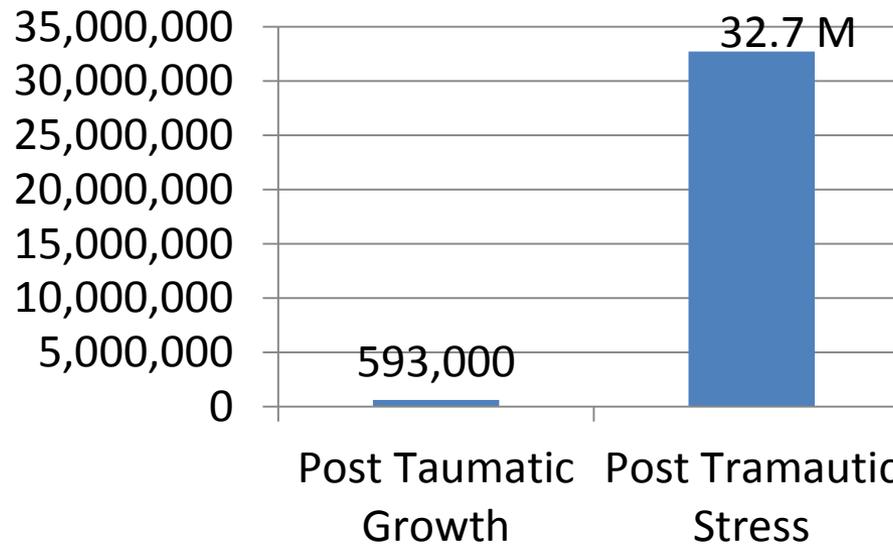
Begin: In the dark, in headlights...



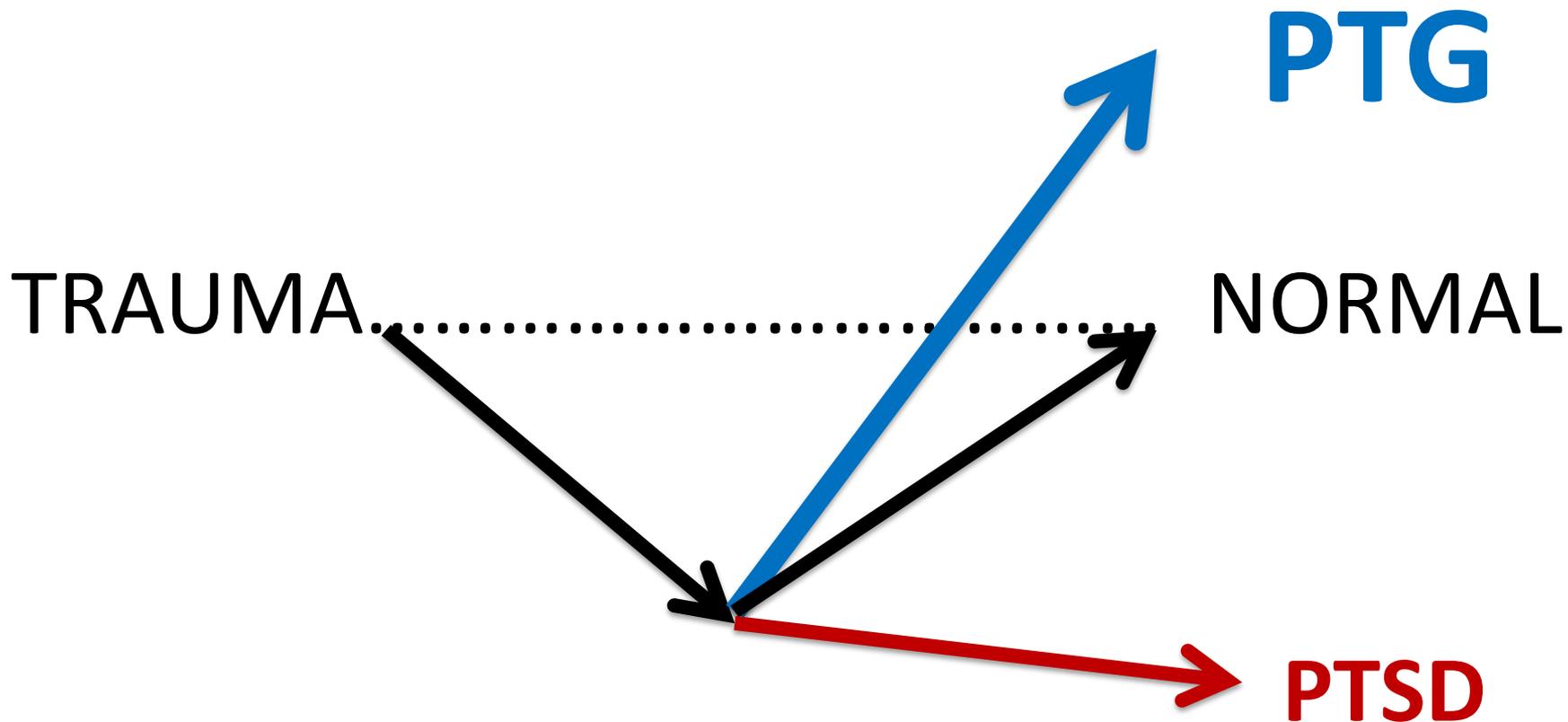
- After 3 years of being in the dark, we received a diagnosis.
- It was Pompe, and for a time, we felt like deer in headlights.
- Years later, she said, “I knew then I had to be strong!”

Don't Despise Small Beginnings

- Resilience and Post Traumatic Growth are emerging priorities in psychology.
- Although Post Traumatic Stress has 55 times more Google references

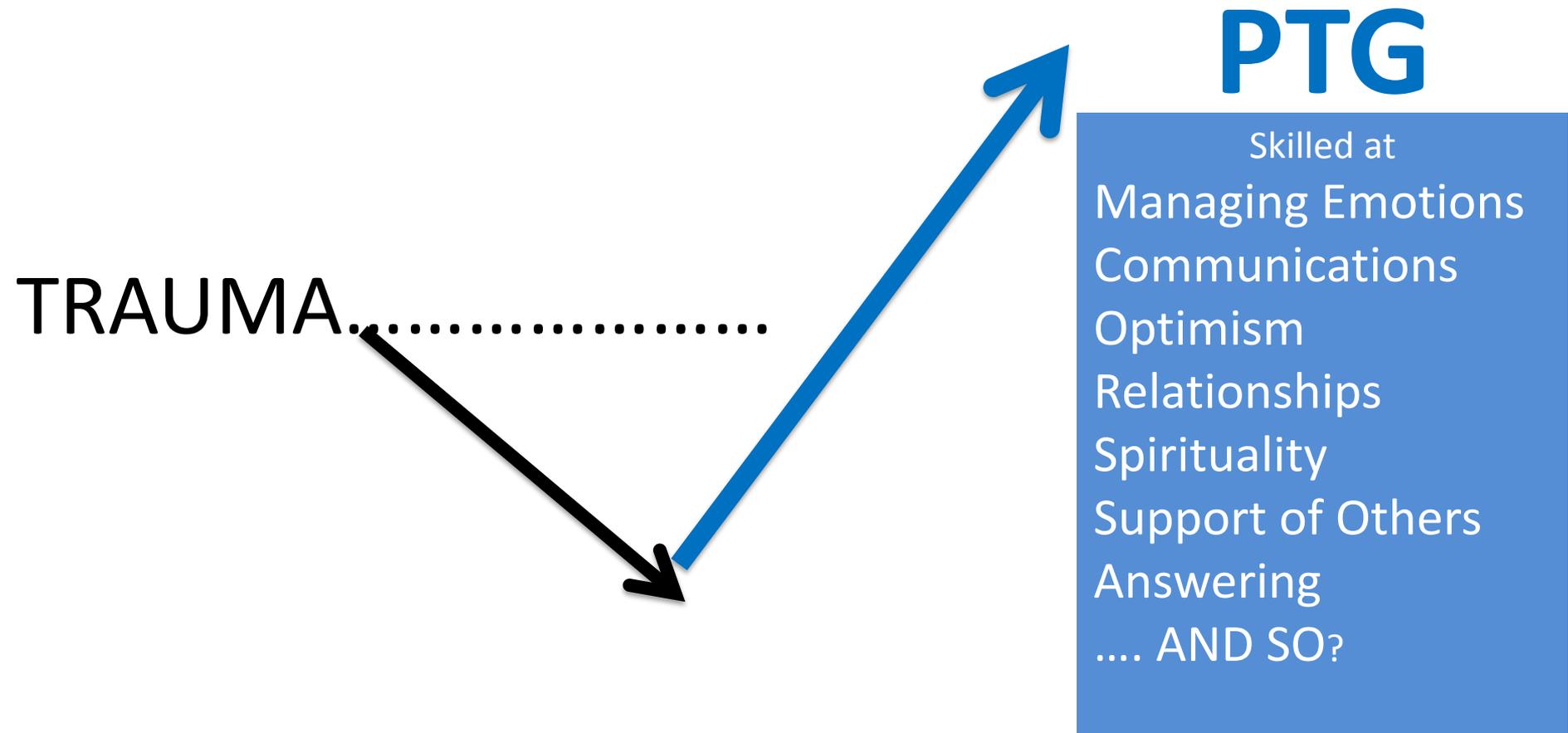


POST TRAUMATIC GROWTH



ME → WE - & ME

POST TRAUMATIC GROWTH - TOGETHER



And So? Knowledge, Attitude, Opportunity, Skill



Live Life Full, Moments at a Time



In Closing— “Be good to yourself and yours”



Connect if you like dave.milam@yahoo.com



Rare Disease Caregiver Support & Resources:
Taking Care of Yourself While Taking Care of Your Loved Ones
Global Genes/Rare Project | Kathleen Coolidge, LICSW, Genzyme, a Sanofi company

November 21, 2013

Martha, Caregiver - USA

www.genzyme.com |

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Disclaimers

- I am an employee of Genzyme
- Genzyme provides financial support to the Caregiver Action Network
- Genzyme provides financial support to the Global Genes | RARE Project, which is hosting this webinar

Rare Disease Caregiver Support & Resources

Introduction and Welcome

My professional background and role

- LICSW
- History as a hospital social worker
- Currently Associate Director of Patient Advocacy, Genzyme

Why I am sharing my experiences

1. Importance of connecting with a community
2. What if there is NO community?
3. Social Isolation; what happens during social isolation?
4. How is being a rare disease caregiver “different”
5. Stages of grief? Recognize your own grief.
6. Rare Disease Caregiver Support

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Importance of Connecting with a Community

Value of Social Connection:

- Patients who received emotional support after a heart attack were 3 times more likely to survive.
- Another found that participating in a breast cancer support group actually doubled women's life expectancy post survey.
 - Shawn Achor, *The Happiness Advantage*, 2010
- These statistics are for patients, and the same can be said of caregivers and the physical and emotional stress of caregiving.
- Finding a community to help cope is important!

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What if There is No Community?

We know that there are over 7000 rare diseases, and there are currently less than 400 treatments approved by the FDA.

On both Global Genes and NORD's websites there are communities for hundreds of rare diseases.

- *What if your loved one's rare disease is not one that has a vibrant community?*
- *What if your loved one's rare disease is not even listed?*
- *Or, what if you've reached out to those communities and not felt the connection?*

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Social Isolation

This can lead to social isolation

- Our need for social support isn't just in our heads. Evolutionary psychologists explain that the innate need to affiliate and form social bonds has been literally wired into our biology.
- When we make a positive social connection, the pleasure inducing hormone oxytocin is released into our bloodstream, immediately reducing anxiety and improving concentration and focus.
- Each social connection also bolsters our cardiovascular, neuroendocrine and immune system so that the more connections we make over time, the better we function.
 - Shawn Achor, *The Happiness Advantage*, 2010

Isolation and the Benefits of Social Support

Benefits of a social support network

- Mayo Clinic online newsletter
- Numerous studies have demonstrated that having a network of supportive relationships contributes to psychological well-being. When you have a social support network, you benefit in the following ways:

Sense of belonging.

- Spending time with people helps ward off loneliness. Whether it's other new parents, dog lovers, fishing buddies or siblings, just knowing you're not alone can go a long way toward coping with stress.

Increased sense of self-worth.

- Having people who call you a friend reinforces the idea that you're a good person to be around.

Feeling of security.

- Your social network gives you access to information, advice, guidance and other types of assistance should you need them. It's comforting to know that you have people you can turn to in a time of need.

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Caregivers' Needs

Caregivers' needs are different.

Caregivers of rare disease patients are even more different.

How is caregiving different than being a patient?

- You've heard from Dave & Gloria about their experiences as spouses/parents of patients
- Hearing directly from them is the most important message you can hear, but I want to share my experiences as a hospital social worker...

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Rare Disease Caregiver Difference

How is Being a Rare Disease Caregiver “Different?”

- Lack of access direct information (from medical provider); example of CF clinic.
- Lack of access to same level of support (support groups in hospitals/on-line are frequently just for the patient) or, for the patient and family member
- Few groups specifically for caregivers to express their feelings, thoughts and needs.

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Acknowledging Your Own Grief

- When Dave and Gloria and I talked about this webinar, we talked about the importance of acknowledging that grief is experienced NOT just by the patient who receives the diagnosis but by the whole family and by the caregiver.
- Each person goes through grief in their own way, and at their own pace, sometimes experiencing complicated grief reactions, just like the affected patient.
- Recognize your own grief. Acknowledge that you're allowed to have and experience grief

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The Foundation of Social Networks

Give and take: The foundation of social networks

A successful relationship is a two-way street. The better a friend you are, the better your friends will be. Here are some suggestions for nurturing your relationships:

- **Stay in touch.** Answering phone calls, returning emails and reciprocating invitations let people know you care.
- **Don't compete.** Be happy instead of jealous when your friends succeed, and they'll celebrate your accomplishments in return.
- **Be a good listener.** Find out what's important to your friends — you might find you have even more in common than you think.
- **Don't overdo it.** In your zeal to extend your social network, be careful not to overwhelm friends and family with phone calls and emails. Save those high-demand times for when you really need them. And while sharing is important, be wary of "oversharing" information that's personal or sensitive, especially with new or casual acquaintances and on social networking sites.
- **Appreciate your friends and family.** Take time to say thank you and express how important they are to you. Be there for them when they need support.

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The Bottom Line

Social networks and social support are important for patients and caregivers

- They are especially important when caring for a rare disease patient
- Create and find your support.
- If you can't find it—reach out. You just took the first step by calling into this webinar! There ARE resources here to help you.

Thank you.

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November is National Family Caregivers Month!

Family Caregivers - Now More Than ever!

[Read the Presidential Proclamation here!](#)

**NATIONAL
FAMILY CAREGIVERS
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November 2013

Get started here! Click one of the caregiving situations below.



I JUST REALIZED I'M A FAMILY CAREGIVER
NOW

"I can't believe this just happened!"

"Since he came back from Iraq, he depends on me."

"My wife has been diagnosed with MS."

[We CAN help you be resourceful in your new role as a caregiver.](#)



I HAVE BEEN A FAMILY CAREGIVER FOR YEARS.

"My husband has Parkinson's and I'm his primary caregiver."

"Since my wife's stroke, I handle everything."

"It's been 10 years and I don't know how much longer I can do this."

[We CAN help you manage the many challenges of higher-burden caregiving.](#)



I LIVE FAR AWAY AND I'M ON THE CAREGIVING
TEAM.

"How do I know that my parents are OK living alone?"

"Since mom died, I am all dad has."

"It's so hard to make things happen for him when I don't live nearby."

[We CAN help you provide care from afar.](#)



I HAVE A JOB AND I'M THE CAREGIVER FOR MY
LOVED ONE.

"I'm what they call a 'sandwich generation' caregiver."

"I care for my mother with Alzheimer's in addition to my three children."

"I can't stop working so how do I manage?"

[We CAN help you be both an employee and a caregiver.](#)



- [Patient File Checklist](#)
- [Doctor's Office Checklist](#)
- [How to Find a Support Group](#)
- [Alzheimer Caregiving Videos](#)
- [Incontinence Assessment Tool](#)
- [Medication Checklist](#)
- [Independent Living Assessment](#)
- [Financial Planning for Family Caregivers](#)
- [Safe and Sound: How to Prevent Medication Mishaps](#)
- [Saturating: On-line Care Coordination](#)
- [Eldercare Locator](#)
- [Caregivers and Depression](#)
- [Intimacy: A Casualty of Caregiving](#)
- [When Keeping Your Loved One at Home Means Bringing In Help](#)
- [Care for the Caregiver: Care Counseling](#)
- [Respite: Time Out for Caregivers I, II](#)
- [Changing Relationships, Changing Lives](#)



November is National Family Caregivers Month!
Family caregivers - now more than ever!

[Read the Presidential Proclamation here.](#)

Get started here! Click one of the caregiving situations below.



MY LOVED ONE HAS BEEN A CAREGIVER FOR YEARS.
"My husband has Parkinson's and I'm his primary caregiver."
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[We CAN help you be resourceful in your new role as a caregiver.](#)
[We CAN help you manage the many challenges of higher-burden caregiving.](#)

MY LOVED ONE IS FAR AWAY AND I'M ON THE CAREGIVING AM.
"How do I know that my parents are OK living in a care home?"
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For privacy reasons it is recommended that you create a forum display name

[Click here to create a forum display name](#)

All Categories

• [I'm a New Caregiver... What Do I Do?](#)

I'm a New Caregiver... What Do I Do?

 16 discussions 42 comments Most recent: [Newbie...](#) by [Jo1124](#) 2:09PM

• [Dealing With Caregiver Depression](#)

Up to 50% of caregivers experience symptoms of Depression. How do you handle it?

 9 discussions 24 comments

• [Working Through Your Frustration and Isolation](#)

Frustration and isolation are often considered two of the biggest personal issues for family caregivers to deal with. What helps you get past these difficult emotions?

 20 discussions 110 comments

• [Technical and Practical Advice for Caregivers](#)

Technical and Practical Advice for Caregivers

 7 discussions 23 comments Most recent: [Unsure Of Next Step - Continue Home Car...](#) by

[charMing](#) November 5

• [Dealing with Medical Professionals](#)

Getting doctors to pay attention to us can be difficult. What techniques have worked for you?

Go

Welcome!

If you want to get involved, click one of these buttons!

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[Apply for Membership](#)

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[de-stressing](#) 2

[brain](#) 1

[long-term](#) 1

[siblings](#) 1

[familyissues](#) 1

[faraway](#) 1

[bi-polar](#) 1

[stroke](#) 1

[evicted](#) 1



Take care of your own health so that you can be strong enough to take care of your loved one.

“What can I do to help?”



Powered by
Lotsa Helping Hands
create community

Lotsa Helping Hands powers online caring Communities that help restore health and balance to caregivers’ lives. The service brings together caregivers and volunteers through online Communities that organize daily life during times of medical crisis or caregiver exhaustion in neighborhoods and communities worldwide.

The hallmark of the service is the caregiver-focused Help Calendar, which enables members to schedule and sign up for tasks that provide respite for the caregiver including meals for the family, rides to medical appointments, and visits. Members can also communicate with one another through message boards, post personal blogs, share photos, and send well wishes to the family. And Coordinators can safely store and retrieve vital information for the family - from medical and health records to financial and legal documents.

Now, when someone asks “what can I do to help?” the answer is “give me your name and email address” - the system takes over and allows people to sign up and start helping.

Share This Page



Learn how to **communicate effectively** with doctors.

Caregiving is hard work so **take respite breaks** often.

Watch out for signs of depression and don't delay in getting professional help when you need it.



Help for Caregivers

A wealth of resources at your fingertips

[Family Caregiver Forum](#)

[Peer Network](#)

[Story Project](#)

[Family Caregiver Toolbox](#)

[10 Tips for Family Caregivers](#)

[Agencies and Organizations](#)

[Coping with Alzheimer's](#)

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[Media Room](#)

[Social Media](#)

[Send To A Friend](#)

[Feedback](#)

[CAN Corporate Partners](#)

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Toolbox

Coordinate the Care

Powered by Saturing

Manage the Medications

Powered by Saturing

Track the Progress

Powered by Saturing

Plugged-In Caregiving

Technology for Family Caregivers

Communicating Effectively with
Healthcare Professionals

Webinar On-demand

Safe and Sound: How to Prevent
Medication Mishaps

Webinar On-demand

Financial Planning for Family
Caregivers

Create a Community of Help

Lotsa Helping Hands

How to Talk to Your Parents
The 40/70 Rule

Home Instead Senior Care

Incontinence Assessment

Independent Living Assessment

Eldercare Locator

Respite Care

Care.com

How to Find a Support Group

Locate Your Local Area Agency on
Aging

Patient File Checklist

Medication Checklist

Doctor's Office Checklist

Caregiver Depression

Alzheimer Caregiving Video Series

Bereavement Series

Be open to new technologies that can help you care for your loved one.

Organize medical information so it's up to date and easy to find.

Make sure legal documents are in order.





Financial Planning for Family Caregivers

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NETWORK
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[Home](#) [CAN](#) [Join CAN for FREE](#) [Family Caregiver Forum](#) [Create a Community](#) [Caregiving Tools](#)

Reaching Out for Financial Help

Make the most of what you have—Get more of what you need

How can you set a value on what you do? For family caregivers in the United States, the American Association of Retired Persons (AARP) estimates their efforts were worth approximately **\$375 billion** in 2007. In addition, the average family caregiver for someone 50 years or older spent \$5,531 on out-of-pocket caregiving expenses in 2007—more than 10 percent of the median income for a family caregiver that year, according to AARP.

It's clear that being a family caregiver can be financially challenging. [Allsup](#) and the [Caregiver Action Network](#) would like to help.

On February 24, 2011, we launched the family caregiver webinar, "Reaching Out for Financial Help: *Make the most of what you have—Get more of what you need.*" The webinar focuses on issues related to gaining control of someone else's finances and included an

Toolkit

[Advocacy Organizations](#)

[Providing Direct Support](#)

[Download a Check List of Documents You'll Need](#)

[Financial Planning Calculators](#)

[Glossary of Financial Terms](#)

[Locating Benefits](#)

[Locating Food Assistance](#)

[Locating Free or Subsidized Health Care Services and Prescription Medications](#)

And, finally, Number 10:

Give yourself credit for doing the best you can in one of the toughest jobs there is!

And, now...

Time for your questions!

Global Genes Upcoming Webinar

World Rare Disease Day 2014 Planning Webinar

December 11, 2013– 11:00 am PST/2:00 pm EST

Register today at
<http://globalgenes.org/webinars>