Caregiver Support and Resource Webinar
Taking Care of Yourself While Taking Care of Your Loved Ones

November 21, 2013
11:00 am PT
Sponsored by:

A SANOFI COMPANY
Family Caregivers - Now More Than Ever!
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 you can find tools to:

- Stay strong
- Ask for help
- Stay organized
- Balance demands with limits
Everyday, practical ideas from

✓ Family Caregivers
  • Gloria
  • Dave

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....
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:

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
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<tbody>
<tr>
<td>8 am</td>
<td>Breakfast meeting</td>
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<tr>
<td>9 am</td>
<td>Meeting</td>
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<tr>
<td>10 am</td>
<td>Enter your details</td>
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<tr>
<td>11 am</td>
<td>Lunch at home</td>
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<td>12 pm</td>
<td>Wash and Bathe</td>
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<tr>
<td>1 pm</td>
<td>Play outside</td>
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<tr>
<td>2 pm</td>
<td>Professional meeting</td>
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<tr>
<td>3 pm</td>
<td>Professional work</td>
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<tr>
<td>4 pm</td>
<td>School performance feedback</td>
</tr>
<tr>
<td>5 pm</td>
<td>Dinner at home</td>
</tr>
<tr>
<td>6 pm</td>
<td>Professional work</td>
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<tr>
<td>7 pm</td>
<td>Professional work</td>
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<tr>
<td>8 pm</td>
<td>Professional work</td>
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<td>9 pm</td>
<td>Professional work</td>
</tr>
<tr>
<td>10 pm</td>
<td>Professional work</td>
</tr>
<tr>
<td>11 pm</td>
<td>Sleep</td>
</tr>
</tbody>
</table>
Fitting This Dream Into Your Life

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

- Capacity to support others
- Emotional
- Social
- Physical

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

[Images showing various activities and emotions related to physical, social, emotional, and capacity to support others]
• 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
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
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.
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

TRAUMA ............................................ NORMAL

PTG

PTSD
ME→WE- & ME
POST TRAUMATIC GROWTH - TOGETHER

TRAUMA

PTG
Skilled at
Managing Emotions
Communications
Optimism
Relationships
Spirituality
Support of Others
Answering
.... AND SO?
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
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
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”
6. Rare Disease Caregiver Support
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.

• 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!
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?
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.

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.
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...
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.
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
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.
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.
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.

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
Saturing: 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
Seek support from other caregivers. You are not alone!

- **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 101124-2:09PM

- **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 Care... by chatMing November 5

- **Dealing with Medical Professionals**
  Getting doctors to pay attention to us can be difficult. What techniques have worked for you?
Take care of your own health so that you can be strong enough to take care of your loved one.
Accept offers of help and suggest specific things people can do to help you.

"What can I do to help?"

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

facebook | twitter | google | linkedin
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.
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.
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

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<th>Toolkit</th>
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<tr>
<td>Advocacy Organizations</td>
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<td>Providing Direct Support</td>
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<td>Download a Check List of Documents You’ll Need</td>
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<td>Financial Planning Calculators</td>
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<td>Glossary of Financial Terms</td>
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<td>Locating Benefits</td>
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<td>Locating Food Assistance</td>
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<tr>
<td>Locating Free or Subsidized Health Care Services and Prescription Medications</td>
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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