The New Normal: Managing with Uncertainty

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2015 NATIONAL PATIENT & FAMILY CONFERENCE
Providing & Pursuing Answers: Advances in Research, Treatment and Care
This talk today will focus, and be about

YOU, THE CAREGIVER
What we will talk about today…

1. Acknowledging the reality of the stress – What’s the Big Deal?

2. What we do/Why we do it: The New Normal

3. What we can do differently: Managing Uncertainty
There is Help!

- We’ll talk about things you can do TODAY that may help
- Design a plan that works for YOU
- Identify support resources

- Learn to recognize your own stress
- Figure out when to ask for help
- How 15 minutes a day can give you the strength to keep going
Message Today: Put your mask on first!!!
Things are going along fine....

Then, out of the blue...disaster
Nothing is the same

You may feel any of these and more...maybe all at once!

• Disbelief
• Anger
• Doubt
• Fear
• More anger
• Grief
• Hope

It’s a roller coaster, but not in a good way!
• Realize that things are NOT going to return to how they were the day before the news

• You start to adjust to this New Normal without even knowing it

• So much uncertainty… it feels so different
Challenges for Those caring for people with a **Brain Tumor**

Cognitive

psychological

behavioral

Changes
Brain Tumor is different

Emotional
- Depression
- Anxiety
- Obsessive behavior
- Irritability
- Personality changes

Thinking and memory
- Difficulty processing information
- Short term Memory problems
Brain Tumor is different

Concentration
- Confusion
- Distracted
- Can’t plan

Executive functioning
- Judgement is impaired
- Decision making affected
Brain Tumor is different

- Sudden nature of Dx
- Intensive Tx’s
- Short trajectory of illness
- High rate of mortality
- Young population
Symptoms with Brain Tumors

- Change in personality
- Mood swings
- Reduced mental capacity
- Physical impairment
- Low Quality of Life
- Hyper dependence on caregiver at home (family)
Let’s talk about

RECOGNIZING
CAREGIVER STRESS
Problems caregivers face

- Anxiety
- Depression
- Sleep disturbance
- **Role changes**
- Fatigue
- Frustration
- Isolation

- Psychologically
- Physically
- Financially
“Caregivers overwhelmingly described the work of providing care as mentally and physically exhausting, and caregivers expressed feeling angry, frustrated, and guilty for losing patience…”

“I’m sure (the HCP) is quite talented, but I understood nothing the (HCP) said”

I think seeing my soul mate change a little more every day is the hardest thing I've ever had to experience. I miss my best friend so very much....and he is still here :( 
The last time I held the woman who was my wife was the morning of her brain surgery. I still have my wife, but it's not the same person, and that can be very, very hard.
I worry that after all this is over if I'll be bitter and fearful for the rest of my life. Most days I am just numb.
Realities of the Caregiver

- Putting Pt first
- Exhaustion
- Rewarding/meaningful
- Loneliness
- Lack of focus from team on caregiver

Realities of the Caregiver

- No preparation for new role as caregiver
- No personal time (only 3 hrs per week)
- Finances stretched (41% reduced/stop working)
- Depression (50%)

Wasner, et.al. “Psychosocial Caregiving for PMBT Patients”
The signs of stress:

- Feeling tired and run down
- Trouble concentrating
- Feeling resentful more often
- Difficulty sleeping
- Over reacting to minor issues
- Health problems
- Anxiety
- Depression
- Irritability
- Wish for it to end
Stress leads to **Burnout**…

- Constantly exhausted
- Neglect your own needs
- Your life revolves around caregiving
- You can’t relax, even when you have help
- More and more impatient and irritable
- Feeling **helpless**
- Feeling **hopeless**

These symptoms, behaviors, are **harder** to resolve
What doesn’t help

• Negative self-talk
• Isolating yourself
• Avoiding dealing with your emotions
• Not asking for help
Why it Matters

“When the pt-caregiver dyad is treated as the unit of care, important synergies are achieved that contribute to the well being of both patients and caregivers.”

In case you hadn’t heard….

AARP SAYS YOU ARE STRESSED!
2015 AARP National Caregiving Survey
age 40 and older

• 64% felt emotionally stressed
• 59% found it difficult to take a break
• 58% felt stressed in trying to balance job and family
• 39% felt financially strained.
Accepting and dealing with...

YOUR NEW NORMAL
What can help?
First and Foremost…

You are not alone.
Strengthen your coping...

- Acknowledge → Know what you need
- Prioritize → Know limits
- Set Goals → Have success
- Ask (accept!) for help → Don’t isolate
- Re-evaluate → Review often
- Repeat → Accept the ups and downs
Acknowledging your emotions/reactions

• Acknowledge
  – You can’t fix or change if you don’t see it there

Use Reflective writing as a way to identify your emotions
Prioritizing and solving problems

- Very Important
  - Seizure
  - Getting groceries
  - Cleaning the house

- Somewhat Important
  - Schedule an appointment

- Not Important

- Not Urgent
- Somewhat Urgent
- Very Urgent

- American Brain Tumor Association®
  Providing and pursuing answers®
Set Bite Sized Goals

- May be only one thing today
- Use your organizational skills
- Lists
- Experience success
Ask for Help

People want to help, but they need you to tell them what you need!

Pick 3 things you’d like help with; Think of who might want to help

- Asking for help is *not giving up*
- Asking for help does not mean you are *helpless*
- Asking for *help takes courage*
- Asking for help will make you *feel stronger*
Re-Evaluate

• Things change quickly
• Your role may change several times
• If it’s not working, re-evaluate
• There’s no one way to do something
BE KIND TO YOURSELF
A few words about exercise and sleep

DO IT!

WHEN YOU CAN
Four Concrete suggestions

Journal

Post-It Reminders, Inspiration

Time for Yourself

Write down 3 good things before you go to bed
You **Can** Do This

Set aside at least 15 min a day for **yourself**.

- Read
- Walk
- Sit
- Listen to music
- Write
- Etc.

Will it fix anything – **No**
Will it change your reality – **No**

Will it give you a little more strength and focus to deal with what you must – **Yes!**
Caregiver Self-Assessment Questionnaire

How are YOU?

Caregivers are often so concerned with caring for the relative’s needs that they lose sight of their own well-being. Please take just a moment to answer the following questions. Once you have answered the questions, turn the page to do a self-evaluation.

During the past week or so, I have ...

1. Had trouble keeping my mind on what I was doing… □ Yes □ No
2. Felt that I couldn’t leave my relative alone…………….. □ Yes □ No
3. Had difficulty making decisions…………………………. □ Yes □ No
4. Felt completely overwhelmed…………………………… □ Yes □ No
5. Felt useful and needed…………………………………… □ Yes □ No
6. Had back pain………………………………………….. □ Yes □ No
7. Felt ill (headaches, stomach problems or common cold)…… □ Yes □ No
8. Been satisfied with the support my family has given me………………….. □ Yes □ No
9. Found my relative’s living situation to be inconvenient or boring to care □ Yes □ No
What would help? Here’s what AARP Says is Very Helpful:

- Information about caregiver resources 88%
- Respite Care 85%
- Assistance with chores 78%
- Assistance with transportation to medical appointments 78%
- Connecting with other caregivers 72%
Resources on line

- ABTA.com – Caregiver Resources
- Caregiver Action Network
- National Caregivers Library
- Family Caregiver Alliance
- National Brain Tumor Society
- Caregiver Café
- Lots a Helping Hands
- Care Bridge
- Care pages
- Todays’ Caregivers
- National Family Caregiver Association
- Well spouse Association
References

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