The Emotional Roller Coaster:
Psychosocial Challenges faced by Caregivers of People with VHL &
Techniques to Manage Them

2015 VHL Patient/Caregiver Annual Meeting
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October 17, 2015
Who Are Caregivers?

- **Group Introductions**
  - Name, city, what is an up and down of your caregiving experience?

- 43.5 million, 18% of US adults
- 60% female
- 49 years old
- 80% care for 1 person
- 85% care for relative
- 75% 4 years or less

(The National Alliance for Caregiving (NAC) and the AARP Public Policy Institute, 2015)
What Do Caregivers Do?

- **What do You Do?**
  - 24 hours per week, 25% say 41+ hours, *on-call*
  - **Activities of Daily Living**
    - Moving from bed to chair, Dressing, Bathing, Feeding, Bathroom
  - **Instrumental Activities of Daily Living**
    - Transportation, Shopping, Housework, Meals, Finances, Medications, Arranging services
  - **Medical/nursing tasks**
  - Monitoring health of recipient
  - Communicating with health care professionals
  - Advocating with providers, services, agencies
  - Tending to emotional needs of recipient
  - Working, taking care of their families, themselves??
What is the Impact of Caregiving for a Person with VHL?

- Emotional
- Social
  - Others
  - Partner
- Physical
- Occupational
- Financial
Emotional Impact of Caregiving

- 1/3 of caregivers report significant distress
  - 1/4 warrant intervention
- Sadness, loneliness
- Anxiety, worry
  - Uncertainty—waiting game—scanxiety
- Anger, frustration
- Resentment--choice
- Guilt
  - About own health, abilities, not doing enough
- Thoughts about the future
  - Grief, decreased hope, thoughts of death
- Fatigue, lack of energy
- Love, commitment, meet needs, personal reward
Depression

- Period of two weeks, experiencing at least 5, nearly every day
- Depressed mood (sad, empty, irritable)
- Less Interest and enjoyment from activities
- Fatigue, lower energy
- Psychomotor retardation or agitation
- Changes in Appetite/Weight
- Changes in Sleep
- Decreased Concentration
- Increased Guilt or Feelings of Worthlessness
- Thoughts of death or suicide
- Interferes with normal social, occupational, and other important areas of functioning
Social Impact of Caregiving

• Isolation from family and friends

• Social constraints—
  ◦ Not feeling able to talk to others/partner about health/ issues surrounding tumor risk
    • Try to protect others—don’t want to upset them by talking
    • Think they won’t be supportive if you talk
    • Leads to worse Intrusive thoughts, Body pain, Physical role functioning, Mental health

• Relationship stress
  ◦ Especially around test result time
  ◦ Arguments about non-adherence

• Practical problems

• Some feel closer, enjoy and appreciate life and each other more
Physical Impact of Caregiving

• Negative health behaviors
  ◦ Poor nutrition, less exercise
  ◦ More tobacco and alcohol
  ◦ Miss medication doses, don’t stay in bed when ill
  ◦ Missed doctor appointments

• Disturbed Sleep

• Pain, back problems, migraines

• At risk for Injuries

• Effects of chronic stress
  ◦ Digestive difficulties
  ◦ Impaired immune function, Inflammation
  ◦ Cardiovascular disease

• Poor health, Early death
Occupational/Financial Impact

- Strain between home and work
- Attendance changes
  - Go in late/leave early, Reduce hours
- Career Growth
  - Pass up projects, opportunities for promotion
- Stop working
  - Resign, retire early, self-employment
- Changes in Income and benefits
  - Medical bills, reduced income, less retirement investment
How Are YOU?

- Caregiver self-assessment
  - Take a moment to complete and score

- Caregivers are often so concerned with their care recipient’s needs that they lose sight of their own well-being

What Increases Caregiver Distress?

- Less social support
- Younger Age
- Have Children
- Residence with the care recipient (usually spouses)
- Hours spent caregiving
- Depression
- Financial stress
- Lack of choice in being a caregiver

- Caregiver stress is linked to patient distress

(Adelman et al., 2014; Lammens et al., 2011)
Coping Strategies for Caregivers of People with VHL

- How do you COPE?

- Apply strategies you’ve used to cope successfully in the past to this situation

- Find strengths and build on them
<table>
<thead>
<tr>
<th>Stressor Coping Strategies</th>
<th>Controllable Problem-Focused</th>
<th>Uncontrollable Emotion-Focused</th>
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</thead>
<tbody>
<tr>
<td><strong>Active</strong></td>
<td>Get more Information</td>
<td>Reappraise the situation</td>
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<tr>
<td></td>
<td>Set goals</td>
<td>Reframe thoughts</td>
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<td></td>
<td>Engage in focused activities</td>
<td>Do something to feel better</td>
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<td></td>
<td>Ask for help</td>
<td>in the moment</td>
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<td></td>
<td>Resolve conflicts</td>
<td>(Exercise, massage, meditation,</td>
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<td></td>
<td>Make decisions</td>
<td>mindfulness).</td>
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<td></td>
<td></td>
<td><strong>Express Emotions</strong> (Talk with</td>
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<td></td>
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<td>others, journal, art)</td>
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<td></td>
<td></td>
<td><strong>Accept negative emotions</strong></td>
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<td></td>
<td></td>
<td>(Soften and soothe)</td>
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<tr>
<td><strong>Avoidant</strong></td>
<td>Behavioral Avoidance</td>
<td>Escape Avoidance</td>
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<td></td>
<td>Cognitive Avoidance</td>
<td>(Smoke, drugs, drink, eat,</td>
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<td></td>
<td>Denial</td>
<td>sleep)</td>
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<td></td>
<td>(Don’t think about it,</td>
<td><strong>Stop caring for yourself</strong></td>
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<td></td>
<td>don’t take steps to work on</td>
<td>(Don’t take medication, miss</td>
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<td></td>
<td>it)</td>
<td>appointments)</td>
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<td></td>
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<td><strong>Stuff Feelings</strong></td>
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</table>

(Kilbourn, K. 2014; Carver & Scheier, 1994)
Coping Strategies cont.

- **Take care of your health**
  - Notice barriers to caring for your own health
  - Do you think you are being selfish if you put your needs first?
  - Are your health needs less important than your care recipient?
  - Is it frightening to think of your own needs?

- **Set Realistic Goals and Learn to Say ‘No’**

- **Ask for help**
  - Overcome resistance to do everything yourself and fear that you are imposing.
  - Do you feel inadequate if you ask for help?
  - Do you feel you have to prove that you are worthy or capable?
  - Family/friends often feel helpless and want to help in some way.
  - [www.lotsahelpinghands.com](http://www.lotsahelpinghands.com)
    Free service with a private, group calendar where family and friends can sign up for tasks.
Coping Strategies cont.

- **Get Connected**
  - Learn about resources available in your community

- **Social Support & Emotional Expression**
  - Maintain your connections with family and friends
  - Set aside time each week for connecting
  - Talk to supportive others about thoughts and feelings
  - Join a Support Group or Online Forum
  - Seek support from professionals Medical Team, Social Workers, Therapists, Clergy
  - Posting, Journaling
Unhelpful Thinking Styles

- **All-or-Nothing Thinking/Overgeneralization**: “I can’t manage it all, I’m useless.”

- **Fortunetelling/Catastrophization**: “The results will show the tumor is back.” “We are going to end up homeless”

- **Disqualifying the Positive/Magnifying the Negative**: “We can’t doy partner will not love me as before my treatment.”

- **Emotional Reasoning**: “I feel scared, something bad is probably going to happen.”

- **Labeling**: “What a jerk!” “I’m stupid.” “That meeting was a total waste of time.”

- **Mind-reading**: “She thinks I’m exaggerating” “He doesn’t want to hear about my problems.”

- **Personalization**: “My spouse is depressed, and it’s my fault.”

- **Unhelpful rules/Should and Must statements**: “I should not ask for help” “If people care about me, they ought to be able to tell I need help.”

- **Maladaptive Thoughts**: “Our lives will never be the same again.”

(Beck, 1995)
Challenge Unhelpful Thinking

- Thoughts are not facts
- Examine **Evidence, Alternatives, and Implications**
- Ask yourself some questions:
  1. What kind of unhelpful thinking style could I be making?
  2. What evidence is there that this thought might not be 100% true?
  3. Is there an another way of viewing this?
  4. What is the most realistic outcome of this situation?
  5. What is the effect of my believing this thought and what could be the effect of changing my thinking?
  6. What would I tell a close friend/family member if he/she had this thought?
  7. What should I do now?

(Beck, 2008)
Worry and Anxiety

“His headache is a sign of a tumor.”

Unrealistic Worry

Think Differently

YES

Take Action (Problem-solving, treatment options, manage pain)

Realistic Worry

Is there a step you can take to resolve the problem?

NO

Practice acceptance and self-soothe

Unclear if Realistic

Collect more info

(Greer, et al., 2010)
Stress Management and Relaxation

- What do you do to Relax?
- What are your mini-breaks?
Stress Management and Relaxation

- Exercise, Pleasant and Social Activity
- Relaxed Breathing
  - Learning to breathe like a baby
- Positive Imagery Rehearsal
  - Visualizing a peaceful moment like a movie
- Progressive Muscle Relaxation
  - Learning to relax all the muscle groups of the body
- Mindfulness Meditation
  - Stopbreathethink.org
  - Pay attention to the present moment on purpose
  - Observe, Describe, Participate
  - Nonjudgmentally, One-mindfully, effectively
Relaxed Breathing

Diaphragmatic breathing

- Slow down and regulate breathing
- In and out through nose, or out through narrow lips
- Length that feels comfortable for you (e.g., 4, pause 1-2, 4 out)
- Varies by person, by day
- Notice the pause between breaths, air at your nose and down your throat, how your chest, shoulders, and stomach move
- Imagine balloon in your belly that fills up with air as you inhale and deflates as you exhale
- Put hand on your chest and another hand on your belly
- See if you can make your belly rise with each breath
- Practice non-judgmentally, notice thoughts come and go

**Short:** Take 6-10 breaths

**Long:** Practice for 10-30 minutes daily
Caregivers are often so concerned with caring for their 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. Felt lonely □ Yes □ No
7. Been upset that my relative has changed so much from his/her former self □ Yes □ No
8. Felt a loss of privacy and/or personal time □ Yes □ No
9. Been edgy or irritable □ Yes □ No
10. Had sleep disturbed because of caring for my relative □ Yes □ No
11. Had a crying spell(s) □ Yes □ No
12. Felt strained between work and family responsibilities □ Yes □ No
13. Had back pain □ Yes □ No
14. Felt ill (headaches, stomach problems or common cold) □ Yes □ No
15. Been satisfied with the support my family has given me □ Yes □ No
16. Found my relative’s living situation to be inconvenient or a barrier to care □ Yes □ No
17. On a scale of 1 to 10, with 1 being “not stressful” to 10 being “extremely stressful,” please rate your current level of stress. ________
18. On a scale of 1 to 10, with 1 being “very healthy” to 10 being “very ill,” please rate your current health compared to what it was this time last year. ________

**Comments:**
(Please feel free to comment or provide feedback.)

__________________________________________
__________________________________________
__________________________________________
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__________________________________________
Self-evaluation
To determine the score:
1. Reverse score questions 5 and 15.
   (For example, a “No” response should be counted as “Yes” and a “Yes” response should be counted as “No.”)
2. Total the number of “yes” responses.

To interpret the score
Chances are that you are experiencing a high degree of distress:
• If you answered “Yes” to either or both questions 4 and 11; or
• If your total “Yes” score = 10 or more; or
• If your score on question 17 is 6 or higher; or
• If your score on question 18 is 6 or higher

Next steps
• Consider seeing a doctor for a check-up for yourself
• Consider having some relief from caregiving
  (Discuss with the doctor or a social worker the resources available in your community.)
• Consider joining a support group

Valuable resources for caregivers
Eldercare Locator
(a national directory of community services)
(800) 677-1116
www.eldercare.gov

Family Caregiver Alliance
(415) 434-3388
www.caregiver.org

Medicare Hotline
(800) 633-4227
www.medicare.gov

National Alliance for Caregiving
(301) 718-8444
www.caregiving.org

National Family Caregivers Association
(800) 896-3650
www.nfcacares.org

National Information Center for Children and Youth with Disabilities
(800) 695-0285
www.nichcy.org

Local resources and contacts:
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