Amyloidosis Research Consortium

Tips for Surviving & Thriving as a Support Partner

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A chronic illness is a
"we disease" not a "me disease"

When one person in a family has a chronic illness…

- The whole family lives with it
- Like a stranger who shows up at your door, a chronic illness
  - Arrives uninvited and unexpected at your door
  - Spreads its stuff all over the house
  - And doesn't go home

Each member of the family has to make their peace with the illness – and find space for it without giving it more space and attention than it needs

"Find a place for the illness while keeping the illness in its place"

(Gonzalez et al., 1989)

So why do I use the term "*care partner*"?

- "Caregiver" sounds too much like a one-way street
- A "*care partnership*" implies:
  - Mutual caring, concern, respect
  - Give and take
  - Compromise
- A care partner can be a spouse/partner, family member, friend
- With few exceptions, even individuals with severe impairments can give something to their care partner in return – a smile, a thank-you, an acknowledgement...

Polling Question #1

How long have you been a care partner?

- 1-5 years
- 6-10 years
- 11-15 years
- 16+ years

Polling Question #2

What is your relationship?

- Spouse/partner
- Parent
- Sibling
- Other family member
- Friend
- Other (write it in the Q&A)

Polling Question #3:

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Which of the following describe you? (Pick your top 3)

- Lonesome
- Resentful
- Proud
- Grieving
- Guilt ridden
- Exhausted
- Contented
- Anxious
- Frustrated
- Other (write it in the Q&A)

Why you need to
“put on your own oxygen mask first”

In addition to being a care partner, you are

- A person who:
  - Has responsibilities in addition to your care partner role
  - Has needs, feelings, and priorities of your own

- A person whose health and wellness are just as important as your loved one's
  - Adequate sleep
  - Regular exercise and physical activity
  - Preventive healthcare visits
  - Alone time
  - Social interactions
  - Emotional wellbeing

Polling Question #4:

What's missing in your life today? (Pick your top 3)

- Time to think/meditate/pray/be alone
- Quality sleep
- Regular exercise/physical activity
- Recreational activities/hobbies
- Time with friends
- Time for your work
- Time to attend to your own healthcare needs
- None of the above
- Other (write it in the Q&A)

Polling Question #5:

What is stopping you? (Pick your top 3)

- Too much to do
- Poor planning/prioritizing
- My loved one can't be left alone
- Not enough help
- Guilt
- Other people's opinions/judgments
- None of the above
- Other (write it in the Q&A)

Putting on your oxygen mask first….

Ensures that you are attending to you own wellness

Helps to ensure that you have the physical and emotional strength you need to care for the person you love

Makes it easier for you to plan, prioritize, problem-solve in a constructive way

Ensure that you have the emotional and physical reserves you need in times of crisis

Some Tips for Surviving and Thriving

- Know that communication (both talking *and* listening) lays the foundation
  - Working with a mental health professional can be invaluable when trying to jumpstart difficult conversations
- Recognize that self-care isn't self-ish; it is self-sustaining
- Acknowledge that one person's needs/feelings/priorities are no more important than another person's
- Learn to set limits without guilt – boundaries matter!
- Work to achieve some degree of *balance* in your partnership
  - Each partner needs to contribute in whatever way they are able
  - Each needs be on the giving and receiving end of care and support
  - Each partner needs to feel valued/useful/important
  - Partners need to make decisions together whenever possible

Some More Tips for Surviving and Thriving

- Plan for the worst and hope for the best
  - Planning for the best = putting your head in the sand
  - The goal is to avoid having to make big decisions in a crisis

- Talk together about:
  - Your finances
  - Long-term care options
  - Housing that optimizes safety and independence
  - A neighborhood with good transportation and resources

The more ducks you have in a row,
the fewer things you'll have to worry about
in the middle of the night!

And lastly

- Build your support network – as strong and wide as you can – and use it!
- Write your own version of the Serenity Prayer; here's mine:

Every day I need:

Courage, Patience, and Resilience (CPR)
to accept what I cannot change

Strength and Creativity
to change the things I can

And the wisdom and sensitivity to recognize the difference

What's yours?