Caregiver Burden Track Six Essentials

1:45-2:45

2015 HDSA National Convention, Dallas, TX Saturday, June 27, 2015

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Huntington's Disease Society of America

Six **Essentials**

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Presenter Disclosures

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The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:

No relationships to disclose





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Goals of this session

To empower **you**... The HD Caregiver With Six Essential items That will help as you encounter Your own progressing Physical, emotional and psychological challenges On this HD journey



Caregiver Burden-Six Essentials

- When we embark on a journey, we pack the essentials.
- The very basic "go-to" items.
- These items go in our "carry on" luggage.











- These items in your "carry on", will help you while caregiving a loved one with Huntington's Disease.
- Because Huntington's Disease is a journey, you own "carry on" piece will expand.









- It will grow to receive the limitless ideas and possibilities you can add as your own "go-to" items.
- The six essentials will help you to:





The Six Essentials:

Patience
Humility
Food, Tea, and a Blanket
A Doodle Pad
Forgiveness
Humor



1- Patience

- The journey with HD is a long one.
- We need a lot of patience as we accompany our loved one through the changes and stages of HD.
- Most of all, we need PATIENCE with OURSELVES while enduring a life forever changed.





Patience Cont.

 As a caregiver, PATIENCE helps you find YOUR own comfortable pace in the ups and downs of this marathon journey of ' `.







2- Humility

- "I cannot do this alone."
- A humble person knows, is aware of, and recognizes their limitations.
- It takes courage and inner strength to break the silent suffering of going it alone.
- A humble person knows it's okay to:





Humility Cont.

• With a little help, your luggage will be lighter to carry on this journey.



 Create a "Wish List". A "List" of things to do for those who "Wish" to help you, know you need help and have been waiting for you to ask. Here is your chance to delegate something specific for them to help you recharge and conserve all the energy you can.



Humility Cont. The Wish List

| | People I know and trust will help me: | Tasks or chores they can do: |
|---|--|------------------------------------|
| | Mary | Cook dinner once a week |
| | John | Mow Lawn |
| < | Carol | Grocery Shopping |
| | Nancy | Watch Joe for 2 hours on a weekend |
| | | |
| | Create your own | Wish List Now! |
| | | |



3. Food, Tea and a Blanket

- Being a caregiver is tiring.
- For the long journey with HD, we need sustenance for our own mind, body and soul.
- Self care is key.
- We need a healthy diet and know when to rest our mind and bodies.



3. Food, Tea and a Blanket cont.

• Brew a cup of favorite tea.



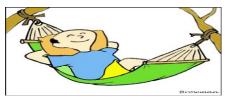
- Have a snack.
- Wrap up in a warm blanket.





- Read a book.
- Take a PTO (Personal Time Out)

Reserve energy and recharge your batteries on a regular basis.



It will keep you strong to continue on this journey with HD and your loved one.



4. A Doodle Pad

 Use a doodle pad, a journal or any type of media, jot down or draw your feelings without judging them.





4. Doodle Pad cont.

- Use any creative outlet to let the feelings out.
- We are human and have feelings that we cannot control.
- We can however, control the way we express them in an healthy and safe way.
- Caregiving a loved one with HD and it's journey is fertile ground for a variety of feelings.
- Give your feelings constructive expression and let them flow.
- It is a great release.





5. Forgiveness

- We need to find any extra weight in our "carryon" that is slowing us down and "LET GO" of it.
- Bitterness and resentment are two "weights" we sometimes carry as caregivers.
- Forgiveness lightens our hearts.
- Accepting the reality of life with HD and living one day at a time allows us to focus on what we CAN do.
- Forgiveness allows us to carry on in the present being available for every precious moment.





6. Humor

We need to laugh on this journey <u>at</u> ourselves and <u>with</u> our loved ones.

APPLAUSE

- Laughter is a great release.
- Humor helps us survive.
- Can you remember a laughable moment? Share one with us
- Thank You!







