

## **You Can't Give From An Empty Well**

**By Susan Bollinger, RN**

Our Stories are unique, yet similar. We are all experiencing loss because of the diagnosis of HD of our loved one. Our loss could be that of our relationship with our loved one or our loss in thinking of what our lives might have been without the diagnosis of HD.

### **We Are Entitled To Our Feelings**

We could be angry with our loved one, the medical community, or ourselves. It is normal to feel sad about our situation and that of our loved one.

#### **GUILT:**

Are there things that you think that you should have or could have done differently? Or that you should be doing now?  
Do you wish that you needed care instead of your loved one?  
Do you feel guilty when you allow yourself time away from your responsibilities?

#### **PANIC AND ISOLATION:**

Do you sometimes feel overwhelmed?  
Are you sometimes short of breath or feel your heart pounding?  
Do you feel alone on your journey?  
Do you feel that you cannot or should not ask for help?

#### **ACCEPTANCE:**

Peace: It does not mean to be in a place where there is NO noise, NO trouble or hard work. It means to be in the midst of those things and still be calm in your heart.  
Acceptance happens in small pieces.

Remember: You and your loved one with HD are going through this together, but from a different perspective. You won't be feeling the same feelings at the same time. Share with you loved one where you are at and let them share the same with you. Honor one another's feelings.

## **STRESS**

Stress is very real and can become a vicious cycle. Our everyday stressors, combined with the fact that HD is so life changing and the uncertainty of the future, definitely increases our stress load.

As we all know, stress can cause:

Poor Dietary Choices   GI Symptoms   Frequent Headaches and Colds

Muscle Tension   Sleep Disturbances   How you feel about yourself

Poor Work and Everyday Performance

**LISTEN TO YOUR BODY!!!**

## **THE EMPTY WELL**

Do you cry more than usual?

Can you sleep at night?

Are your thoughts more negative?

Do you feel like yourself?

Are you having trouble just functioning?

Remember...You are an individual first and a partner second!!!

Find Balance and Take Care Of Yourself!

Give yourself permission to have of life of your own, separate from your partner.

You can't genuinely help your partner or loved one with HD, if you are NOT caring for yourself first.

Remember...It is very easy to get BURNED OUT!

## **MANAGING STRESS**

Assign a monetary value to the stressor. Don't waste \$50.00 on a \$2.00 stress!

Simplify Life. Decide what is really important and don't worry about the rest!

BREATHE     EAT RIGHT OR AS BEST YOU CAN

EXERCISE, (even if it can only be a short walk)

Try keeping a journal with you thoughts and feelings.

Enjoy a hobby...something small and easy to manage is a good choice. It is easier to take the time if you know that you are within earshot of your loved one.

Find a way to do something that you love to do.

READ...use the library!

Go to lunch or dinner with friends.

Find beauty in nature.

Allow yourself to take a nap!

Keep a Gratitude Journal...write down 3 things that you are grateful for each day. Try having your family members do the same. It will help keep you positive!

Listen to Music!

Meditate.

Stay in the NOW!

ASK FOR HELP!

**KEEP ON FILLING THE WELL!**

## **MAKING THE TRANSITION**

Organize a Support System!

Collect a box of "Distraction Materials."

Avoid "The What IF's."

Schedule "Worry Time."

Appreciate the good.

Maintain or form healthy habits.

Talk to a counselor or join a support group!

Perhaps talk to your doctor about an antidepressant, or a medication that may be appropriate for you.

**USE YOUR SUPPORT NETWORK!!** You need a place to share and a safe place to vent. You can get ideas from others. You are NOT alone...other people are experiencing this as well.

Give yourself time to grieve and move on.

Try NOT to judge.

Think outside the box.

## **KNOW THAT YOU ARE ENTITLED TO YOUR FEELINGS**

LOSS ANGER FEAR DENIAL SADNESS

ACKNOWLEDGEMENT COURAGE FEARLESSNESS ACCEPTANCE

OPTIMISM

## **RECOGNIZE WHEN YOUR WELL IS RUNNING LOW**

**FILL YOUR WELL AND KEEP IT FULL!!**

## **COURAGE**

**It does not always ROAR. Sometimes it is the quiet voice at the end Of the day saying, "I will try again tomorrow!"**

## **CAREGIVER'S COMMANDMENTS**

Thou Shalt Not Be Perfect or Even Try.

Thou Shalt Leave Things Undone That Ought To Be Done.

Thou Shalt Not Spread Thyself Too Thin.

Thou Shalt Not Try To Be All Things To All People.

Thou Shalt Schedule Time For Thyself And Thy Support Network.

Thou Shalt Switch Off and Do Nothing Regularly.

Thou Shalt Be Boring, Inelegant, Untidy and Unattractive at Times.

Thou Shalt NOT Feel Guilty.

Thou Shalt NOT Be Thine Own Worst Enemy.