Emotional Aspects of Chronic Illness for Individuals and Caregivers

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How do we describe chronic illness?

• Often has an insidious or unrecognizable onset
• May be treatable but not curable
• Symptoms are persistent and recurring
• Impacts mind, body, spirit, and relationships
Chronic Illness ...

• Imposes regular and often immense psychological strain and setbacks
• Challenges the whole family and each individual member
• Impacts and challenges our friends, extended family members, and our physicians
• May bring out the worst in us
• But it can also bring out the best
Typical and Normal Reactions

• Self-absorption: getting lost in our own pain
• Anger, Denial, Depression, Isolation
• Grief: occurs at all stages and phases
• Hopelessness
• Powerlessness
Signs of Caregiver Stress
Courtesy of the Alzheimer’s Association

1. Denial
2. Anger
3. Social withdrawal
4. Anxiety
5. Depression
6. Exhaustion or fatigue
7. Sleeplessness
8. Irritability
9. Lack of concentration
10. Health problems
Note the common elements ...

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It is very common for caregivers to put their own needs last

• And what about guilt?

• Ask yourself if you’re feeling guilty and if that guilt is preventing you from taking good care of your self and addressing your own needs.

• The advice of flight attendants at the beginning of each flight is absolutely true ... you need to take care of yourself first in order to provide adequate care to others.
How Many Hats Do You Wear?

• Patient
• Parent or single parent
• Spouse
• Caregiver to spouse, parent, children
• Caregiving professional: e.g., nurse, teacher, mental health professional
So where do we go from here ....?

First, remember that:

• Adaption to illness is a journey.

• The path is far from straight.
Lesson 1: Educate Yourself

The more you know about your illness:

• The greater your sense of control.

• The better position you will be in to make good decisions for your treatment.

• The more confidence you will have to move forward to make timely decisions.
Lesson 2: Maintain Social Relationships

• Making and keeping social connections is the single most important key to resilience (that is, the ability to adapt, thrive, and persevere in the face of adversity).

• Connections come in many forms, including family ties as well as civic, social, educational, or religious groups.

• “Connection is why we’re here. We are hardwired to connect with others. It’s what gives purpose and meaning to our lives, and without it there is suffering.” Brene’ Brown, Ph.D.
Lesson 3: Learn to Ask for Support and Help

• If you have trouble asking for and accepting help or support, think about why that is and learn how to ask for and accept help and support.

• Brene’ Brown on asking for and accepting help and support:
  Until we can receive with an open heart, we are never really giving with an open heart. When we attach judgment to receiving help, we knowingly or unknowingly attach judgment to giving help.”

• Think about how important it may be to you to help friends and relatives who are going through a difficult time. Don’t deny others the opportunity to give to you.
Lesson 4: Focus on the Positive - Maintain Hope

• Maintain an awareness of the negative but keep it in perspective.
• Focus on the things that you can change and/or control.
• Focus on what you can do rather than what you can’t do.
• Remember that hope is based on realistic expectations.
• Avoid seeing problems or crises as insurmountable.
• Questions to ask yourself when you’re struggling to maintain hope:
  • Can I look at things differently?
  • Does this problem or difficult issue provide new opportunities?
  • Is there any good that can out of this?
Lesson 5: Remember the Mind – Body Connection

• There’s an intricate relationship that’s not always well defined, causing some to believe that the mind and body are inseparable.

• The mind and body affect but do not control each other.
Some things we know about the mind – body connection:

• Physical and emotional stores are restocked during sleep.
• Sleep impacts immune function, energy, mood, concentration, motivation, outlook, and pain level.
• Chronic stress, grief, and depression affect immune function adversely and impair the body’s self-healing potential.
• Exercise affects hormones, circulation, muscles, heart, bones, lungs, nervous system, and protects against depression.
• Exercise is associated with lower mortality and better health outcomes.
Lesson 5, bottom line:

Maximize your emotional adjustment by taking care of yourself physically. Maximize your physical adjustment by tending to your emotional needs. Exercise, eat healthy meals, maintain a healthy weight, get enough rest, spend time with people whose company you enjoy and who are supportive to you, and identify multiple ways to de-stress, relax, and have fun. Discover what works for you.
Lesson 6: Roles and Goals

• Set goals for yourself, and encourage others to do the same. If you don’t know where you’re going, you may end up getting nowhere.

• Be proactive. Focus on things that you can change. Take action and address problems to maintain a sense of control.

• Remember that you don’t do anyone any favors by taking away their roles. If they can no longer do some of what they used to do, perhaps it’s time to identify new roles...

• ... because **we all need to feel a sense of accomplishment**, a sense that we can contribute and make a difference.
How to Know When You’re in Trouble ... When It’s Time to Seek Help

• When you’re uncomfortable to the point that you want to do something asap.

• When your feelings and/or behavior interfere regularly with your ability to function on the job, at home, or as a member of your family.

• When you feel overwhelmed and unable to manage everyday stress.

• When you feel like you’re “stuck.”