Emotional Aspects of Chronic Disease

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Introduction

- Introduce myself and express gratitude for the opportunity to speak at this conference
- Indentifying with the audience: I am 37 year old man living with Polymyositis—was diagnosed with PM in January of 2006 (results from a muscle biopsy, high levels of CPK, etc.)
- Professional experience/credentials

Overview of this session

- Reflections of the past
- * Reflections of the present (emotional impact)
- Experiencing Grief
- Moving forward from grief
- Goal setting
- Closure

Reflections of the Past

What was life like for us and our loved ones prior to diagnosis?

Adjectives to describe our emotional situation (make a check mark next to the corresponding feeling words on your feelings sheet)

Reflections of the Present (emotional impact)

- What is life like for us and our loved ones now (post diagnosis)?
- What are our feelings now? (circle the feelings on your feelings sheet)

Reflections of the Present (emotional impact continued)

- Physical changes in your abilities
- Emotional symptoms
- Cognitive symptoms
- Social symptoms
- Spiritual and religious symptoms
- Grief starts to set in

Experiencing Grief

Have you really grieved or have you just rolled with the punches?

Have you allowed yourself to experience the emotional impact?

Five Stages of Grief

(Based on the work of Dr. Elizabeth Kubler-Ross) (Pikes Peak Hospice, Colorado Springs, Colorado)

- DENIAL AND ISOLATION
- "No, not me, it can't be true."
- Refusing to even talk about it or even thinking about the diagnosis
- Making ourselves busy attending to others' needs and neglecting our needs
- Don't want to be around people

2. ANGER

- "Why me?"
- Often directed outwardly onto other people
- Related to feeling out of control and helpless
- Often accompanied by feelings of guilt ("What could I have done?" "If only...")
- Often a difficult and confusing emotion to cope with

3. BARGAINING

- Most bargains are made with God and usually kept secret
- Often promises are associated with guilt
- Disbelief that we can somehow control this situation
- An attempt to postpone the reality of the loss

4. DEPRESSION

- Manifested when denial, anger and guilt no longer hide the full impact of the loss.
- Clear realization as to the extent of the loss—the loss of talents, potential, companionship and perhaps shared dreams, hopes and plans.

5. ACCEPTANCE

- Not necessarily a "happy" stage.
- Finding a sense of peace with the reality of the loss.
- A realization that not all things in life are understandable or fair.
- An acceptance of our lack of control over many life events.
- A letting go of the anger, fear and guilt

Moving Forward From Grief

(Taken from the works of William Worden)

- Accept the reality of the loss
- Experience the pain of grief (so that you can truly move forward)
- Adjust to the new environment
- Reinvest in life—Emotional relocation

Moving Forward From Grief (continued)

- Select someone in your circle of friends or a family member to grieve with
- Grieve alone if you can't find anyone
- Allow yourself to grieve, cry, mourn, shout, journal, talk to a pastor or counselor, etc.
- Let go of what you cannot control and grasp onto what you can control
- Choose joy!

Goal Setting

Reading of the poem called Happiness

Story of the two men in the nursing home

Write down on the index card three things you are going to do to move forward from your grief and take it home and put it on your refrigerator or mirror

Closure

Audience questions, comments, feedback, input, etc.

Audience completes a five-minute feedback form on this speaker and this presentation/session listing strengths of this session as well as improvements for the future.