

The Experience of Caregiving in Serious Illness

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Emotional Suffering

- **Lived Moment-** Nothing will ever be the same
- **Hidden Feelings:** Anxiety, Fear, Guilt, Resentment
- **Unwanted transitions:** roles, schedules, future
- **Anticipatory Grief:** Lost dreams
- **Bittersweet waiting**
- **Alone**

Caregiver Interactional Suffering

Suffering as a result of an interchange with the health care system

- **1. Lack of attention** (Invisible)
- **2. Understanding** (not listened to)
- **3. Communication** (who & when to call, call back)
- **4. Competence** (making sure nothing goes wrong)
- **5. Limitations** (limitations of medicine)

ACTION STEPS

1. Implementation of the TRIO Guidelines

Focus on policies, practices, environment that lead to interactional suffering

2. Recognition of Social Work as Caregiver Advocate

- ◆ Qualifications-Education/certification

- ◆ Staffing standards: Once a month is NOT enough

3. Standardized caregiver assessments; depression, anxiety, health

1. Tested interventions focused on improving caregiving experience

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For additional information on the experience of caregivers
and patients with serious illness see
www.Dbocancerjourney.blogspot.com