

Clinical Research from the Patient Perspective

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Introduction to the Principles & Practices of Clinical Research

January 23, 2006

SESSION OUTLINE:

I. Understanding the Patient

- Impact of illness on patients
 - Debility
 - "Grief"
 - Disorientation
 - Loss of control

- Struggling with the clinical environment
 - Difficulties in navigation
 - Loss of personal identity
 - Apprehension regarding clinical trials
 - New faces, new rules

- Levels of knowledge about disease

- The power of palliative care

II. Understanding Family Caregivers

- Life disruption
- Worry about the patient
- Inability to "fix" the problem
- Financial burdens

- Overload
- Struggling to learn about the disease and its impact
- Learning to provide care
- How caregivers can help you
- What caregivers need from you

III. Key Components in Patient Support

- **Becoming an expert patient communicator**
 - Basic skills
 - Treating the whole person
 - Realigning allegiances
 - Understanding today's "new" patient
 - Listening - more than a 9-letter word
 - What you do and don't do matters
 - Questions Make the Difference
 - Language issues
 - Taming the Clinical Beast
 - Being present
- **Managing Bad News**
 - Settings
 - Language
 - Company
 - Timing

- Ethics
- Support

- **End of Life Issues: When Cure Isn't Possible**
 - Palliative care -center stage
 - Understanding hospice care

 - What matters to your patient?

 - Advance directives

IV. Empowering your Patients

- Why this helps you and your patients

- Encouraging assertiveness: techniques and suggestions