

# Clinical Research from the Patient Perspective

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*Introduction to the Principles & Practices of Clinical Research*

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## SESSION OUTLINE:

### I. Understanding the Patient

- \* Why people participate in clinical trials
  
- \* 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

### 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
  - Being present
- \* Effective introduction to a clinical trial
  - Institutional attitudes make all the difference
  - Respectful presentation

- The truth about: randomization, money, side effects, life style

- \* 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