

# THE EDUCATED PATIENT: A PATIENT'S PERSPECTIVE

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- I. Who is an educated patient?
  - a. A partner – someone willing to learn, reflect, act and teach along the way
  - b. A seeker and a source of a wealth of mission critical information
  - c. The captain of the ship with an accomplished crew
  - d. A sharer of responsibility of the “healthy path”
  - e. A grown up – knowing what can be controlled and what can't
  
- II. Why educate patients?
  - a. Self-determination – it's the patient's body and life
  - b. Minimization of error, improvement of outcomes
  - c. So real choice can be presented and achieved in the provision of care
  - d. So burden of decision making can be reasonably shared
  - e. Consequences can be understood, experienced and shared together
  - f. Partnership can be achieved, relationships can be built
  - g. Patients can have dignity and respect (and HCPs too)
  - h. Patients and families can make good decisions based on facts and likely outcomes.
  - i. Avoid misinformation, conjecture and “quack” science
  
- III. What impedes patient education?
  - a. Patients:
    - i. No invitation, No importance given
    - ii. Low self-esteem, beaten down by diagnosis
    - iii. Fear
      - of loss of control of “inputs”
      - of losing hope
      - of encountering unwanted information
      - of upsetting the doctor/HCP with “questioning”
    - iv. Depression
    - v. Denial
    - vi. Information overload
    - vii. Misdirected research often lead astray by “search engines”
    - viii. Family screening (based upon fear, control, cultural traditions, etc.)
    - ix. Too much of an emotional burden with disease
    - x. Information often filled with jargon and directed to HCP's
  - b. HCP's:
    - i. Not trained
    - ii. “It's complicated...”
    - iii. Time not scheduled (short term gain = long term loss)
    - iv. Unguided research and subsequent overload
    - v. Sensitivity about identified “expert”
    - vi. Desire to keep patients from charlatans
    - vii. Patients resist
    - viii. Families resist
    - ix. Father knows best
    - x. You'll be happier if I just...
    - xi. Compassion gone awry
    - xii. “Preserve” hope by keeping it simple
    - xiii. Judging the right time, hesitating for the “learning moment”

- IV. Some thoughts on educating patients:
- a. HCP must be honest, accurate and complete.
  - b. Honesty and kind directness build trust and relationships (and save time)
  - c. HCP must commit to partnership to the end – whatever that end might entail.
  - d. HCP must acknowledge the insights both the HCP and the patient bring to the relationship
  - e. Patients have a natural “hope” seeking missile within – new hope will be found.
  - f. Loss of professionalism? Perhaps loss of professional mystique.
  - g. Search engines are mostly fine and helpful as a basic research tools re: diagnosis ABC’s and clinical trials, etc. Most patients are savvy about “urban legends.”
  - h. We need to give patients basic info about their disease very early so their research can be targeted accurately.
  - i. We need to refer patients to good information sources early. How about a research packet by diagnosis to hand out at initial appointment?
  - j. We need to offer a “syllabus” or learning guide to patients that emphasizes the key information to be learned along the course of their disease
  - k. Over the top information addicts must be given a contact at the HCP’s office that can help process information. Time tends to reduce this need.
  - l. HCP’s must “read” a patient’s learning style and interpret the patient’s use of “outside” information. There’s often a deeper story going on. A story that reveals the beginnings of a partnership – if understood and harnessed – and the beginnings of mistrust – if by-passed and ignored.

# The Educated Patient: A Patient's Perspective

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## Who is an educated patient?

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  - A sharer of responsibility for the “healthy path”
  - A grown up – knowing what can be controlled and what can't
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## Why educate patients?

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- Self-determination – it's the patient's body and life
  - Minimization of error, improvement of outcomes
  - So real choices can be presented and achieved
  - So decision burden can be reasonably shared
  - So consequences can be understood and shared
  - Partnership can be achieved, relationships built
  - Patients & HCP's can have dignity and respect
  - Patients and families can make good decisions based on facts and likely outcomes.
  - Avoid misinformation, conjecture and "quack" science
- 

## What impedes patient education?

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- For Patients:
    - No invitation, No importance given
    - Low self-esteem, beaten down by diagnosis
    - Fear
      - of loss of control of "inputs"
      - of losing hope
      - of encountering unwanted information
      - of upsetting the doctor/HCP with "questioning"
    - Depression
    - Denial
    - Information overload
    - Misdirected research often lead astray by "search engines"
    - Family screening (based on fear, control, culture, etc)
    - Too much of an emotional burden with disease
    - Information often filled with jargon and directed to HCP's
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## What impedes patient education?

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- HCP's
    - Not trained to teach it
    - "It's complicated..."
    - Time not scheduled (short term gain = long term loss)
    - Fear of creating a monster (OCD pt w/non peer reviewed new treatment "discoveries")
    - Unguided research and subsequent overload
    - Sensitivity about identified "expert"
    - Desire to keep patients from charlatans
    - Patients resist
    - Families resist
    - Father knows best
    - You'll be happier if I just...
    - Compassion gone awry
    - "Preserve" hope by keeping it simple
    - Awaiting the right time, hesitating for the "learning moment"
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## Some thoughts on educating patients:

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- HCP must be honest, accurate and complete.
  - Honesty and kind directness build trust and relationships (and save time).
  - HCP must commit to partnership to the end – whatever that end might entail.
  - HCP must acknowledge the insights both the HCP and the patient bring to the relationship.
  - Patients have a natural "hope" seeking missile within – new hope will be found.
  - Loss of professionalism? Perhaps loss of professional mystique.
  - Search engines are mostly fine and helpful as a basic research tools re: diagnosis ABC's and clinical trials, etc. Most patients are savvy about "urban legends."
  - We need to give patients basic info about their disease very early so their research can be targeted accurately.
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## Some thoughts on educating patients (cont):

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- We need to refer patients to good information sources early. How about a research packet by diagnosis to hand out at initial appointment?
  - We need to offer a “syllabus” or learning guide to patients that emphasizes the key information to be learned along the course of their disease
  - Over the top information addicts must be given a contact at the HCP’s office who can help process information. Time tends to reduce this need.
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## Continued Collaboration?

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