

Difficult Conversations: Bridging the Communication Gap with your Oncologist

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Choosing your Care Team

- No one is prepared for a diagnosis of a life threatening illness
- Explore your options
- Build your supportive team
- Enlist the help of trusted advisors

Preparing for a Consultation

- Ask for information
- Obtain all **necessary records** including biopsy slides for review and imaging studies on disc, check that everything was received and reviewed prior to your visit
- Learn about **resources** available at the Cancer Center or Oncology office you are visiting
- Patient navigators? Resource rooms? Patient libraries? Support groups? Social workers? Supportive services?
- Arrive early to observe the staff and facility, get a “feel”

What are the Ground Rules?

- Punctuality
- Respect
- Transparency
- Costs
- Resources
- Flexibility



Becoming Partners



"My approach is nontraditional, but from a uniquely Western perspective."

Setting Expectations

- Doctors are not mind readers, you need to participate in the conversation
- Who will return your phone call and when?
- Who covers for your doctor at night or weekends?
- Where does your doctor admit her/his patients?
- Who are the members of the professional team?
- What is important for you and your family?

Establishing Means of Communication

- In person?
- Phone?
- Time expected for call back? After hours?
- Email or MyChart?
- Can you record a visit?
- New technologies for recording symptoms or asking questions?
- What about weekends?

Exchanging Information

- You are an expert in your life, your worldview
- Your oncologist is an expert in the treatment of your disease
- Don't hesitate to ask questions, bring materials to review
- Don't worry about burdening the clinician or clinic staff
- Bring a friend or family member to appointments as a second set of eyes and ears, an advocate
- Keep notes or a journal to refer to

Empowered Decision Making:

- **Current tests and scans**
 - Location, volume
- **Pathology**
 - Type of tumor
- **Hereditary mutation status**
 - *Genetic testing recommended for all ovarian cancer patients*
 - BRCA
 - Lynch Syndrome? BROCA Panel?
- **Other information**
 - Molecular profiling?
 - Assays?
- **Communication**
 - Open and honest dialogue
 - Ask questions; Negotiate
- **Plan to manage side effects**
- **Be your own advocate**



Empowered Decision Making: Clinical Trials

- Consider using clinical trials to expand treatment options.
- Consider participating in clinical trials sooner. The fewer lines of therapy someone has had, the more trials they can qualify for.
- Many novel drugs and targeted therapies are paired with approved drugs in trials. Discuss with your medical team whether it is reasonable to delay using those particular approved drugs to help maintain eligibility down the road.



<http://www.cwrf.com/phase-i-ii-iii-or-iv/>

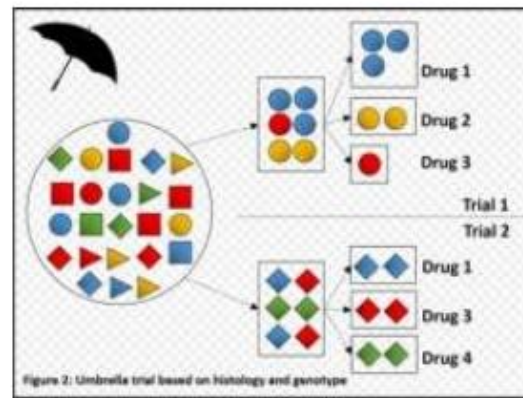


Figure 2: Umbrella trial based on histology and genotype

<http://www.bhdsyndrome.org/>

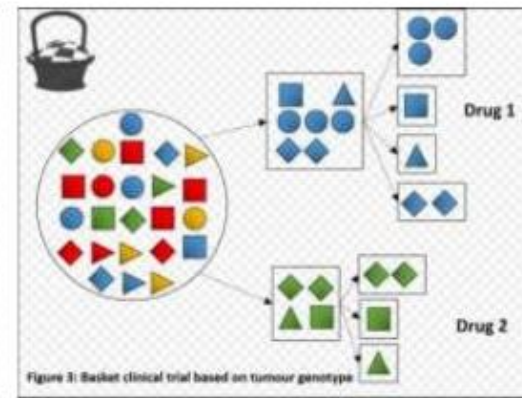


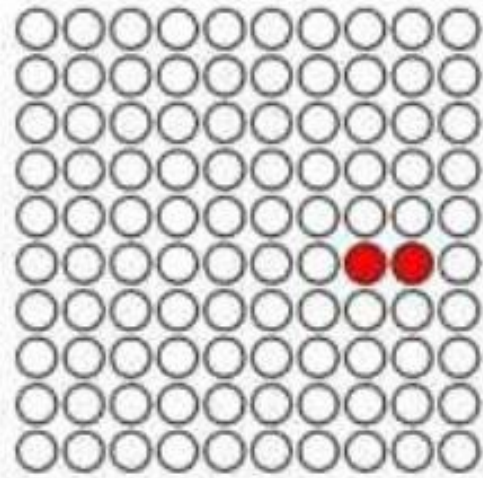
Figure 3: Basket clinical trial based on tumour genotype

<http://www.bhdsyndrome.org/>

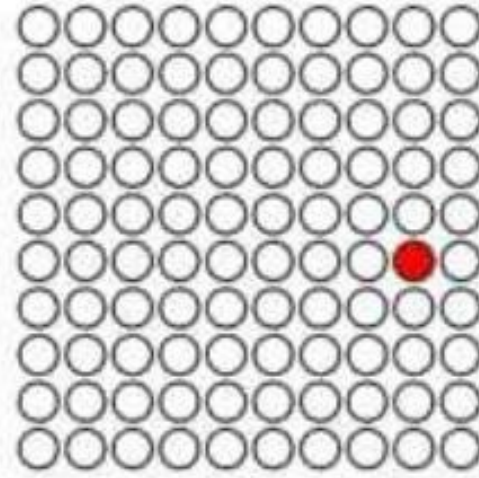
Understanding Medical Jargon

- Technical language is frequently unclear, ask for clarifications
- Misunderstandings are common
- When treating a patient, doctors use numbers from research studies to tell them which treatments are likely to work
- Common words may take on different meanings: such as “cure”, “treat”, “risk”, “disease-free survival”, “overall survival”, “response”

Framing



A 2 in 100 chance if you don't take aspirin.



A 1 in 100 chance if you do take aspirin.

Doctor A might say “ A study shows that aspirin will reduce your risk of a heart attach by 1 percent (from 2 percent) and Doctor B will say “Your risk is reduced by one half, or 50%

What is Remembered

- Many studies show that doctors and patients often have different recollections of what was discussed during a medical visit
- It may help to summarize what you heard and understood at the end of each visit
- There may be a nurse or social workers in the cancer center or doctor's office who may be available to debrief or clarify some of the concepts discussed
- Written After-visit summaries are helpful

Understanding Prognosis

- The word prognosis may be unfamiliar
- Prognosis: a prediction of the course of disease, the outlook for the chances of survival or the estimate of recurrence of disease
- Some people prefer not to hear or discuss time frames or statistics
- Most people want to know their prognoses if the news is good... but fewer want to hear the details if it's not so good

Doctors may have Difficulties Communicating

- Clinicians may not have had adequate training in communication
- They may seem distant or uncomfortable with display of emotion
- They may “censor” information if they sense a patient prefers not to know or seems emotionally fragile

I Want to be Known as a Person

- Historical Evolution of the patient role: from victim to empowered participant in their care
- It is important to feel known and heard, as a person bearing the illness

A Satisfying Relationship

- Communication is meaningful and knowing you have access can be comforting
- What do you need from your oncology team? Promptly returned phone calls? Candor regarding side-effects and possible outcomes? Respect for your preference to continue integrative therapies or complementary therapies or avoid more toxic treatments?
- Partnering in your care, feeling you are in the loop when decisions are being made, is likely more satisfying than taking a more passive approach
- Different people prefer different levels of involvement in making decisions, ask yourself what is best for you

Handling Bad and Disappointing News

- Each of us finds our own way of coping with the shock of unwelcome news
- Spending more time with loved ones, pursuing passions and activities that had been put on hold, achieving insight
- Putting a plan in effect to “fight”, organizing information and findings options

Joan Sommer:

“Surviving and living with ovarian cancer is not an arbitrary period like five years. It is an everyday thing where you wake up, take a deep breath in spite of your fears and pain, and find a way to take your place in the world”

“Surviving cancer is not a place you strive for in the distance. It is here and now. You are in it. It is up to you to be part of it, to find your hope.”

“Hope is falling asleep and expecting to wake up each day in spite of what you might have heard. It is thinking about the possibilities not probabilities. It is preparing to die but expecting to live.”



**“When faced with uncertainty
there is nothing wrong with hope.”**

Helping Each Other

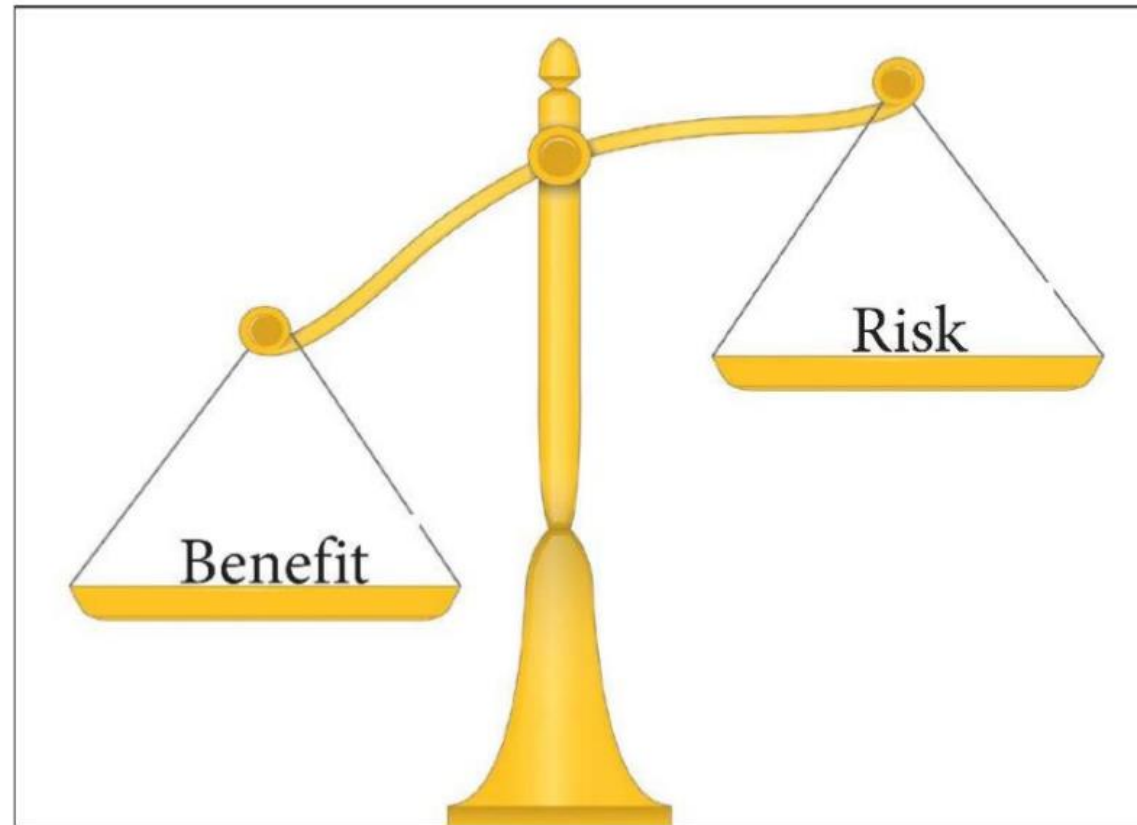


"How long did I tell you you had to live?"

Negotiating Different Perspectives

- It is important to understand your choices
- It is also important to respect the needs and wishes of your family to be involved (or not)
- It may be helpful to ask yourself what determines your quality of life

There are Risks and Benefits to Every Treatment Decision



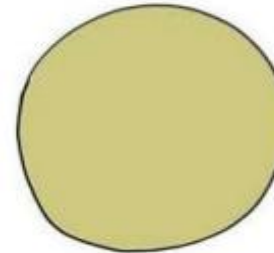
Initiating a Difficult Conversation

- Doctors and patients can be equally reluctant to speak openly about an incurable illness or the failure of a treatment to provide a good result
- Sometimes there are no good choices
- Uncertainty makes people feel anxious and does not allow the oncologist to be precise in charting a way forward
- Living with uncertainty is challenging, many patients find comfort in action
- Ask yourself, what will I regret putting off?
- Make a “bucket list”
- Consider your wishes for advanced directives so that your loved ones know what they are

Coping

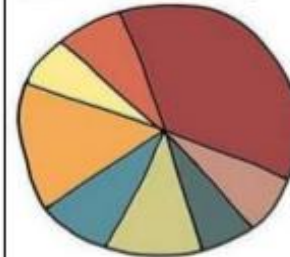


WHAT PEOPLE THINK ANXIETY FEELS LIKE



☐ WORRYING ABOUT EVERYTHING, ALL THE TIME

WHAT ANXIETY ACTUALLY FEELS LIKE



☐ sweating, a lot
☐ second-guessing yourself
☐ muscle tension
☐ trouble sleeping
☐ chest pain
☐ over-thinking all the things
☐ increased heart rate
☐ Your mind and body refusing to cooperate, no matter what you know is rational

Involving Family and Informal Caregivers

- Being ill can be isolating
- Friends and family may not always understand what you are going through and may be experiencing various degrees of emotional distress
- Avoiding any possible difficult conversation with family, putting it off – is common. Ask yourself why? Who are you protecting?

An Inspiring Thought

“It’s been little over a year now since I discovered I have a fatal disease. In trying to explain to family and friends what having this period of time has meant to me, I have found it helpful to characterize it as a gift.”

“To live in the bright light of death is to live a life in which colors and sounds and smells are all the more intense, in which smile and laughs are irresistibly infectious, in which touches and hugs are warm and tender almost beyond belief... I wish that the final chapter in all your stories can have a chapter in which you are given the gift of some time to live with your fatal illness.”

-Bill Bartholome, MD

Finding Sources of Support

- Family and loved ones also need support
- Peer support through social media, support groups
- Religious or spiritual counselors
- Nature, solitude
- Professional help
- National Helpline: 844-ASK-SHARE



Various internet sources, SHARE and Robin Cohen