

When the news isn't good: Having the conversation



Survivorship Forum 2015
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BC Cancer Agency
CARE & RESEARCH

Today's presentation

- Cancer Course
- Challenges
- Frameworks
- Guides and considerations



The Cancer Course

- **Diagnosis** “Existential Crisis”
- **Treatment** “The Long Haul”
- **Rehabilitation/Remission** “Limbo”
- **Survivorship** “Sword of Damocles”
- **Recurrence/Metastasis** “Life in Balance”
- **Terminal** “In a Strange Land”



Challenges at Diagnosis

- Existential Crisis – “Why Me”?
- Facing Mortality
- Understanding Complex Information & Systems
- Making Decisions
- Telling Family & Friends





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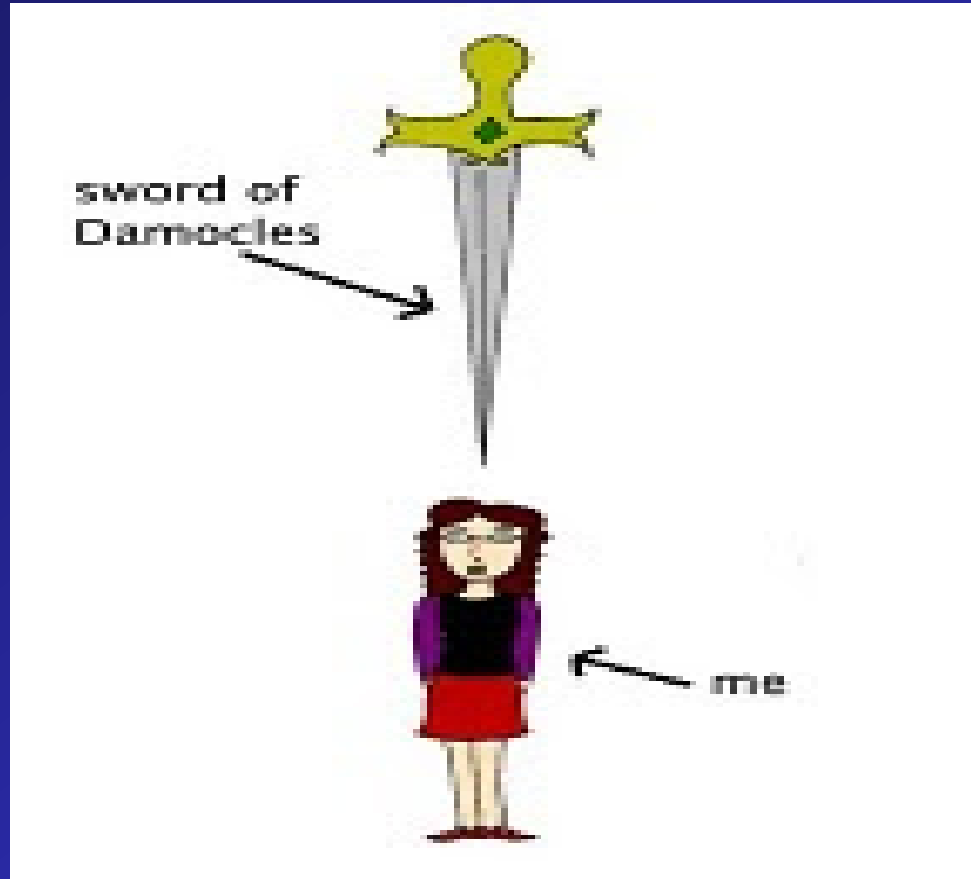
What do people want/need

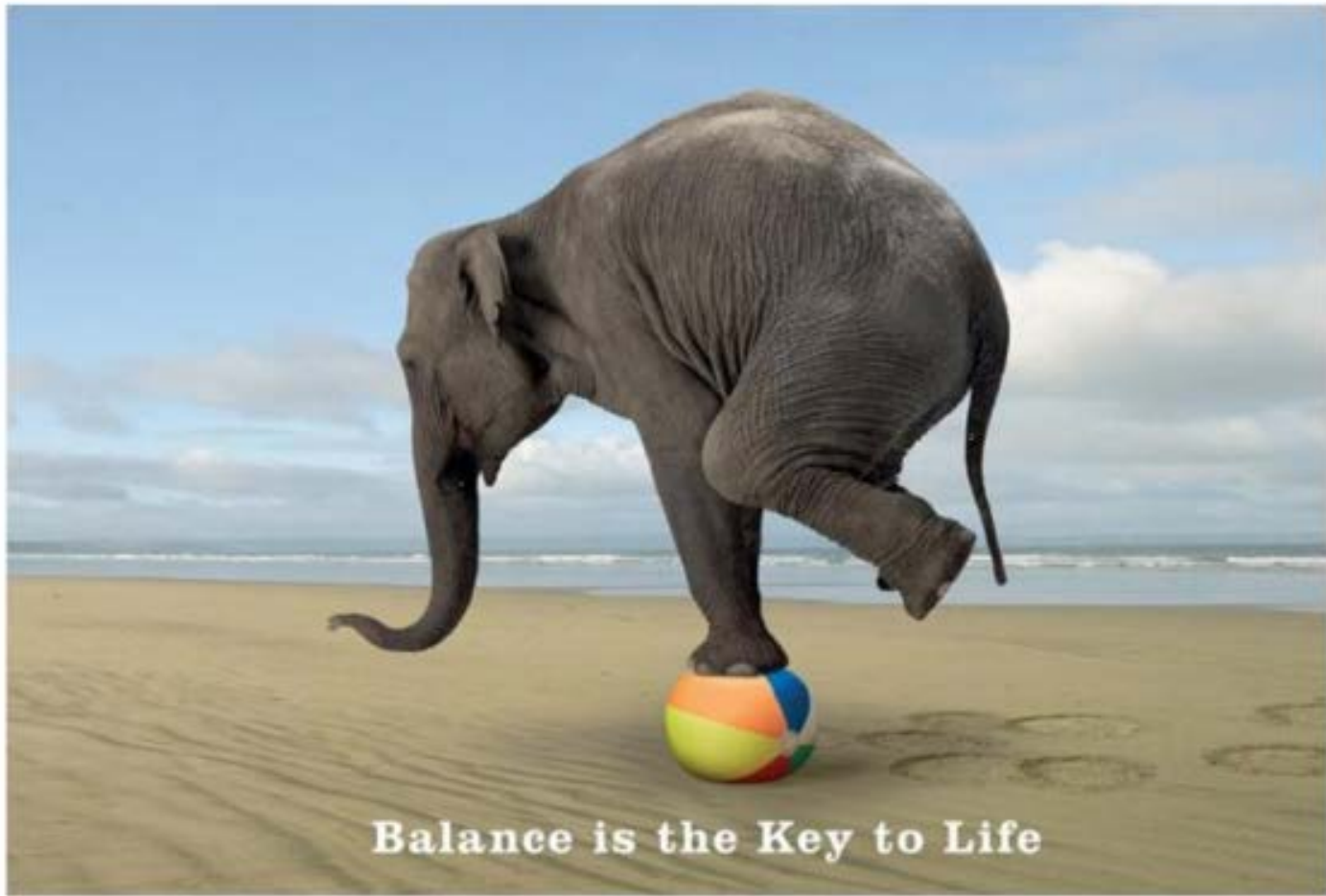
- Recognition – someone to notice
- Having agency – to remain active
- Community- a sense of connection



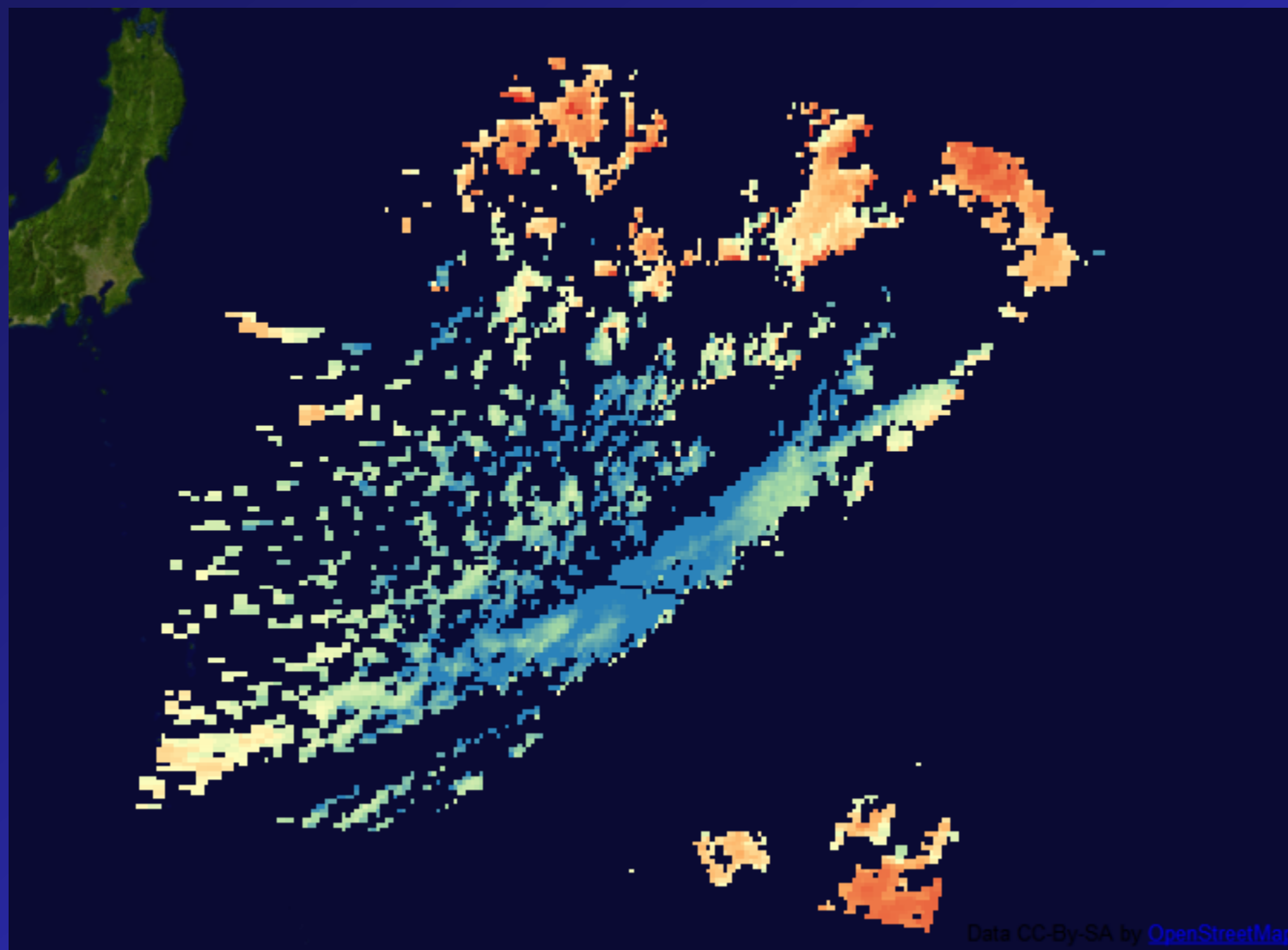


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The “New Normal”

- Transitioning to “Survivorship”
- “Now What?” & What will life be like now?
- Lost and found
- Fears of Recurrence
- Longer term impact on daily living
- Others may not understand it’s not *over*
- Not a “one size fits all” process
- Physical & Emotional components

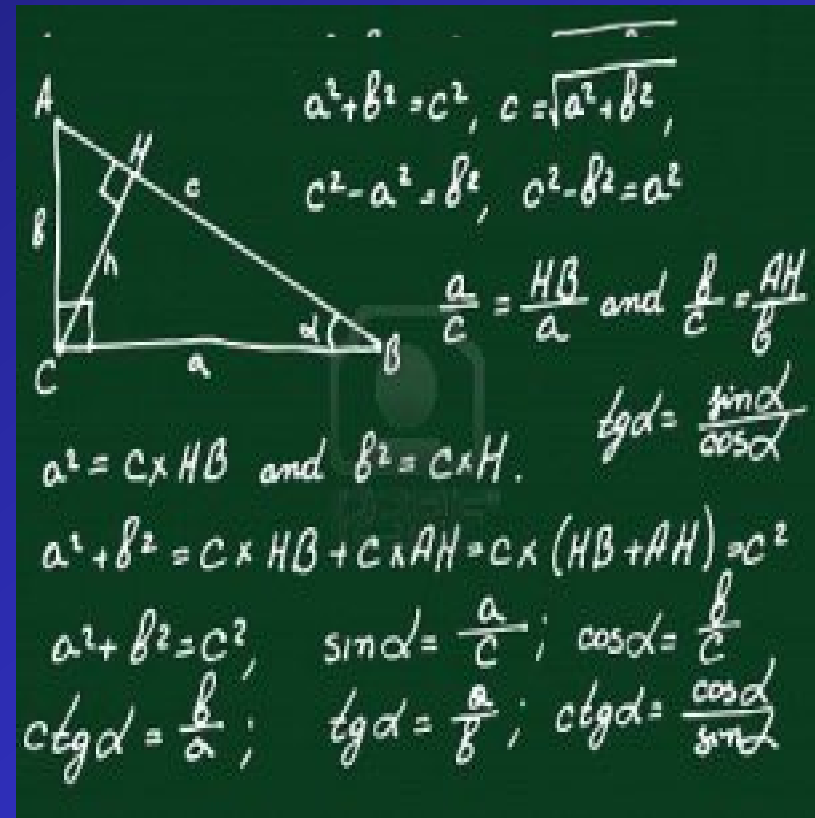


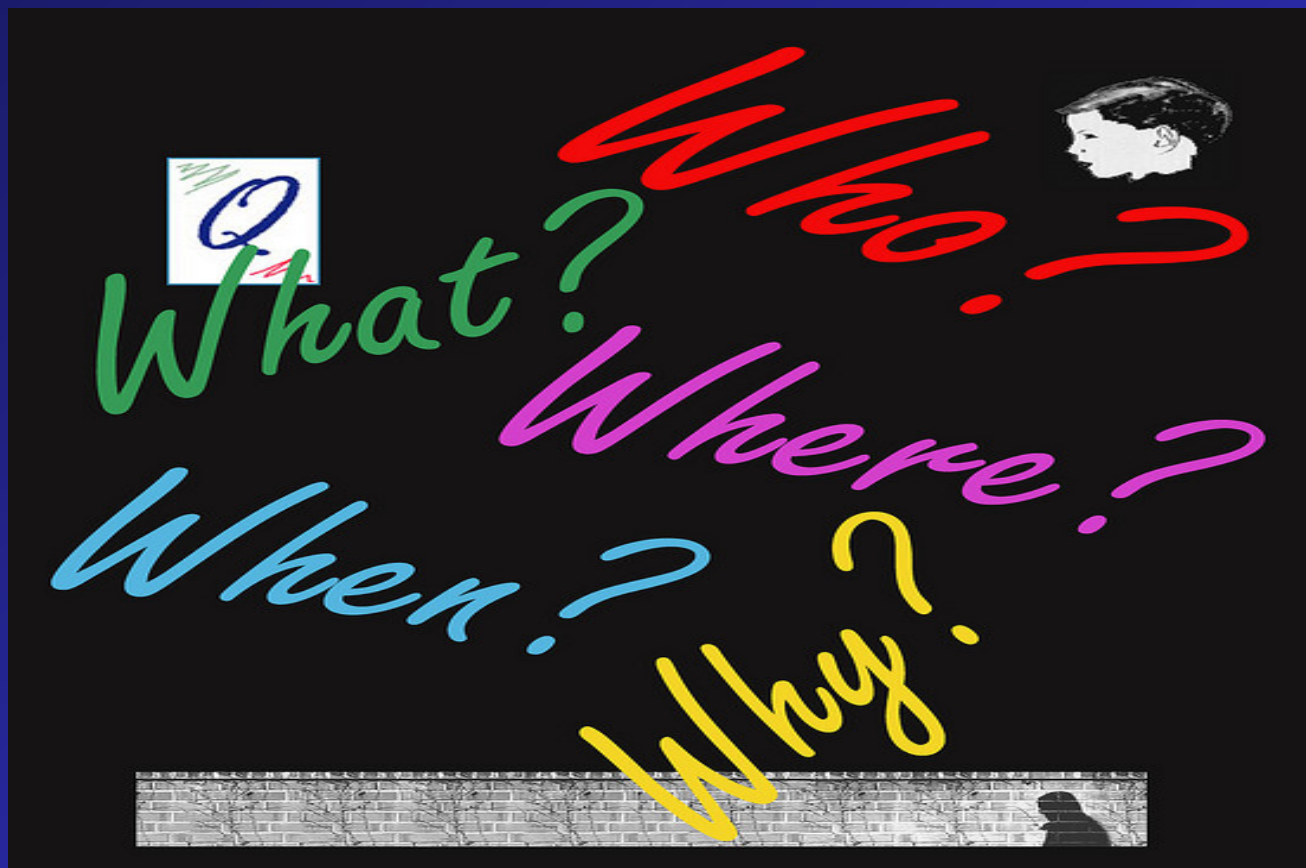


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There is no “one” formula for conversation

The answer is:
??????????







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It will depend on:

- Cancer Trajectory
- Previous life experiences
- Individual developmental stage
- Family Life Cycle
- Role in family
- Support systems
- Relationship



Considerations:

- Previous experience
- Self-esteem
- Stage of cancer
- Stage of life
- Beliefs/values
- Role in family
- Other life struggles
- Personality
- Coping resources
- Spirituality/faith



A framework for the experience

- Arthur Frank, medical sociologist, names three kinds of stories that people tend to make in the wake of illness and suffering
- The stories intersect and overlap
- Naming the story can provide a way to know where one is on the map



The quest story

- **A person journeys through and faces suffering in the belief that something is to be gained from the experience.**
- **A story of transformation and change**
- **Most approved story.**



The restitution story

- In western society there is a belief in restorable health.
- I was healthy, now I am sick, but tomorrow I will be healthy again.
- People with chronic illness do not fit this story and find it difficult to tell a story which does not appear to have been restored.
- Process of finding restitution



The chaos story

- Frequently unheard; lived chaos cannot be told; least approved story; overwhelming
- Often disjointed and without sequence





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Guides

- Give yourself time to absorb the news /speak your truth
- Talk to counsellor
- Chose a special time/place
- Acknowledge emotions
- Opportunity to ask questions
- Making plans to meet again



Guides cont'

- You might like to write down what you would like to say
- When ready , talk with your partner or other adult support person about what you would like to say to your children



Discussion with children :

- Information about the cancer
- Feelings and concerns
- Changes which may affect your children
- Research demonstrates that open and honest communication promotes resiliency/ post traumatic growth in children





The Guest House

*This being human is a guest house.
Every morning a new arrival.
A joy, a depression, a meanness,
some momentary awareness comes
as an unexpected visitor.
Welcome and entertain them all!
Even if they're a crowd of sorrows,
who violently sweep your house
empty of its furniture,
still, treat each guest honorably.
He may be clearing you out
for some new delight.
The dark though, the shame, the malice,
meet them at the door laughing,
and invite them in.
Be grateful for whoever comes,
because each has been sent
as a guide from beyond.*

-Rumi 13th C poet



