

Building Resilience, Sharing Stories of Hope

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Hope can be...

- A statement of preference
- A comforting emotion
- A source of motivation
- An expectation (perhaps unrealistic)
- A vulnerability to disappointment



Hope and human struggle

- Hope predates modern medicine by 1000's of years
- Legends, stories, myths feature moments when hope emerges after all seems lost



The roller coaster

- Sequence of medical events (test results, screening results, surgery impacts, etc.) create a series of hope and disappointment

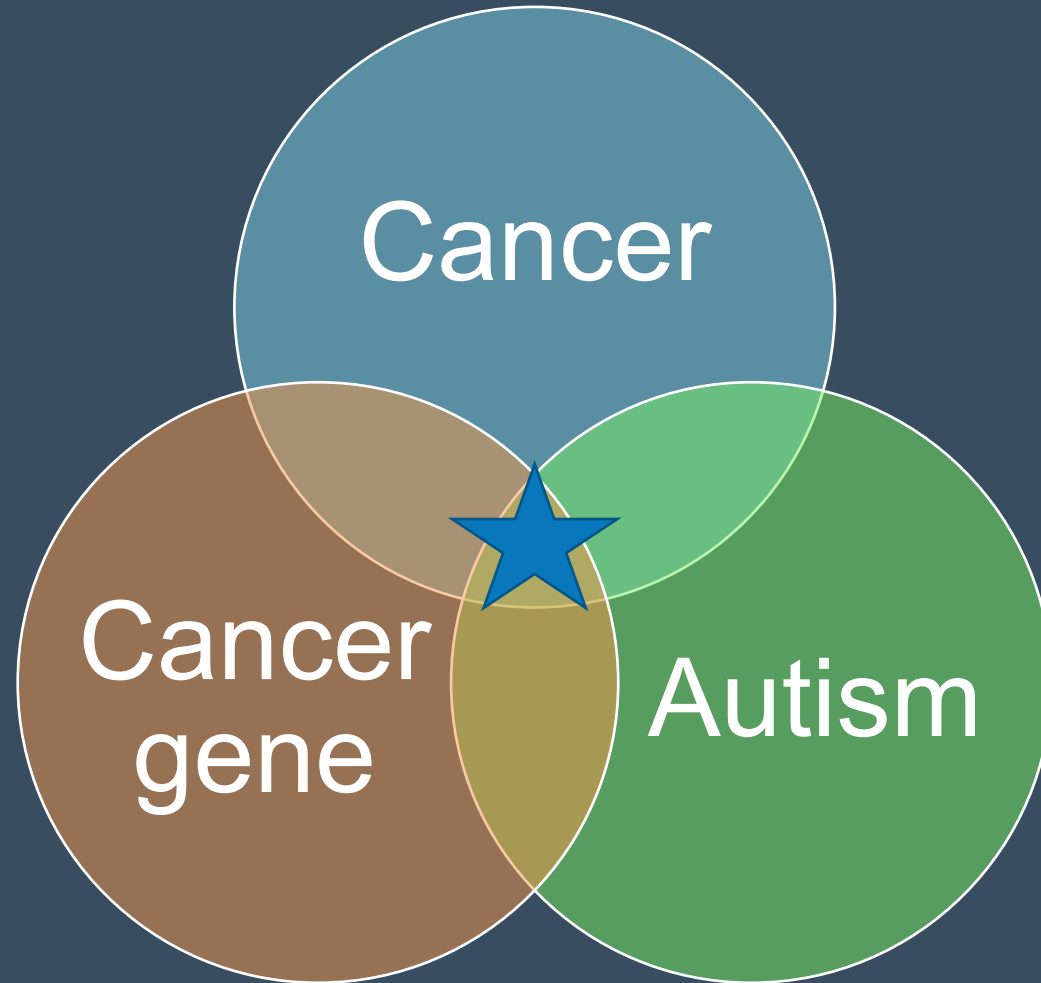


Randomness

- Genetic risk is random –science cannot explain who gets it and who doesn't
- Goes against beliefs about order and fairness



Finding support



When you're the one...



What is resilience?



Invincible hero?



Special magic?

Adjusting your quality of life

- Re-prioritize:
 - What's important to you now?
- Re-calibrate:
 - What's your measure of a good day?
- Re-define
 - How do you define "quality of life" today?
- Re-focus:
 - What *can* you do? What's going well?



Matisse

“By the time he made this picture, Matisse was over 80 and too ill to paint. So he came up with a new technique [cutting up] colored paper...he called this “drawing with scissors.” With his assistant’s help, the shapes were then arranged and glued down. This method is known as collage, from *colle*, the French word for glue.”



Rosie Dickens, *The Children’s Book of Art*

J.'s (age 9) list of what you could or couldn't do if you broke your arm:

Can't do

- “Cook as well (it would be hard)”
- Paint walls
- Play
- Move the arm
- Go swing
- Hang stuff up
- Any sport”



Can do

- “You could pour water in a cup
- You could walk
- You could still paint stuff but different
- Color
- Use your phone
- Take a picture
- Write
- Read a book”



Positive self-coaching



Reducing hassles

- More closely tied to moods than other kinds of stress
- Big events (even positive ones) can trigger landslide of hassles
- “What’s one thing you can simplify?”



Respite

- Stress followed by respite *increases* tolerance for new challenges
- Stress without respite *decreases* tolerance
- People avoid respite due to guilt, worry, or negative beliefs

Invisible losses

- Life plans
- Imagined future self
- Imagined child's future



Family challenges with autism

- Behavioral problems prevent access to important forms of support (e.g., church, family gatherings) and recreation
- Almost half of families report no outside support

Resilience, family style

- Smooth routines that accommodate everyone's needs
- Prioritize enjoyable activities
- Couple/adult time
- Attention to each child
- Stable adult allies



What is resilience?

Resilience is something we
do: Creating good
outcomes in the face of
challenge

Resilience is always *now*:
What's one step you can take
to get closer to back on track?

Hope and resilience

- “...quality of life is not just what [people] have in their life (a certain list of important things) but also *how* to be in that life.”





Every life deserves world class care.