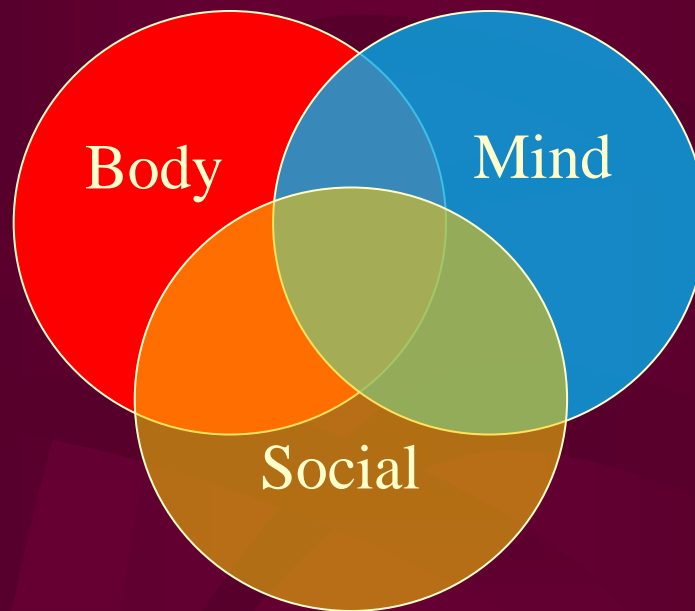


# Healing Beyond The Body: Emotional Health After Childhood Cancer



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# Why Are We Talking About This?

- Childhood cancer can affect people years after treatment
- Effects can be
  - Negative
  - Positive
  - Often both



# Why Are We Talking About This?

- Understanding cancer's effects can help:
  - Manage the ones that need managing
  - Weave them into a personal history that is meaningful



# Understanding Long-term Effects

- What are common psychological late-effects?
  - Emotional adjustment
  - Learning & work
  - Social adjustment
  - Enhanced growth & meaning
- How does the childhood cancer experience change personal development in young adulthood?

# Problems in Perspective

Most survivors in CCSS are well-adjusted

- 83% had no severe mental health problem
  - 94% employed
- 
- Distress is common in the general population
    - Almost half of Americans have a mental disorder in their lifetime

# Common Challenges

Survivors at **increased** risk for

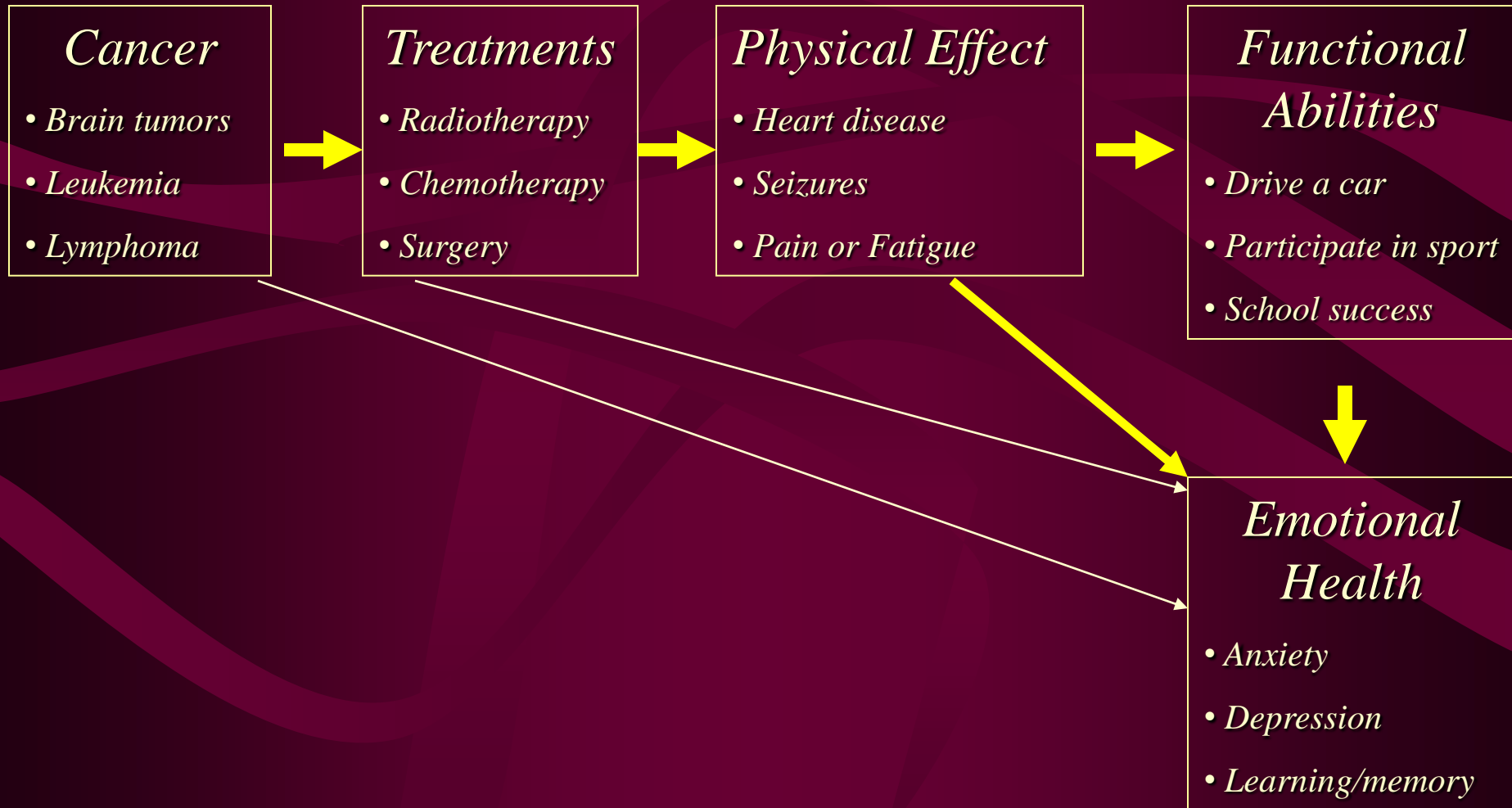
- Depression & anxiety
  - Usually not severe, but enough to affect quality of life
- Learning, school & work problems
- Worry about future
  - Health, work, independence, fertility
- Not “fitting in” well with peers
  - Talking about cancer, sexuality & dating
- Tension with family

# Common Challenges

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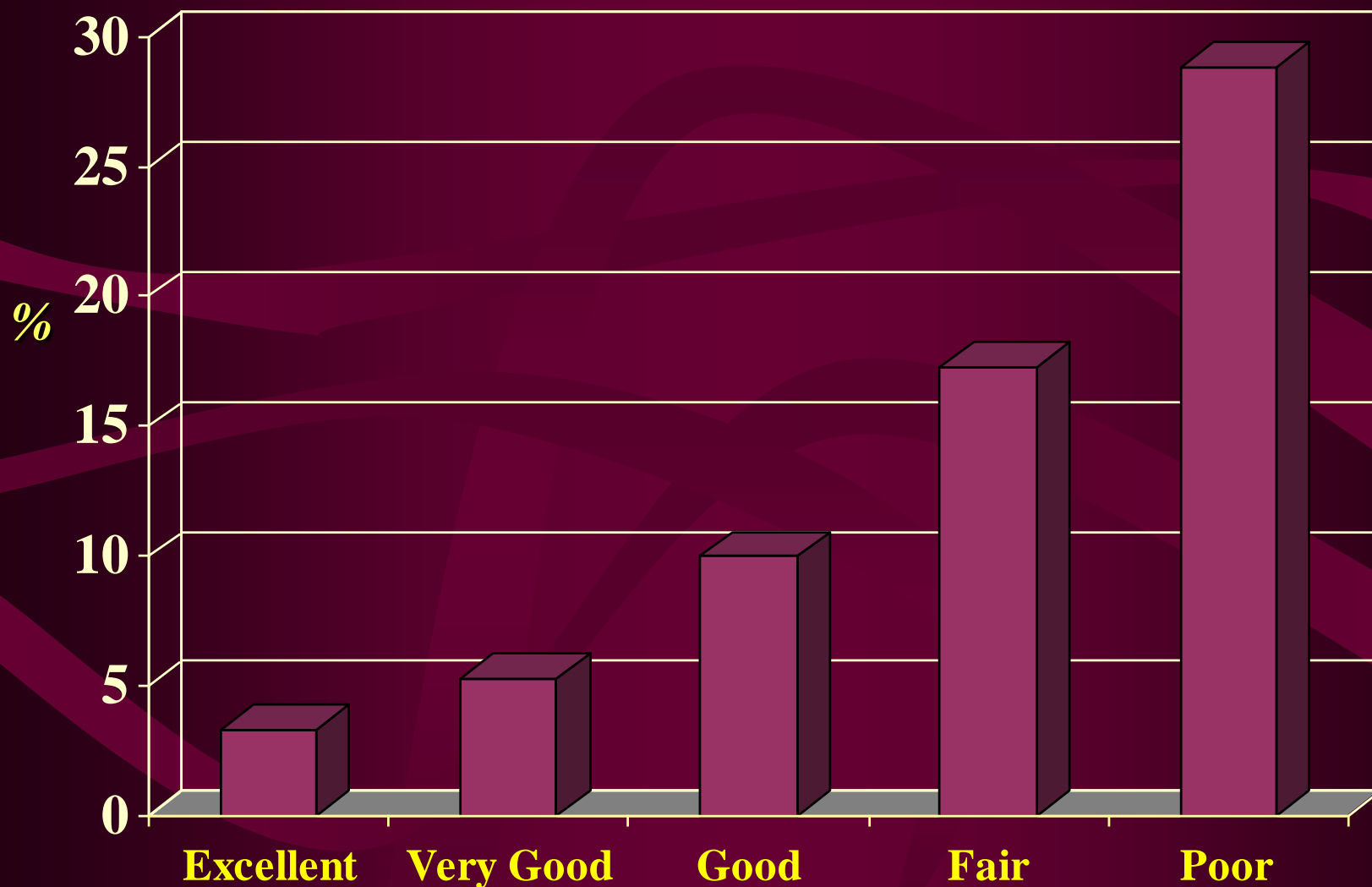
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# Cancer and Distress: A Conceptual Model





# Health Ratings & Suicide Ideation



# Common Challenges

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# Cancer Treatment & The Brain

- Children's brains are particularly sensitive to the effects of radiation & some chemotherapies
- Cancer or cancer treatments that affect the brain can cause later problems in attention, learning & memory
- These problems can make school, work and social situations more challenging
  - Can lead to depression & other adjustment problems

# John—19 years old

## Medical History

- Had osteosarcoma at 14.
- Ongoing problems with a bone graft;
- 11 surgeries in 5 years.
- At 19 is told he needs a new bone graft
  - Has not finished high school, is on disability
  - Family has significant financial problems
  - Is acutely aware he is being “left behind”

# John

- Talks openly about symptoms of depression in interview and on self-report rating scales
- Sad, lonely, hopeless—especially in relation to school/career
- Some thoughts of suicide, but no plan or past attempt
- Functioning ok with moderate depression

# Jennifer—28 years old

## Medical History

- Had Advanced Hodgkin's disease at 15
- Originally misdiagnosed with a different cancer
- Anxious and passive young girl from a family with history of anxiety disorders.
- Hated needles throughout her treatments
- Had ongoing problems with nausea and vomiting.

# Jennifer

- Now 28 is healthy, married, not working, thinking about children
- Continues to be “a worrier”
  - Avoids news stories about cancer or health
  - Avoids reminders of her own illness
  - Panic attacks in college treated with medication & therapy—since resolved
- Has many anxiety symptoms but no serious impairment

# Common Challenges

Survivors at **increased** risk for

- Depression & anxiety
  - Usually not severe, but enough to affect quality of life
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# Adolescence: A Critical Period

It is the time of acquisition of skills and interests, occupational, educational, and interpersonal, that will be relied on into old age;

*Jessor & Jessor, 1977*

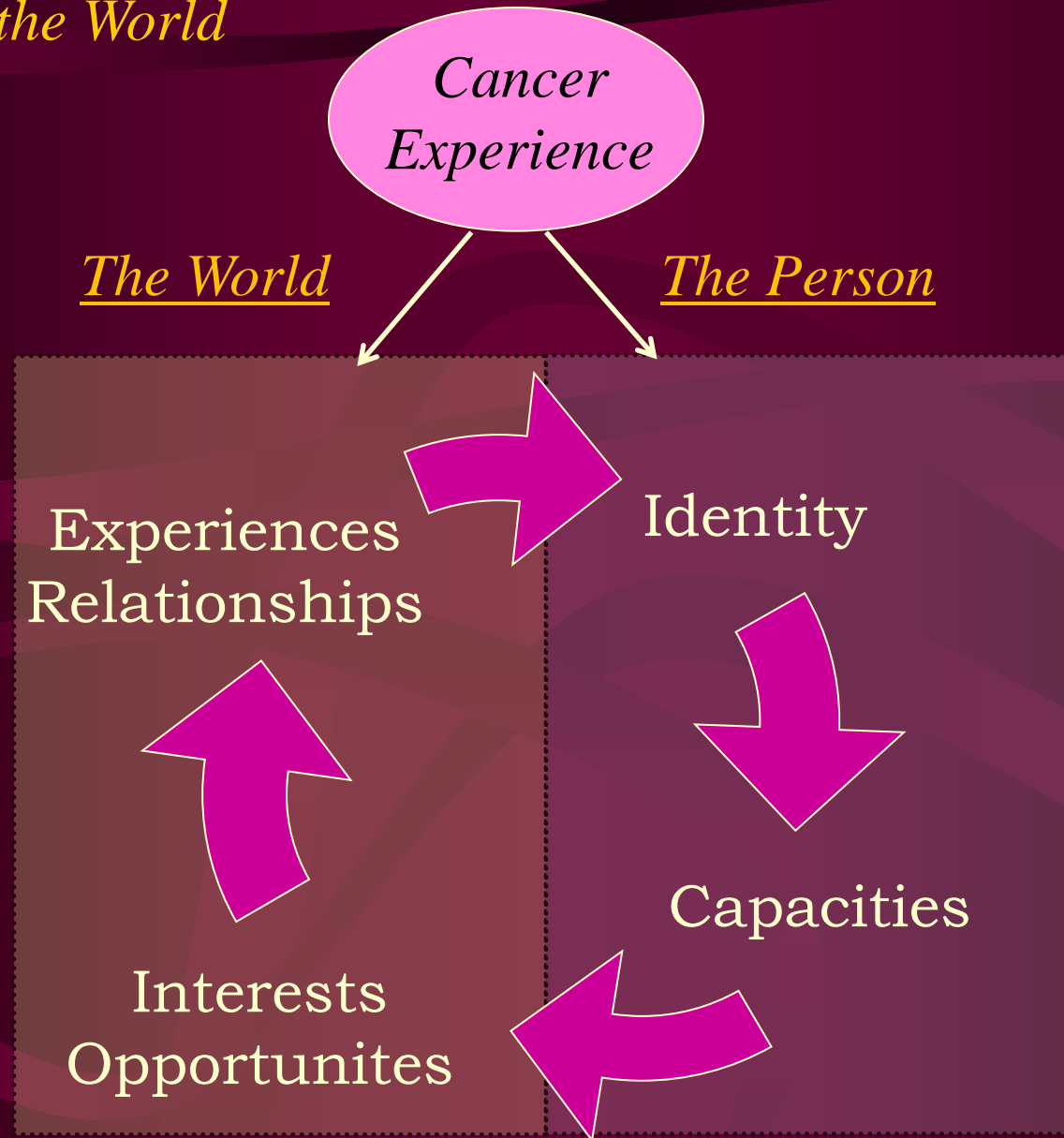
...and it is,...the time of more lasting self-definition, the working out of a sense of identity that will serve to organize experience and guide behavior through much of adulthood.

*Jessor & Jessor, 1977*

# Re-working Family Ties

- Maintaining family relationships provides support and guidance, & connection to valued family experiences and identity
- More separation from family allows for exploring of new roles, capacities & relationships

*Development:  
Person in the World*



# Effect of Illness on Adolescent Tasks

*Physical changes*

*Mental changes*

*Social Changes*

*Family Changes*

# Effect of Illness on Adolescent Tasks

*Physical changes*

*Mental changes*

*Social Changes*

*Family Changes*

- *Slower/delayed growth*
-  *energy & stamina*
- *limitations*

# Effect of Illness on Adolescent Tasks

*Physical changes*

*Mental changes*

*Social Changes*

*Family Changes*

- *Decrease opportunity*
- *Out of step with peers*
  - *Can't relate to some activities*
  - *Feel older/ more serious*
  - *Feel younger/ left behind*
- *Feelings of loss*
-  *Close relationships*

# Effect of Illness on Adolescent Tasks

*Physical changes*

*Mental changes*

*Social Changes*

*Family Changes*

- *Increased Contact*
  - *Change in family dynamics*
  - *Closeness & conflict*
- *Family worry & focus*
  - *All eyes on you*



# Tom

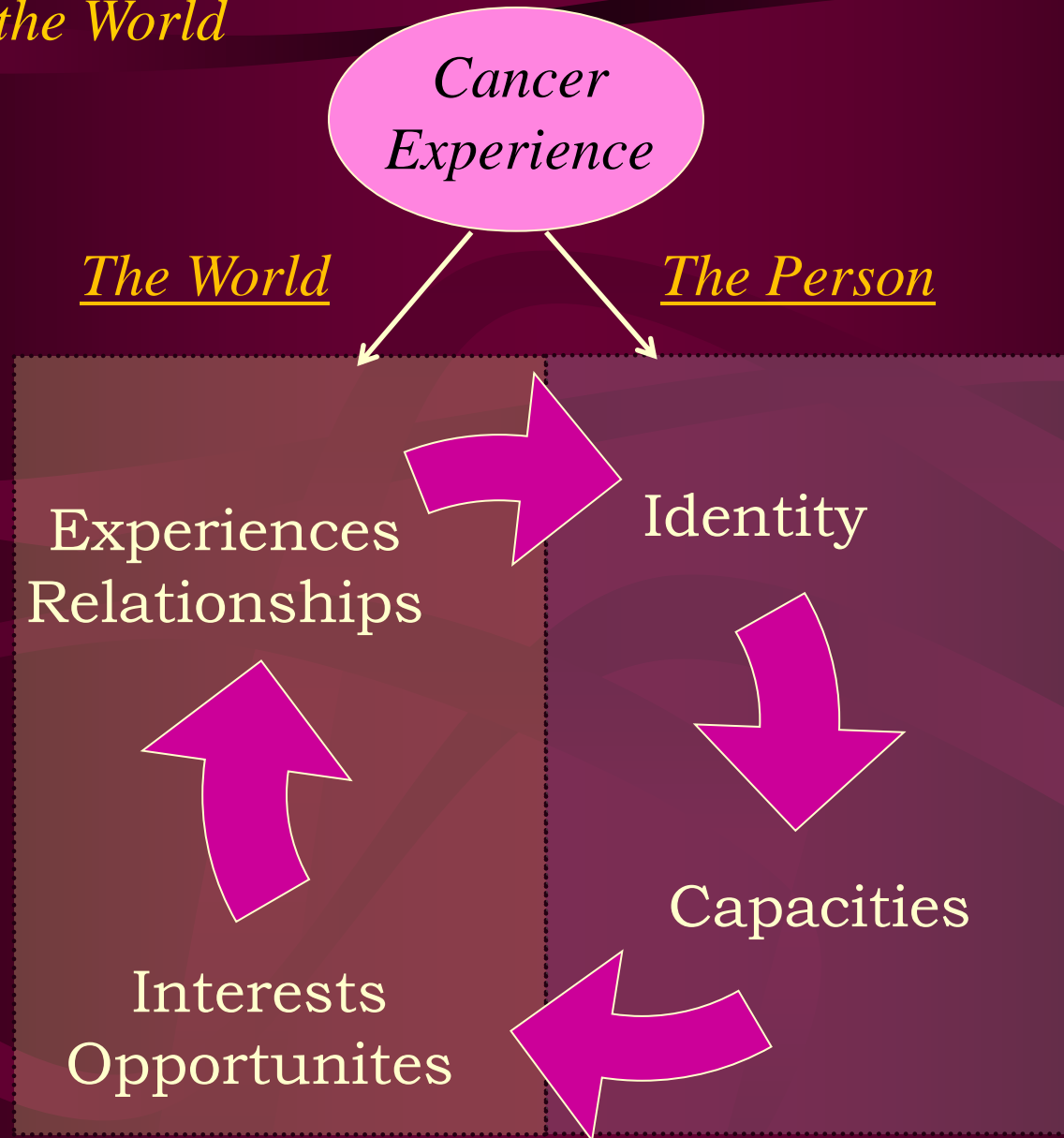
- Diagnosed at 14 with a rare tumor
- Treatment lasted several years in high school
- Family & friends provided great support
- Excellent student in High School—But
- Had a terrible time adjusting to college, which he attributes to cancer and its aftermath.

# Tom

“I was not really depressed or anything during my treatment, I was a pretty happy camper, but I look back and think of that time as my ‘lost years.’”

“When I got sick kids were starting to play “spin the bottle,” you know...and when I got back everyone was going steady and having sex. What was I supposed to do? I was shit out of luck, there was no one for me to play spin the bottle with and I wasn’t ready for sex.”

*Development:  
Person in the World*



# Tom

“I couldn’t relate to anyone but drinking and drugging turned out to be a great way to break the ice and try to fit in. I know I am not the first person to screw up in college—believe me I knew all the other screw-ups, but I see now that cancer really messed with my adolescence in ways I never understood and it really set me up to fail.”

# Jenna

- Osteosarcoma at 15 required surgery, radiation and chemotherapy.
- Driven student won a scholarship to a prestigious college, but dropped out after one year.
- Spent 5 years working in a variety of human services jobs eventually completing her college degree and joining the Peace Corps. At age 26 now taking pre-med classes.

# Jenna

Arrived at college and hated it. “I had seen a lot of life you know in the cancer hospital and I did not want to sit around reading poetry with a lot of privileged kids. I knew life could be short and I wanted to get out and DO something, and working in shelters and soup kitchens felt much more real to me. A lot of people feel the same way in college, but maybe I felt it more and I knew I could do something about it.”

# Jenna

“Cancer gave me the courage to do something different. It is not that I think it made me stronger than other people--I think everyone has a lot of inner strength—it’s just that I had been tested so I knew my strength at an early age. That’s what let me take this crazy and great ride across the world and back.”

# Intimacy Challenges

Variable but typical ones are...

*I can't relate to these kids*

*I don't know anyone here*

*I don't know how to do (something)*

*I can't have fun like that (sex, drugs, R&R)*

*My parents treat me like a child*

*I am not allowed to/able to...*

*What do I say to people about—*

*Feeling different*

*Looking different*

*Worried about cancer, health, finances, fertility, sex...*



# Survivor Burden

What has been a major challenge or burden related to having had cancer? the after affects of the treatment; poor health and quality of life - little enjoyment. Constant pain, poor memory; a feeling that my entire body is worn out. Hard to make plans, goals for the future.

What other information would you like us to know about your experience as a cancer survivor? It is hard for me feeling the way I do about myself and my life knowing that others who have died would <sup>have</sup> loved to be in my shoes and not felt this way about their life and themselves. I should be grateful even for this lifestyle and not complain, but it's hard when you have little quality of life.

Your feelings are your feelings; You may want to change them, understand them, or get over them, but you have to feel them first.

# Experience of Enhanced Growth & Meaning

Many survivors report:

- Clarified values
- Enhanced meaning or sense of purpose
- Increased closeness with family
- Appreciation of life
- Less concern about “small stuff”

# Survivor Challenges & Opportunities

- Some are unique to childhood cancer
  - Particularly medical late-effects
  - But with time more people have similar ones
- Many are common challenges in adolescence & young adulthood
  - Prior cancer may complicate them, but they are based on common needs

# Survivor Challenges & Opportunities



# Effect of illness: Could be better/Could be worse

Illness facilitates some aspects of development but impeded others

- + Clarifies values, increases sense of strength, increases family support
- Disrupts social opportunities, may limit differentiation from family, physical & emotional challenges

# Risk & Protective Factors

- Physical late effects
- Family support
- Other stressors or worries
- Other medical or psychological conditions
- Coping
- Individual values & preferences

# Vulnerable Periods: Life Transition

- Health Changes
  - New symptoms or diagnosis
  - New screening or medical needs
- Move to a new environment
  - Loss of special status
  - Question of disclosing cancer history
- Career changes
  - Questions about insurance and employability
- Intimate Relationships
  - Questions about disclosing cancer history
  - Concerns about body image, sexuality and fertility



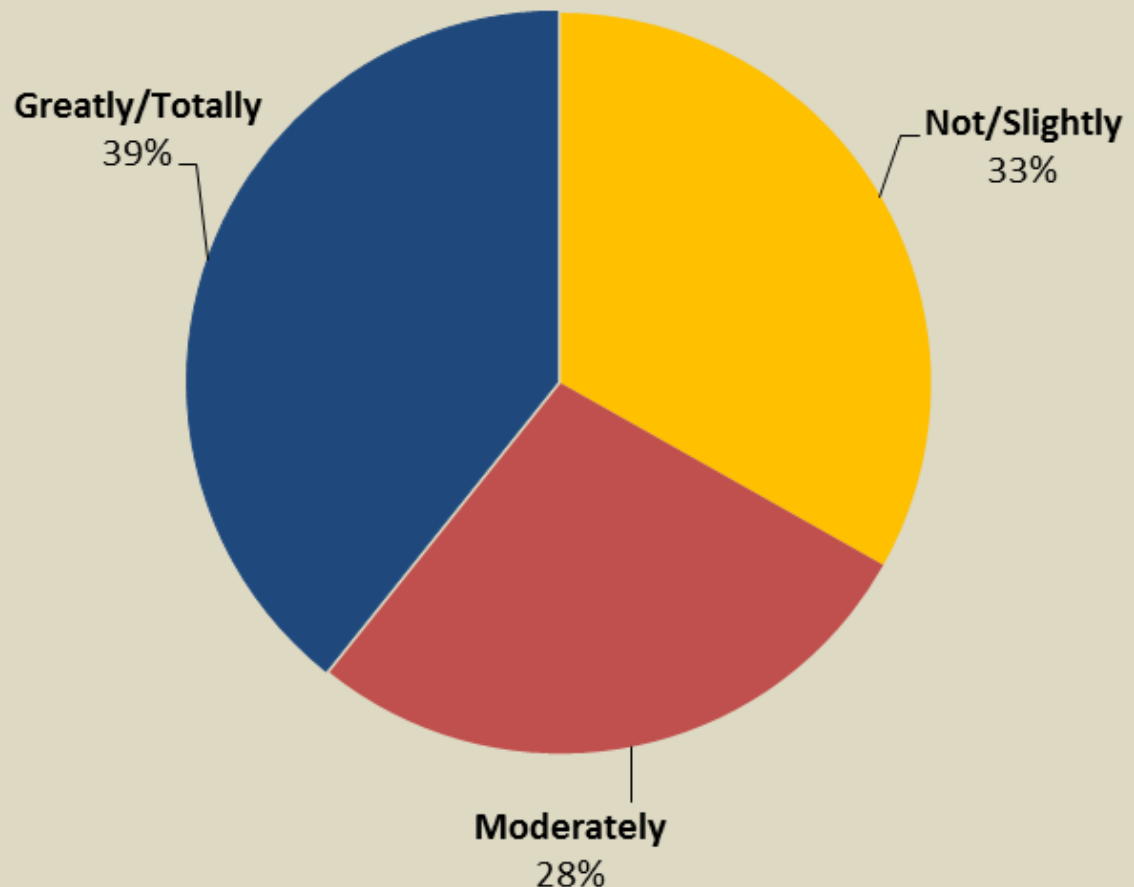




# *How much has cancer affected your sense of who you are?*

*197 CCS  
Median age 27*

*No relationship to  
psychological  
health, health  
behaviors or  
quality of life*



# Psychological Self-Care for the Survivor

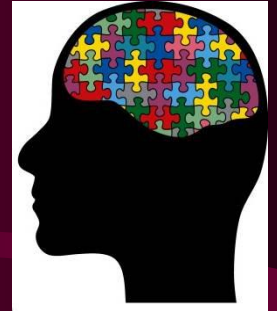
## Take care of the body

- Regular medical follow-up/surveillance
- Diet, physical activity, smoking & sleep
- Mind the alcohol and other recreational drugs
- If you have health problems, make sure your providers know all the ways in which it effects you
- Advocate for what you need to feel well.



# Self-Care For The Brain

- If you have problems with attention, concentration or memory get that evaluated
- Talk to your health care providers
- Have a neuropsychological evaluation
- Get good recommendations for school & work settings where you can succeed
- Make plans that are realistic—where you can grow but not be set up to fail



# Self-Care for the Mind



- Monitor your own anxiety & depression
- Everyone has good & bad days, but do the bad days—
  - Get so bad so you can't accomplish goals?
  - Happen most days?
  - Leave you hopeless, helpless, overwhelmed?
- IF So—you may need to do something about it
- Compare notes—get perspective of friends, family, health care providers.
- Seek support groups or professional care as needed

# Psychological Self-Care for the Soul

- Find friends that are fun and supportive
  - Take risks that could lead to intimacy & romance
- Find important things to invest your time in
  - Work, school, relationship, children
  - Politics, crafts, helping others, fundraising,
- Consider reflecting on your cancer experience
  - Take stock of the challenges & the opportunities & strengths
  - Mourn the losses you may have
  - Don't overdo it – make time for new experiences—cancer affected your life but should not become your whole life
  - Consider journaling, support group, POGO weekends or a therapist to help with this work.



Your comments & questions please