



## Coping with Anxiety, Depression, & Grief

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## You're Not Alone

Survey conducted by the Chordoma Foundation showed the top three emotional challenges reported by patients and survivors were:



# Patients and Survivors

## Skull Base

- 53% - anxiety/fearfulness
- 51% - fear of recurrence
- 45% - depression/sadness

## Mobile Spine

- 56% - fear of recurrence
- 44% - anxiety/fearfulness
- 34% - depression/sadness

## Sacral

- 52% - fear of recurrence
- 47% - anxiety/fearfulness
- 41% - depression/sadness

# You're Not Alone

The top three emotional challenges reported by co-survivors (spouses/partners, parents, family members, and friends) were:



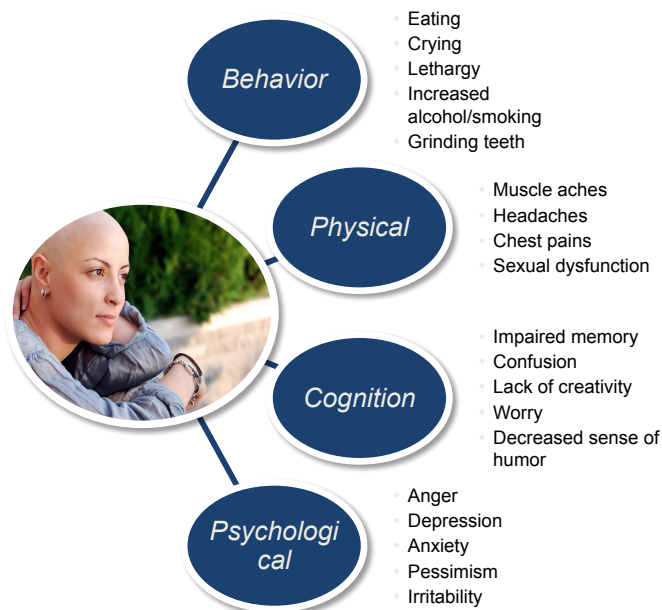
# Co-Survivors

- 79% expressed anxiety/fearfulness
- 63% expressed depression/sadness
- 50% expressed feelings of grief/loss

## Key Stress Periods

- Diagnosis (sometimes earlier)
- Treatment (side effects)
- Termination of treatment/ survivorship
- Advanced disease (chronic, clinical trials, end-of-life issues)
- Bereavement





## Depression

- Affects 15%-25% of people with cancer
  - Compared with 7.1% of the general population
- Affects men and women equally in cancer
  - Compared with 8.7% female and 5.3% male in general population
- Impacts caregivers too

# Things to Look For...

- Ongoing sadness, hopelessness, or “empty” mood almost every day for most of the day
- Loss of interest or pleasure in activities that were once enjoyed
- Major weight loss (when not dieting) or weight gain
- Sleep changes (cannot sleep, early waking, or oversleeping)
- Extreme tiredness or less energy almost every day
- Other people notice that you are restless or “slowed down” almost every day
- Feelings of guilt, worthlessness, and helplessness
- Trouble focusing, remembering, or making decisions
- Frequent thoughts of death or suicide, or attempts at suicide

# Why Does One Become Depressed?

- Genes
- Brain chemistry
- Stress, health and hormones
- Daylight and seasons
- Life events
- Family and social environment
- Reacting to life situations

# Treatment for Depression

- Medication
- Talk therapy
- Exercise
- Nutrition

## Anxiety and Fearfulness

- Anxiety and fear related to scans - “scanxiety”
  - Patients and caregivers often become anxious or nervous leading up to imaging scans and follow up appointments
  - Imaging is often how patients are initially diagnosed and how medical teams monitor the tumor for recurrence. These appointments can be triggering

# Anxiety and Fearfulness

- Quality of life changes or challenges can also lead to increased feelings of anxiety and depression
  - A Chordoma Diagnosis often impacts levels of physical function, pain levels, fatigue, and other symptoms following treatment

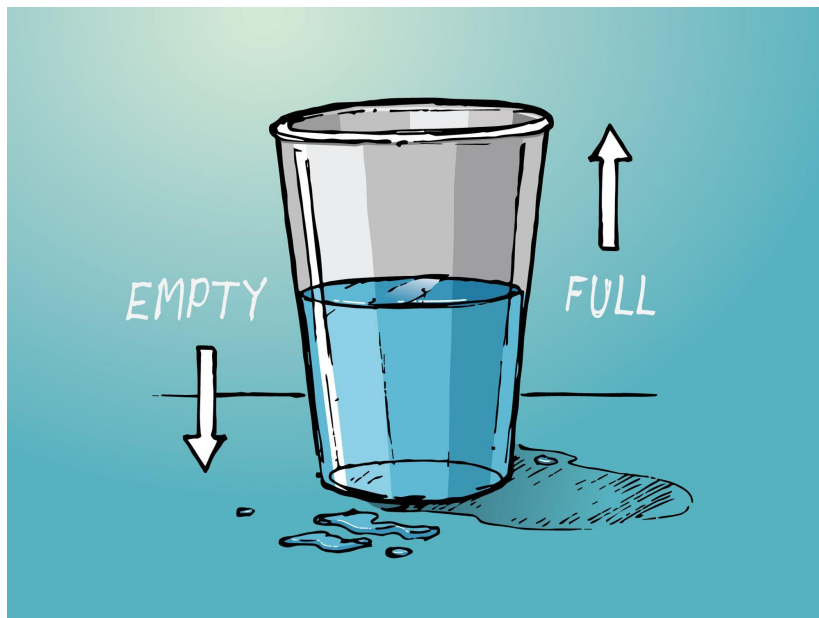
# Loss and Grief

- Coping with changes, loss, and grief
  - Loss of “normal” and establishing a new sense of “normal”
  - Changes in identity and roles
    - Role changes or role reversals in relationships
      - Romantic
      - Family/Friend
      - Work
  - Changes in sexuality and intimacy

# Resilience

*"The process and outcome of successfully adapting to difficult or challenging life experiences, especially through mental, emotional, and behavioral flexibility and adjustment to external and internal demands."*

- The American Psychological Association





## Six Primary Factors Aiding Recovery from Extreme or Traumatic Stress

- Actively facing fears and trying to solve problems
- Regular physical exercise
- Optimism
- Following a moral compass
- Promoting social support, nurturing friendships, and seeking role models
- Being open minded and flexible in the way one thinks about problems; avoiding rigid and dogmatic thinking

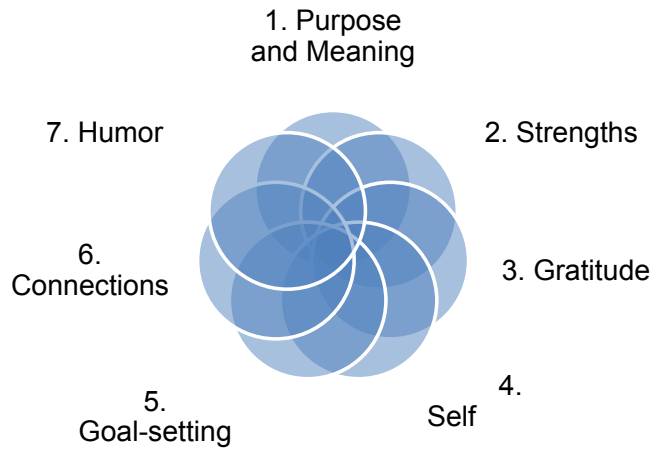
Haglund M, Cooper N, Southwick S, and Charney D (2007). 6 keys to resilience for PTSD and everyday life. *Current psychiatry*, 6, 23-30.

## 7 Characteristics of Highly Resilient People

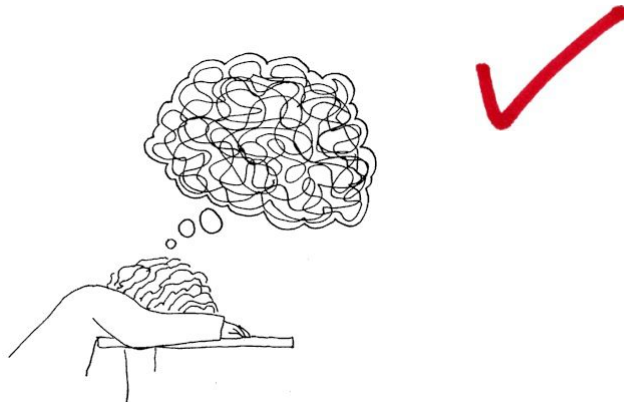
- Calm, innovative, non-dogmatic thinking (out of the box)
- Decisive action
- Tenacity
- Interpersonal connectedness and support
- Integrity
- Self-discipline and self-control
- Optimism and positive thinking

Everly GS, McCormack DK, Strouse DA (2012) Seven characteristics of highly resilient people: Insights from Navy SEALs to the "Greatest Generation". *Int. Journal of Emergency Mental Health* 14 (2) 137-143.

# 7 Areas to Nurture Resilience



## Non-Productive Thinking



# Language is Important

- **All-or-Nothing Thinking:** black and white
- **Overgeneralization:** single event is seen as a pattern, "I can't take chemotherapy because it makes me sick."
- **Mind Reading:** you know what people think/feel, "My family doesn't care about me."
- **Catastrophizing:** worry about worse case scenario
- **Personalizing:** compare self, all about me
- **Should Statements:** inflexible rules



Pain is inevitable.  
Suffering is optional.

Haruki Murakami

 quotefancy

# Anchors

- Affirmation about oneself
- Visual cue (look at the sky)
- Touch (river rock, piece of jewelry)
- Ritual (movement – happy dance/stamp feet, exhale, toss rock)



# Affirmations

“I trust in the flow of life”

“I am balanced and peaceful”

“I am capable and competent”

“I listen to my spirit”

“I move forward with love and trust”

# Opportunities for Self-Discovery

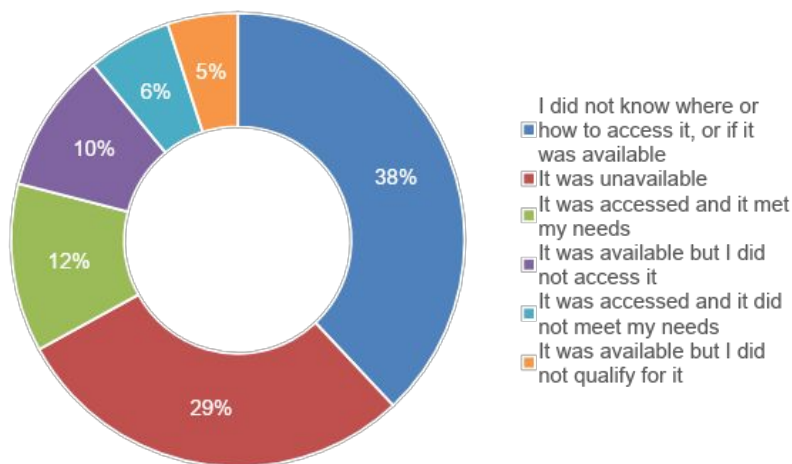
When was the last  
time you did  
something for the  
first time?



# Expectations



## Where Do I Turn?



## Where Do I Turn?

- Discuss with your treating physician
  - They may be able to direct you to institutional resources or help you locate community resources
- If you are comfortable, discuss with your support network
  - Family, friends, spiritual communities, etc.
- Formal sources of support
- National organizations - Chordoma Foundation

# Patient & Caregiver Support

Individual  
Counseling

Support  
Groups

Peer to Peer  
Support

## Counseling

- Discuss with your treating physician
  - There may be counselors within the institution, or they may be able to recommend a community counselor
- Contact your insurance company to find in-network licensed counselors
- PsychologyToday.com
  - An online data base of licensed counselors

# Support Groups

- The Chordoma Foundation
  - Patient/Survivor support group
    - The second Tuesday of each month at 6:00 PM Eastern Time
  - Caregiver/Co-survivor support group
    - The third Wednesday of each month at 7:00 PM Eastern Time

# Peer to Peer Support

- Chordoma Connections
  - Private online community through the Chordoma Foundation





# Journaling

- Journaling can help you process emotions
  - Write down the emotions you're experiencing and what is causing some of those emotions
  - Brings you awareness to how you are feeling
- Some people use a "gratitude journal" where they record big or small things that they are grateful for
  - Looking back on these moments of gratitude when they are

feeling down

# Journaling

- May help you regain control in situations that leave you feeling out of control or helpless
- Can help with your short-term memory
- Serves as an outlet for emotions you may not feel ready to share with others

# Journaling

- Where to start
  - Write down three things that you are feeling in that moment along with any other reflections or sentiments you want to add
  - Try to stay consistent
    - Set aside 5-10 minutes every day or every other day

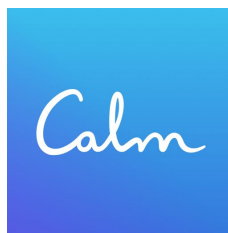


# Mindfulness

- Benefits of mindfulness can include:
  - Reduced stress or feelings of anxiety
  - Promotes better sleep
  - Uplifts your mood

# Mindfulness Tools

- Mindfulness exercises and apps
  - Calm, Headspace, Insight Timer



# Mindfulness Exercise

