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:

- Fear of Recurrence
- Anxiety or Fearfulness
- Depression or Sadness
You’re Not Alone

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

- Anxiety or Fearfulness
- Depression or Sadness
- Feelings of Loss or Grief
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


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

7 Areas to Nurture Resilience

1. Purpose and Meaning
2. Strengths
3. Gratitude
4. Self
5. Goal-setting
6. Connections
7. Humor

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
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?

- 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