

Managing Uncertainty

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Survivorship Statistics

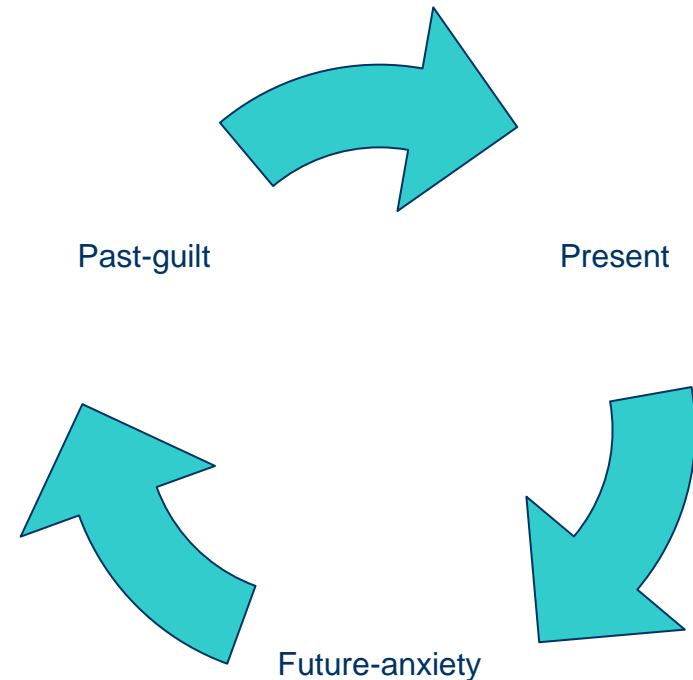
- Long-term survival rates for adult and pediatric cancers continue to improve
- Nearly 10 million Americans are living with a cancer diagnosis- some considered cured, others in remission or in treatment (American Society of Clinical Oncology)
- 14% of women with cancer will have a cancer of the lung or bronchus, 15% of men with cancer will have a cancer of the lung or bronchus.

What about me?

- How do these statistics relate to me?
- Most of the numbers are based on other cancers!
- How do I manage uncertainty, when no-one can guarantee me a cure?
- How can I keep my anxiety in the background so that I can live life?

How do you gain a sense of control?

- How to balance planning for the future with the competing focus on the present.
- Managing future anxiety and past guilt.



Uncertainty

- “...an unpredictable thing... something that nobody can predict or guarantee..”
- “...an unpredictable event that may or may not occur in the future..”

The Psychological Response

- Hearing a diagnosis of cancer or living with the risk of getting cancer results in a crisis, generating a psychological and existential plight.
- The emotional response to this traumatic event includes expected and normal emotional distress.
- Emotions can come out of nowhere and may be contrary to what one is experiencing.
- Common emotional responses: disbelief, denial, shock, numbness, inability to concentrate, intense fear.

Diagnosis to Completion of Treatment

- Often the initial emotional responses change over time as one adapts to the treatment.
- At periods of time those same feelings might re-emerge. (during scans, tests, recurrence)
- The end of treatment may be a difficult time where one worries more and feels down or sad.

Coping

- Adopting ways of thinking and behaving that address the situation in a constructive way and that safeguard one's emotional state and promote adjustment.
- The style of coping that works best for one person may not work so well for another.
- People can learn or modify skills.

Depression and Anxiety

- The incidence of depression, anxiety and other serious psychiatric illnesses is about the same in cancer patients as it is in the general population.
- A certain level of depressive or anxiety related symptoms are normal and expected.
- Ongoing high levels of psychological distress should be treated aggressively.
- Coming to emotional terms with the disease is one of the greatest challenges facing those who have recently received a cancer diagnosis.

Denial, Not Such a Bad Thing

- Denial and compartmentalization can be adaptive and allows us to function better in the face of uncertainty and danger.
- It does not mean that you are not in touch with reality.
- Emotionally healthy people use denial every day.
- If people thought about all of the bad things that could happen they would be immobilized by fear and anxiety.
- Denial and compartmentalization helps people 'buffer' fear and process it more gradually.

'Managing' Emotions

- You don't control your emotions.
- You control whether you express or contain them, where you talk about them and how much you allow yourself to experience them.
- Feelings are not a call to action.
- Feelings you ignore will eventually resurface. Unfortunately, by that time they are often disguised which makes them harder to recognize, understand and address.

Finding a Balance

- There needs to be some time, space and permission to experience the emotional aspects of cancer.
- Talking about distress often helps relieve it.
- Unrelenting pressure, internally or externally to be positive is draining and may increase distress. (different from hope)

The Human Side of Living with Cancer

“...acknowledging that this is a difficult period that will elicit mixed emotions varying from hopeful to hopeless, from confidence to insecurity, from fearful to feeling in control and on top of things, from sadness to gratitude for being alive...”

Strategies for Managing Uncertainty

1. Pacing, Modifying and Reworking Daily schedules to shift focus from worrying about illness and focusing on uncertainty to more constructive, manageable tasks.
2. Educating yourselves, learning as much as possible about the management of your disease.
3. Aggressively treating side effects and symptoms (pain, nausea, insomnia, anxiety). Understanding where symptoms originate and anticipate side effects of any new treatments.

Strategies cont.

4. Making downward (“this could be much worse”) and upward (“others have survived this side effect”) comparisons.
5. Setting goals: identifying short-term goals as focal points for certainty.
6. Compartmentalizing: being a cancer patient is not your primary identity, focus on other elements of your identity and engage in non-cancer discussion, activities, relationships etc.
7. Find a safe place to let down, to share distress with those who are able to understand and support. Choose a supportive network: selectively sharing illness information with those who are likely to offer support rather than create more distress.

Strategies cont.

8. Take charge in making decisions about your illness and its management. Patients who are in active collaboration with their medical team have less distress than those who are more passive.
9. Take care of yourself with exercise programs, dietary modifications, support groups, mind-body techniques etc.. This helps people regain some sense of mastery and control over their lives.
10. Think about what resources (internal and external) you have used in the past to help you cope with uncertainty and stress.

Strategies cont.

11. Keep life as predictable and normal as possible.
12. Reduce as many current stressors as possible. Pay attention to close relationships, engage family members in your efforts to manage uncertainty.
14. Think about any other past or present stressful events that may be contributing to how you are feeling currently, these may be heightening your feelings of uncertainty. Talk to someone about these if you find that helpful.
15. Rituals reduce feelings of uncertainty and provide some structure and support. (support groups, classes, spirituality, social outings)

Conclusion

“The diagnosis of cancer creates a sense of urgency about time that goes along with the uncertainty it causes. However, the person who can say “I’m just going to take one day at a time” is able to stay focused on the tasks of that day. The person who hardly enjoys today because of concerns and worries about tomorrow has a much harder time dealing with illness..... Hard as it is to keep thinking that way, coping with cancer is easier if you try not to focus on all the challenges that may lie ahead, but rather, stay focused on today, during which you can accomplish something despite the problems caused by the treatment.”

(Holland, 2000)