

A New Normal

After Treatment Ends

**1st National Breast Cancer Conference for
Australian Young Women Affected by Breast Cancer**



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Introduction

Cancer Survivorship

'Living Through' Cancer

Transition

- A life transition is initiated when a person's current reality is disrupted. Selder (1989)
- The process of transition involves bridging the gap between the old reality and the newly constructed reality.

Ponder this...

Where would you put cancer in your life?

Where would you like it?

How do you describe yourself in relation to cancer, someone who had cancer, someone who has cancer, a cancer survivor ?

The St. Vincent's Post treatment Study

The Diagnosis Experience

Domain and Transition Phase: *'Well Person' to 'Cancer Patient'*.

Experience: *Shock, Bewilderment.*

Adjustment Task : *Managing shock. Making treatment related decisions.*

Coping Strategy: *Cognitive adaptation: 'appraising the threat'.*

“...one of those moments that will live on in life. It’s scary. I hope I never have to have that moment again when she tells me it’s cancer.”

She described the scene like a photographic still with,
“the crying, the feeling of tears, mum was at the end of the bed and she burst out crying and ran.”

The Treatment Experience

Domain and Transition Phase: *'Cancer Patient'*

Experience: *'Just Getting Through', Psychological and Physical Trauma*

Adjustment Task: *Managing a disrupted reality. Learning to live with uncertainty. Adapting to physical and emotional changes. Coping with the impact on others.*

Coping Strategy: *'Avoidance', 'Not thinking about treatments', 'Positive thinking', 'Focusing on tasks', 'Social Supports'*

“It was just awful. It was as bad or worse than I ever expected it to be... each time you have a dose of chemotherapy, it takes longer for your body to get better, ... I just really couldn't see it ending.”

“.... during treatment you're in go forward mode, well I didn't stop to think about what was really happening to me ...”

The Treatment Completion Experience

Domain and Transition Phase: *'Cancer Patient' to 'Cancer Survivor'*.

Experience: *Relief mixed with ambivalence and fear, beginning to process the experience and plan for the future.*

Adjustment Task : *Adapting to changes in values, attitudes and expectations Constructing a new reality.*

Coping Strategy: *Looking back and appraising from a distance. Looking forward and developing new goals.*

Claire happily said,

“I can do cartwheels down the street !”.

Gayle stated, *“I told my doctor, ‘Doctor, that's it I'm not coming here anymore’, it just was so really great...”.*

“Whereas at the time of going through treatment, the time of being operated on and having all of that, it was a time when I didn't really think that I ever really had cancer... looking back I think it was a bit unreal, whereas now it's becoming real” (Annie).

Living through the experience of diagnosis and treatment for breast cancer has many similarities to living through any traumatic experience.

While a person is in the middle of a traumatic experience they are seldom able to focus on the experience itself. Rather, they use of diversion and avoidance are common coping mechanisms for managing trauma.

A major aspect of the survivorship experience following trauma relates to the residual impact of the experience that was avoided.

Study Results Summarised

Phase	Described experience.	Psychosocial resources provided
Diagnosis	Shock, Bewilderment.	Crisis Intervention Full Resources
Treatment.	'Just getting through', Psychological and physical trauma	Monitoring Full resources
Treatment Completion.	Relief mixed with ambivalence and fear, beginning to process experience and plan for the future.	Rarely included as a 'stage' Little or no resources.

Experience of women & their partners.

Phase	Experience of Women With Breast Cancer.	Experience of Significant Others.
Diagnosis	Shock, Bewilderment.	Shock, Bewilderment. The need to take control.
Treatment.	'Just getting through', Psychological and physical trauma	Concern over the practical. Helpless, exhausted, existential issues, isolated, pacing through own trauma.
Treatment Completion.	Relief mixed with ambivalence and fear, beginning to process experience and plan for the future.	Relief tempered with disappointment that 'it's not over' yet'. Tension to 'get back to normal'.

Your own experience

- 'What was the hardest thing about your experience ?'
- 'What was the biggest surprise ?'

What now?

Ongoing Issues

It is common to experience ongoing physical and psychological changes after treatment completion which need to be negotiated as part of the reintegration process -

- physical recovery

- psychological recovery

- social recovery

- spiritual recovery

One of the biggest challenges relates to living with uncertainty in an ongoing way.

Negative impact of uncertainty

- It encourages fear – that in turn can paralyse
- It makes you think you can't plan ahead
- It makes you think you have no control
- It reduces your capacity to live 'in the moment'

Living with uncertainty

- Face fears and put them in their place
- Learn to challenge 'automatic negative thoughts'
- Embrace the moment – today
- Set goals within the limits of what you know and what you feel comfortable with but do set goals (A goal is a dream with a deadline)

The role of meaning in adjustment to cancer

- ... making sense of life situations and deriving purpose from existence (Speck, 2004).
- Meaning based coping – when an ongoing stressful situation cannot be changed by emotion focused or problem focused coping

Meaning based coping

- Positive re-appraisal
- Revising beliefs
- Revising goals
- Finding benefit

What brings you peace, meaning, joy...?

- Raindrops on roses and whiskers on kittens
- Bright copper kettles and warm woollen mittens
- Brown paper packages tied up with strings

...These are a few of my favourite things.

Joy is ...

- New pyjamas
- Holding your hand
- An afternoon in the garden with friends
- Sailing on a sunny day
- The trees outside our bedroom window
- Undying friendship
- The rain on the roof

What brings you meaning?

- *“Family (partner) ... my house ...the garden...I put all my bulbs in this year and for the first time in some time I didn't wonder if I'd be alive when they came up they would come up, which is rather nice...[These are] the little moments which all add up together to make a life”. (Beth)*

“I pray to God every night and I feel like he is listening and just says I'm watching over you and I'm not going to let you fall”. (Jacinta)

Things to Reflect on

1. What is your goal(s) or dream(s) for the future ?
Has this changed since you had this experience?
2. Three things:
 - I would rather not do or have in my life anymore.
 - I really value & appreciate about my life.
 - I would like to have in my life that I don't have right now.
 - ways I limit my success.
3. Can you think of one word (or statement) to describe you before you had cancer and one word to describe you after cancer?

Ponder this...

Where would you put cancer in your life?

Where would you like it?

How do you describe yourself in relation to cancer, someone who had cancer, someone who has cancer, a cancer survivor ?

**And did you get what you wanted from this
life even so?**

I did

And what did you want ?

**To call myself beloved, to feel myself
beloved on the
earth.**

Raymond Carver