

A Multimedia Montage

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**This presentation is intended as a series of snapshots  
documenting the experience of gynaecological malignancy  
as it was for this group of women**

**GYNAECOLOGICAL  
MALIGNANCY  
DEATH SENTENCE  
OR  
LIFE PROCESS?**

**Study of 79 Patient Accounts of Diagnosis,  
Treatments, Survivorship and Palliative Care  
over 15 Years of Comprehensive Psycho-Medical  
Cancer Care (1991-2006)**

**I am looking for something I haven't lost**



**and I must find it no matter the cost**



## INTRODUCTION

### *Do I or did I have cancer?<sup>1</sup>*

Diagnosis of gynaecological malignancy remains a harsh and life-changing experience. Key findings in this study detail the complex emotional and psychosocial impact that accompanies such a diagnosis – that a person is changed permanently and profoundly by the threat it presents. The nature and extent of changes imposed by treatment offers further life-changing challenge.

Palliative care permeates patient and family coping with piercing intensity. In different ways, Survivorship heralds a new challenge. For those with positive capacity, this phase fosters hope, challenge and life revisited.

<sup>1</sup> J Holland and S Lewis, *The Human Side of Cancer*, p. 258.

## FORMAL STUDY QUESTIONS

1. What are the predominant concerns and vulnerabilities of patients in the study?
2. What levels of distress do patients register? When do points of maximum distress occur?
3. How do women cope with problems that arise and how effective are various Coping Strategies in resolving their distress during the gynaecological cancer experience? Are certain Coping Strategies associated with better/worse management of medical factors?

## CRITICAL POINTS

Experiences over time following diagnosis of **the following gynaecological malignancies**: cancers of the cervix, endometrium, ovary, vagina /vulva.

**Time line:** At Diagnosis, During treatments, at Post-treatment Palliative care or early Survivorship, and for those still alive two years later, a further qualitative Survivorship interview.

PATIENT CONCERNS, VULNERABILITY AND COPING AT

**DIAGNOSIS**



**PATIENT CONCERNS, VULNERABILITY AND COPING AT**

**DIAGNOSIS**

**PATIENT CONCERNS, VULNERABILITY AND COPING AT DIAGNOSIS AND  
DURING TREATMENTS**

**PATIENT PREDOMINANT CONCERNS**

**Existential Concerns**

**Concerns about Health**

**Concerns about Family**

**Concerns about Self**

**Concerns about Friends**

**Work/Finance Concerns**

**Costs of Cancer**

**Religious Concerns**

# Diagnosis

## Existential Concerns



*I was frightened I might die...I kept saying that I can't because who will look after the kids?*

Patients in our study remained preoccupied with staying alive and actively maintaining family roles they had built prior to cancer diagnosis:

*I was frightened I might die...I kept saying that I can't because who will look after the kids?*

Fears predominated:

**When it turned out to be cancer, it confirmed a fear which was never allowed to stay. I have always been ...fairly rational so I didn't allow indecision, fear and delay to take over.**

I had last worked in April. I didn't want to give that up permanently, and I hoped to get back there as soon as I could.

# Diagnosis

## Concerns about Health

Once diagnosed the health threat was confronting. Patients registered statements of extreme despair and distress in facing fears associated with managing their unwell bodies:

***They told me the cancer was malignant so that left me no choice but to agree to the hysterectomy.***

Diagnosis

Concerns about Health

*I was stressed and fearful at diagnosis. It was really hard at the start...we talked about my fears.*

# Diagnosis

## Concerns about Family



**She said, 'Don't worry about not being a woman again'.**

The major areas of concern at Diagnosis were how the patient felt she was going to adjust and cope with managing this illness, followed by the panic and distress on the part of children once mum's distress was observed, followed by significant role changes, namely the capacity of the patient, as mother in the family, to continue in her usual family role.

The challenge to retain life meaning in spite of the presenting vulnerability and distress that cancer brings is a painful and serious challenge to all patients in this study. Patients without a strongly supportive nuclear family struggle desperately to find courage and strength enough to endure the challenge that cancer brings.

**My mother-in-law put me in my death bed and uses me as an excuse for her own problems. She said, 'Don't worry about not being a woman again'. That worried and hurt me.**

# Diagnosis

## Concerns about Family



*The kids...come up and check on me. I love it when they all hop into bed with me.*

*We can forget about being sick and just cuddle each other.*

During treatments almost all patients were registering concerns in relation to their families. Over time, as the patient's health care needs increased and increasing opportunity for intimate connectedness with caring family members became more dominant, patient concern for distress experienced by close family members whom they loved dearly became more paramount:

*The kids...come up and check on me. I love it when they all hop into bed with me.*

*We can forget about being sick and just cuddle each other.*

We sat down and had a family meeting. I told them straight out, 'I've got cancer'. My elder daughter(10) asked, '**Are you going to die Mummy?**'... She has pressure problems in one eye and can't see out of it. [She] has been too, too frightened to have the surgery unless I am there. [I can't] because of our financial problems, and my diagnosis now.

# Diagnosis

## **Concerns about Self**



The pain, exhaustion, helplessness and feelings of being a victim attacked by a fateful disease were presented oftentimes by patients under the label of Concerns about Self:

**Overall, our family has not been a close one. I do not turn to my daughters. At diagnosis, I turned to no-one...Often I didn't speak to anyone about the cancer. I was just too down to seek support.**

Having cancer for a young woman in her twenties carries different pain and concern than it does for an elderly widow in her late seventies. Impact on self-esteem, body image, personal and relationship identity are pivotal issues:

***I didn't focus on anything else in my life. I closed it down and pampered myself, decided to take the next six months slowly...I thought I'd been spayed like a cat. My womb was a very special place.I want to thank it for giving me four beautiful children and I grieve the memory of that time. In life one is meant to grieve, and I will.***

# Diagnosis

## Concerns about Self My fertility, lost potential and no children



For young women facing life without children as a consequence of gynaecological surgery, a sense of profound hopelessness is often immovable. The ongoing grief of patient expressed childlessness remains ever present:

*I'm always trying to stay positive... Oh, we've had our ups and downs, like coming to terms with the fact that we can't have children. ...*

*The hysterectomy was actually the beginning of everything going even worse. At 29, I had been looking forward to having children and that was then finished... We looked at adopting ...we could get a toddler or a seven or eight year old ... obviously at that age they'd been through some kind of trauma as well... It was a bit of a roller coaster*

*I'm always trying to stay positive... Oh, we've had our ups and downs, like coming to terms with the fact that we can't have children. ...*



# Diagnosis

## Concerns about Self



*At diagnosis, I turned to no-one...Often I didn't speak to anyone about the cancer.*

*Overall, our family has not been a close one. I do not turn to my daughters. At diagnosis, I turned to no-one...Often I didn't speak to anyone about the cancer.*

*I was just too down to seek support.*

# Diagnosis

## ***Concerns about Friends***



***no friends visit and people ring for money, I start crying and talk to the girls.***

When first diagnosed, the majority of the women shared their concerns with family and friends, but as disease progresses, sharing is not so easy:

***Sometimes everything gets on top of me. I spend the day throwing up, no friends visit and people ring for money, I start crying and talk to the girls.***

For those women living alone, the need for reliable friendships were dominant throughout the cancer management path. Where a strongly supportive nuclear family was absent, single women tend to look more to formalised external support systems and register less reliance on individually intimate and supportive friendships. Over time this group of women have shown that largely their first port of call was to attempt to cope by withdrawing and sorting out concerns before passing these on and sharing

# Diagnosis

## ***Work/Finance Concerns***



Despite the costs of managing emotional, physical and lifestyle changes associated with the experience of cancer, the majority of patients though extremely financially desparate, valued above all else the chance to stay alive and connected to close family members for as long as possible.

One study participant, a senior academic, was at the peak of her career when diagnosed with late stage ovarian malignancy. She stated:

**I am angry and distressed. I can't believe I am losing my mind. Some days I crave for mental stimulation, try to walk and shower. But almost always I feel dizzy. ...I intensely dislike the incredible loss of independence. I cannot walk, get out of bed to go to the toilet, or even shower myself. I will never go home again.**

# Diagnosis

## Costs of Cancer

**When a mother becomes ill, the greatest cost is the labour of the primary caregiver, accounting for 49% of total family costs.**

**Significant financial burden is routinely a serious barrier to patient quality of life.**

In the context of family illness, resulting role changes shift responsibility previously assumed by individual members to new levels. **When a mother becomes ill, the greatest cost is the labour of the primary caregiver, accounting for 49% of total family costs.**<sup>1</sup> The disruption illness brings to work and the ordinary function of each day is oftentimes irreversible. The matter of restoring basic financial stability by putting clear community resources in place is a vital pre-requisite to restoring overall equilibrium to the household of a patient and their family.<sup>2</sup>

The loneliest battle for any cancer patient is managing the threat to staying alive and facing their mortality. Some patients, often with pre-existing problems exacerbated by the illness, are made exceedingly vulnerable by a host of psychological, social and financial stressors working against them. These days life-challenging illness and major financial pressures seem to go hand in hand with, and compound the emotional impact of illness. **The value of collaborative team members working to practically guide patient finances whilst providing a comprehensive continuity of care package is an important health care resource.**

**Significant financial burden is routinely a serious barrier to patient quality of life.** Where patients are not eligible for financial help under conventional social security programs, despite complicated circumstances, fear or embarrassment of mounting medical costs and the inability to afford medication, even travel, can prevent patients from gaining fuller treatment benefits. Cancer patients whose resources are drained by their illness may not realise the extent and negativity of losses until the illness experience is behind them. **They may take years to recover from associated debt, embarrassment or even bankruptcy, given that contact with medical and health care members is now less regular and available.**

# Diagnosis

## Religious Concerns

In our current study, low-level generalised acknowledgment of the role of religion At Diagnosis was made by 20% of study participants, and marginally higher-level concerns were raised by a different and lesser number of study participants during treatments.

**Those who had previously attended church regularly maintained some attention to a private spiritual relationship but little commitment to religious institutions and associated rituals as treatments wore on.**

## VULNERABILITY AT DIAGNOSIS AND DURING TREATMENTS



**She confronted her illness head on with courage:**

cerebral involvement

gynaecological cancer recurrence

dual experimental chemotherapy treatments over a six-month period.

A single mother with five children managed gynaecological cancer and its consequent uncertainties **‘somehow:’**

*My kids weren't scared when I left for check ups in Melbourne. Because my children and I are very close and we didn't have a father, there wasn't a thing that was kept from my children. Many a time the children came to me and asked if I was getting better. Whenever I got crook they were petrified that it might have been rearing it's head again.*

*I was very frightened because the cancer had travelled in my body. That was because it had been left too long and I blamed the doctors for that. I had done what they had said. Then all in a matter of days I became sad, started to worry and feel that I had a death sentence. That took my mind to the children.*

One younger patient continued to suffer in silence for a time:

*I tried to continue attending college ... whenever I was well enough I would put a big hat on and dress a certain way and thought, 'Oh well, I'll just sit here and no one will notice I'm any different'. ...Someone actually raised the question with me, because I obviously looked ill: 'Do you have cancer?'*

## VULNERABILITY AT DIAGNOSIS AND DURING TREATMENT



*She is cross with me for being sick. Really she is deeply missing my affection, loves kisses all the time....*

Increasingly, personal feelings of abandonment, medical hopelessness and fear associate with active withdrawal from all loved objects:

*I've isolated myself from the children. They don't communicate with me. They see me crying all the time... I tell her I have a bad cold but I know she knows something else. She is cross with me for being sick. Really she is deeply missing my affection, loves kisses all the time....All my friends except one disappeared when I was diagnosed.*

Another patient details her increasing sense of life worthlessness and personal hopelessness:

*This illness, the pain and letting my children and husband down depresses me.*

## VULNERABILITY AT DIAGNOSIS AND DURING TREATMENT

*I wish someone had told me that it would stuff up my bowels, cause obstructions, blockages and adhesions.*

*I thought a bit too much and my fertility (or lack of) ran through my mind regularly*

### During treatments

*I was devastated by chemo. Radiotherapy just heightened my shit life. It was all such a drag. It was never explained to me what radiation would do to other major organs in the path of the beam. I wish someone had told me that it would stuff up my bowels, cause obstructions, blockages and adhesions. ...I felt like a drowned rat, like a rung out rag of little use anywhere.*

For someone with a deep spiritual conviction, a profound distrust in 'God's care' persisted:

*I dreaded every check up, every worrying symptom....I felt I was making little positive progress, that now my time was defined and that there was no hope for recovery... I fluctuated between anger and depression on most days. Anger at God, at the unfairness and mostly at the uncertainty of it all.*

*Suddenly my future was scrambled. ...I thought a bit too much and my fertility (or lack of) ran through my mind regularly. I tried not to make it my focus but I felt let down.*



## VULNERABILITY AT DIAGNOSIS AND DURING TREATMENT

### During treatments

**not sure if help could, in fact, help,**



Feelings of being inadequate and not sure if help could, in fact, help, left patients frightened, frustrated and angry:

*As I said earlier, nobody gets as bad as this. It's the out-of-controlness, that we don't have a life of our own anymore. That has been the worst change....They frightened the life out of me when they told me I had a tumour... I wasn't satisfied with the medical information...At times I thought I would never survive this, never get better.*

Another grew distrustful of her health during treatments:

*The chemo reminded me of how unwell I really was. It made me uncertain about whether it was the cancer or the treatment which was just about beating me. I worried all the time that I was dying...I was rattled, nervy, totally devoid of confidence in my health and feeling socially useless....I had no energy to live life normally. As a female I felt sexless. I had little hair and my clothes hung on me like a coat hanger. I was frightened alone.*

Strong emotional reactions to grief and loss persisted:

*I saw my whole body as being disabled by the end of chemo. ...I became a patient and my partner became the carer. We felt like we had nothing normal left... My whole value had disintegrated to nothing.*

The end of chemotherapy emerged in the current study as a very difficult time for some – *being put off the lifeboat, out to sea without a paddle...*<sup>4</sup> Commonly patients registered concern about whether 'my cancer is gone or hiding off the radar screen'...

## STYLES OF COPING AT DIAGNOSIS AND DURING TREATMENTS

**staying alive for as long as possible, aided by intimate and valued personal and professional connectedness gave the coping path much resolution.**

Patients with predominant concerns which pre-dated cancer diagnosis—previous episodes of depression, limited social, financial and life support, child and intimate relationship issues – all tended to cope by use of passive, submissive coping strategies, namely fatalism, withdrawal and blaming of life situations and other people .

During treatments especially, increased physical and emotional pain, exhaustion, helplessness and perceptions of being attacked by a fateful disease with no presenting hope for recovery prevented patients from realistic problem-focussed action .

For patients with terminal disease, particularly the younger ones, death threat was multi-factorial and pressing. As such, a determined commitment to staying alive for as long as possible, aided by intimate and valued personal and professional connectedness, gave the coping path much resolution.

## STYLES OF COPING AT DIAGNOSIS AND DURING TREATMENTS

*My boyfriend bought a van so we could sit near the sea.*

*My girl-friend leaves cup-cakes in my letter-box.*



### At Diagnosis

The dominant COPE Strategies chosen by women in the study were:

- Shared concern – talk with others to relieve distress (COPE Strategy 2)
- Comply with authority – follow medical advice (COPE Strategy 14)
- Redefine based on accepting – accept and redefine the situation, find something favourable and rise above it (COPE Strategy 7)
- Seek information – get guidance from reliable sources (COPE Strategy 1).

### Coping by shared concern; talking with significant others to relieve distress

Signposts pointing to human care and concern are critical during crisis and the delivery of 'casseroles and cupcakes in my letter box' were examples of such care at diagnosis:

*I have been inspired, touched and helped since I have first faced the obstacles this disease has thrown my way. My boyfriend bought a van so we could sit near the sea. My girl-friend leaves cup-cakes in my letter-box. One other brings soup, and yesterday another elderly deaf neighbour brought me a spencer to keep me warm while I recover.*

*We talked about my fears of not being cured and not being able to have children together. My husband used to say that it was me he was marrying, not what I could do for him. We coped by turning to each other...in a way we withdrew from everybody else.*

*Problems have been easier because my husband and I got on well together. I suppose we coped by talking things through and working them out together. He is my best support.*

## STYLES OF COPING AT DIAGNOSIS AND DURING TREATMENTS



*My 6 year old has been my best friend for the seven years of her life. I cry a lot with her.*

*The kids would say 'You've got us mum,' and I always kept that in mind.*

*My 6 year old has been my best friend for the seven years of her life. I cry a lot with her.*

*I've coped during all this time by doing my best for the girls. When I was diagnosed my parents and the girls were my best supports.*

*The kids would say 'You've got us mum,' and I always kept that in mind. In all, we coped by sharing and caring about each other as a family. That pretty well solved the crisis.*

Overall results demonstrate little change over time in patient relationships with their children:

*I regretted that Mum and my daughter had to go through all this with me and I blamed myself for hurting them with my illness. I tried to talk things through with them.*

Women living without the intimate care of a spouse/partner effected significant but different support patterns from those women benefiting from close family supports.

## STYLES OF COPING AT DIAGNOSIS AND DURING TREATMENTS

***I felt they weren't telling me everything but  
I couldn't bring myself to ask***

**Coping by conforming and complying with an authority; doing what is expected or advised**

*The specialist offered me radiation at first as he said surgery was not an option. I told him that I would not have radiation again as I had had it when I was treated 10 years ago for Von Hirschsprings Disease. He said he was prepared to remove the offending organs, to give surgery a go. I had surgery.*

*I regretted not going to the doctor earlier and I blamed myself for that. I didn't ask the doctors, try and establish a relationship even. I felt they weren't telling me everything but I couldn't bring myself to ask. I wasn't confident. I worried and worried, didn't talk about it, not even at home.*

*At first I was not satisfied with any medical information...A day or so after diagnosis I complied with the medical treatment plans.*

## STYLES OF COPING AT DIAGNOSIS AND DURING TREATMENTS

***After the initial shock I became falsely confident. I sat up and reassured everyone that I was going to beat it.***

**Coping by accepting and redefining the situation; finding something favourable and rising above it**

Just under half the study participants At Diagnosis and During treatments exercised a 'Pollyanna' approach visualising only very positive outcomes, never the possibility of failure, to make coping more feasible and more likely:

*After the initial shock I became falsely confident. I sat up and reassured everyone that I was going to beat it.*

*I coped by seeking reliable professional help – getting on then with the treatments to cure me.*

### **Coping by seeking information; getting guidance**

Seeking trustworthy information from a reliable source, is closely tied to patient decisions to comply with trusted medical diagnostic advice and direction.

*I coped by seeking reliable professional help – getting on then with the treatments to cure me.*

*I was satisfied with the medical information and the way that my oncologist handled me. The nurses were honest and they answered my questions.*

### **During treatments**

Dominant strategies chosen by women During treatments were:

- AS FOR DIAGNOSIS Shared concern – talk with others to relieve distress (COPE Strategy 2)
- AS FOR DIAGNOSIS Comply with authority – follow medical advice (COPE Strategy 14)
- Displacement – keeping busy and distracting oneself (COPE Strategy 5)
- AS FOR DIAGNOSIS Redefine based on accepting – accept and redefine the situation, find something favourable and rise above it (COPE Strategy 7)
- Confrontation – taking firm action based on present understanding (COPE Strategy 6) combined with Stimulus reduction – withdrawing socially (COPE Strategy 12).

***If I went down the street, I wouldn't  
like to lose sight of mum in case the world  
turned around and I was lost forever.***

### **Coping by shared concern; talking with significant others to relieve distress**

Sharing concern with close family members During treatments continued to offer profound and pivotal support.

*My husband did the best he could ... came home as soon as he could – he cooked, cleaned and made me feel special. He loved me and reminded me that this was all temporary.*

*My youngest son is 8 and so loving. He makes me a cup of tea any time day or night, sits with me and holds my hand.*

*If I went down the street, I wouldn't like to lose sight of mum in case the world turned around and I was lost forever.*

*exactly what chemo, cancer etcetera mean.*

Yet shared concern had its limitations. Patients registered an oftentimes limited capacity to share concern with friends who had not previously 'experienced cancer:'

*During radiotherapy I preferred to be alone. One particular friend walked as if she was sick. She got into the mood of looking sick when she talked with me. She was not strong enough to accompany me. I see it on their faces.*



***My husband kept saying 'This chemotherapy is our best hope of cure.' So I went to Ward ...again, and again and again.***

**Coping by conforming and complying with an authority; doing what is expected or advised**

*The doctors recommended chemo and I felt I had no other hope of cure so I began treatments as soon as possible.*

*My husband kept saying 'This chemotherapy is our best hope of cure.' So I went to Ward ...again, and again and again.*

***'Why shouldn't treatments work on me?'***

***My doctor said, 'The tumour is going to kill you***

***Sometimes I think 'Will I be around to see my kids grow up?' Mostly I can keep that out of my mind though.***



Pollyanna concept- a power for very positive thinking and a capacity to visualise only the positive outcome, never with the possibility of failure, as widely evidenced throughout treatments for over half the patient population (58.3%).

*Underneath it all I had little courage to face up to the thought that I would die. I always quickly blocked it out, and replaced my fears with hope, making myself hopeful of recovery by saying 'Why shouldn't treatments work on me?'*

*My doctor said, 'The tumour is going to kill you. I was so shocked and upset that from somewhere I got a bit of a fight. I remember making a promise to myself after that. I said, 'I'm going to show you and everyone else that I'm going to make it, that you are wrong.'*

*Sometimes I think 'Will I be around to see my kids grow up?' Mostly I can keep that out of my mind though.*

*... It was hard to say our life was normal because I had the fear of not being cured hanging over my head.*

#### **Coping by seeking information; getting guidance**

*The doctors recommended chemotherapy and I felt I had no other hope of cure... It was hard to say our life was normal because I had the fear of not being cured hanging over my head.*

***Painting was a new career path for me, a purpose, a real meaning in case I didn't live long. As a meditation does, it took me away.***



### **Coping by displacement – keeping busy; distracting oneself**

During treatments, 75% of the study population coped by strength of personal belief. This worked as a method of distracting oneself from the risk of illness failure. Doing other things to distract oneself was relied on by 75% of patients in the study by way of concern for 'the needs of a significant other/support person' and less often, the cancer-based needs of the self.

*Everyone, my neighbors and work colleagues all made a big difference to my life. This all distracted me from the focus on whether I could be dead or alive, whether I would survive this treatment or not. I concentrated on today each day.*

*To get out of my feelings I did housework.*

*Painting was a new career path for me, a purpose, a real meaning in case I didn't live long. As a meditation does, it took me away. I had painting, a 24 hour a day profession to rely on. By throwing myself into purpose and painting I survived.*

***There was a little boy who had his radiotherapy every day and would cry all the way to the hospital.***

***He was in the ambulance we shared with his Mum.***

***That hurt me more than anything, to watch that and be part of it.***



Concern and attention to the needs of significant other/s gave extra strength:

*My grandchildren give me hope, something to go on for. If I died you see, my grandchildren wouldn't have a grandmother so I must keep going.*

*There was a little boy who had his radiotherapy every day and would cry all the way to the hospital. He was in the ambulance we shared with his Mum. That hurt me more than anything, to watch that and be part of it.*

*An old man of 85...90 years waited alone in his wheelchair for his turn at radiotherapy. He was too old to be going through all that ...*

*I had to get really well because my daughter was getting married and she wanted me to give her away. Her dad's not around for her...I got extra strength of some sort and got there....*

***I always asked myself 'Do you want to live?' 'Yes', I said, so I kept going.***



**Coping by confrontation – taking firm action based on present understanding of the problem**

Just under half the patients in the study relied on a combination of coping strategies: Confronting the medical situation During treatments, Taking firm action based on present understanding and Withdrawing socially During treatments.

Having the courage to confront problems additionally requires honest self-appraisal as a pre-requisite of this strategy, which 41.6% of patients applied to dealing with problems and concerns raised During treatments:

*In a strange silent sort of a way I progressed through the treatments, never glancing sideways away from my purpose before me of getting better.*

*I always asked myself 'Do you want to live?' 'Yes', I said, so I kept going.*

*I was pleased to have chemotherapy as I knew the cancer was moving. I knew that if they didn't give me more treatment, I wouldn't be here long. I would never refuse treatment though because I want to keep going as long as I can."*

***I had planned for children of our own and I couldn't have them.***

***My husband pulled me out of it.***

***We discussed other options that seemed hopeful.***



**Coping by confrontation – taking firm action based on present understanding of the problem (continued)**

*When I was faced with treatment I became more realistic. I tried to resist the tired withdrawal into myself. I coped by concentrating on getting through radiotherapy and making it home every day.*

*I had planned for children of our own and I couldn't have them. My husband pulled me out of it. We discussed other options that seemed hopeful.*

*I found out what I was dealing with medically, consulted the specialist about what was our best course of action (in this case it was chemotherapy) and then went through the experience as positively as I could. I had to put my work on hold. I was a Professor at the university and had to give treatment a top priority.*

*My aim was to do everything I had to. I always pushed myself. I managed radiotherapy by sleeping for half of every day.... You need to protect yourself by staying sufficiently in your own atmosphere – your own little haven. I'm learning to rest, nurture myself, trying to have separate breakfasts, lunch and dinner. By putting a priority on that, I feel that I am improving, that my energy is better.*

***We coped by turning to each other...in a way we withdrew from everybody else. That included the doctors because we found them confusing.***



#### **Coping by stimulus reduction – social withdrawal; social isolation**

A significant group of patients in the study commonly withdrew from the world during the weeks in which chemotherapy (in particular) rendered them 'energyless' and low:

*During treatments I coped by sleeping and shutting down from the world. I buried myself in my bed with a couple of science fiction books... People came but I didn't burden them much.*

*I became anti-social because I couldn't rely on feeling well even between treatments.*

*I didn't bother with make-up, how I looked and I preferred not to leave the house. I hardly communicated with anyone. In spite of everyone's support I wanted to be alone, to survive this trap alone. I coped by isolating myself between treatments by going home straight afterwards and hiding (for the following 3 weeks) after each treatment.*

#### **Withdrawing to a safety shell with a significant other**

*We coped by turning to each other...in a way we withdrew from everybody else. That included the doctors because we found them confusing.*



## DENIAL: A SPECIAL FORM OF COPING

Surely there are as many ways of coping as there are people. But the key is to be certain that the diagnosis doesn't paralyse you into inaction and the inability to seek treatment. Coping becomes easier because you have someone who will face the fears with you.

It is the conclusion of this current research study that denial does have a strategic and existential value, acting as a social strategy to preserve things as they were or might be, thus minimising uncertainty and fragility, at least for a while.

During diagnosis, patients interviewed in the current study occasionally attributed meaning to the terms 'Oncology' or 'tumour' that were clearly unrelated to cancer and its associated ramifications. During treatments patients routinely exercised hope for drug-related cure as a key coping concept. At Post-treatment when active treatments had discontinued, palliative patients by majority turned hope to blatant denial and struggled on somehow. For those with dependent children, patients denied the severity of their illness by softening any mortality blow for members of the household. It is only human, however, to consider that unwelcome ideas must be rejected and changed into something else where painful facts are difficult to tolerate.<sup>5</sup>

Just under half the study participants At Diagnosis and During treatments exercised a 'Pollyanna' approach visualising only very positive outcomes, never the possibility of failure, to make coping more feasible and more likely. This linked with CS 7 discussed earlier. Yet to the exclusion of all medical and associated facts, the strategy disconnects with realistic thinking:

*After chemo, I felt I had got rid of the cancer... the octopus had become smaller and smaller. I felt marvellous....As far as I was concerned I was cured and there was no reason to doubt that. I felt I'd beaten it, I didn't need their opinion. I knew that the doctors would find nothing there.*

***After chemo, I felt I had got rid of the cancer... the octopus had become smaller and smaller.***



## POST-TREATMENT PATIENT CONCERNS, VULNERABILITY AND COPING

*It's just a frightening feeling a human gets...that it will come back*

*....I don't trust my body anymore.*

Post-treatment divides into either of two forks in the roadway, one pointing towards Terminal Care, the other towards the equally hard-edged thoroughfare called Survival:

*I'm in line for an electric chair. Death row is where I am at present. I've tried hard, I'm fighting hard. That's all.*

*It's just a frightening feeling a human gets...that it will come back....I don't trust my body anymore.*

Thematic analysis at Post-treatment continued to identify Existential, Health, Self, Family and Friends, Work and Finance, and Religious concerns. By far the greatest number of Patient Concerns at Post-treatment were Existential, closely followed by Health, then Self related concerns.

### **Post-treatment concerns at Palliative care**

The IPC scale indicated that concerns about Health, Self, Existential matters, and Family and Friends became greater over time, whereas Work/Finance, and Religious concerns were of far less importance for most people as the cancer experience wore on.

Heightened feelings of personal hopelessness, giving up and other related concerns associated with anticipating leaving all that life means and all those one loves are clearly aligned with accelerated patient vulnerability at Post-treatment. While patients prefer to strengthen family relations by talking openly about their situation, increased vulnerability arises when such assistance cannot be found or when time registers as particularly short (66.7% at Item 13).



***Still I worry whether I should start distancing myself from the girls. I'm thinking that it might make it harder for them after I die if I stay close now.***



### **Existential Concerns (EC)**

The major concerns patients with terminal illness involved recognition of leaving all that life means and all those one loves. This caused intense anticipatory loss, with associated fears and distress:

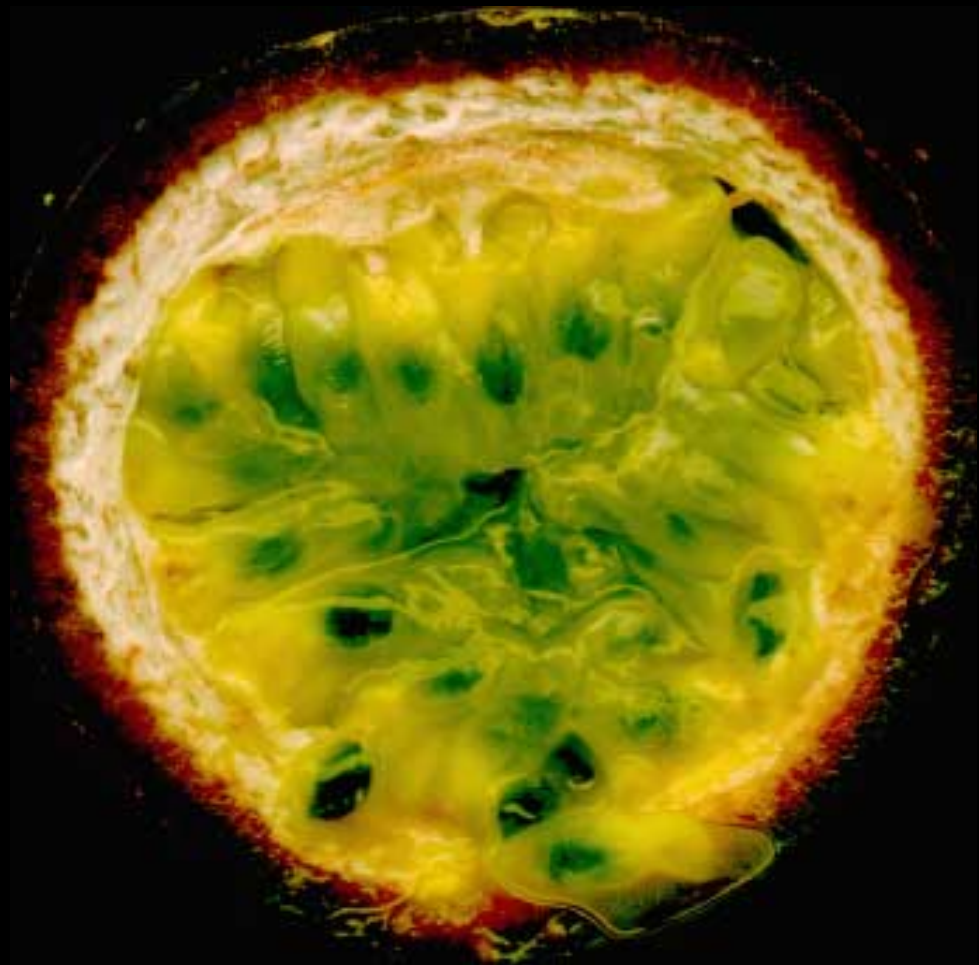
*I am angry and distressed. I can't believe I am losing my mind ...I intensely dislike the incredible loss of independence. .*

During terminal care, health and existential concerns reached a critical peak of distress without respect for age and socio-economic differences. For several young mothers with small children and variable support partnerships, compounded concerns were accelerated by anticipatory anxiety related to dying and leaving young dependant children:

*I know that my husband buries his head and won't look at the present. Still I worry whether I should start distancing myself from the girls. I'm thinking that it might make it harder for them after I die if I stay close now.*

*It's hard to face such a deep fear, such a deep pain. It's a pain beyond tears, touching on acid tears.*

***Could you do something for me? I want deep down to commit suicide. I'm sick of it.***



### **Concerns about Health (CAH)**

Patients at Post-treatment registered pessimism towards the future, exacerbated by personal life uncertainties and fears, increasing physical symptoms, inability to keep up with the demands of daily living, as well as increasing problems related to self-esteem and poor functioning:

*Today my soul feels peaceful, but tomorrow if I wake up fearful and feeling ill, I wonder how many more days I've got. Could you do something for me? I want deep down to commit suicide. I'm sick of it.*

*I know I'm not going to reach my 42<sup>nd</sup> birthday. I'm never going to see the kids grow up or get an old age pension...I'm not even the individual I want to be now because I'm so crook. I'm tired and desperate to control the pain.... I have to get on with the rest of my life, tidy it up as best I can and plan to die.*

*I'm not feeling very well. That gets me down more than anything. I want to be a normal mother. I am really frightened of not getting better, of dying. I can't stand to look at that. What would be left of my life and my dream?*

***I feel frustrated with my progress. Every time I think something good might happen, it doesn't.***

### **Concerns about Self**

As symptoms attached to disease progression became more self-evident, emotional capacity to function with a focus on achieving quality in daily living deteriorated:

*I can't manage the housework. When no-one visits, when the pain is unmanageable and everything is a mess, I give up in despair.*

Patients oftentimes presented the further pain, exhaustion, helplessness and feelings of being attacked by a fateful disease under the label of self-concern:

*I feel frustrated with my progress. Every time I think something good might happen, it doesn't.*

***It annoys me that I'm not going to be around for the girls, that I never finished the mother job, that I got knocked out in the ring just after interval.***



## **Concerns about Family and Friends**

Over time patient concern for distress experienced by family members whom they love dearly became more paramount. As well as accepting themselves as worthy of being loved, patients held a firm belief that their spouse was a very special person who must be cared for as they were. At Post-treatment, 83% of patients registered family concerns involving either or both a spouse and/or children:

*I don't really have any regrets; I just have hope for continuing my life with my husband, the cats, our house for as long as possible. He is my social support ... my friend and companion. We have made a few other friends over the years, from work and the neighbours, but we have each other.*

*Problems are easier because my partner and I get on well together and both our families are always around. I suppose we cope by talking about things and working through them together.*

*I haven't finished the mothering job. It annoys me that I'm not going to be around for the girls, that I never finished the mother job, that I got knocked out in the ring just after interval.*

***The wound is weeping on the left side of my leg. He has done a fantastic job but we can't afford to buy the bandages...***

### **Work/Finance Concerns**

The costs of cancer – emotional, physical, lifestyle, the terrible costs to overall total and independent living – remained an ongoing concern to patients and their families with no let up as palliative needs accelerated:

*We were both on social security. My husband and I nearly split up because of the money problems. We had two of his brothers living with us rent free. We didn't have enough money for food for all of us.*

*The wound is weeping on the left side of my leg. He has done a fantastic job but we can't afford to buy the bandages...We haven't any money to buy much food, pay the house bills or car off.*

The threat of dying and death, being unhappy and predominantly concerned about leaving brings out a deep commitment to do everything possible to delay the inevitable.

***I have faith. I believe that God is there with me all the time. He has supported me all the way to date. I have check-ups with the cancer doctor.***

### **Religious Concerns (RC)**

Results of this research confirm the critical value of spiritual beliefs and practices as major sources of personal strength in facing man's 'most perilous question.' Many patients at Post-treatment raised some level of religious distrust and concern:


*I fluctuated between anger and depression on most days. Anger at God, at the unfairness and mostly at the uncertainty of it all.*

In contrast, most reported positive life changes in relation to spirituality as a result of enduring the illness:

*I cope by crying and doing what the doctors think I should do medically. I pray and talk to the priest.*

*I have faith. I believe that God is there with me all the time. He has supported me all the way to date. I have check-ups with the cancer doctor.*





***Cancer has affected the way I feel as a woman. ...An important part of me is gone.***

## **Vulnerability expressed by patients during Palliative care**

### **The impact on female identity**

At Post-treatment distress was of course experienced differently by women depending on their home and life circumstances and supports. Issues of sexuality, body image and lower self-esteem are closely associated with poorer Post-treatment emotional function, QOL and vulnerability :

*I felt ... like nothing...I was depressed and lifeless....I coped by sleeping and shutting down from the world.*

*Cancer has affected the way I feel as a woman. ...An important part of me is gone.*

Many partnered patients continue to acknowledge that sex, as a form of touching remained an integral part of one's most critical sharing, and fears about losing significant relationships causes great anxiety in most women:

*Even a back massage can be sex if it has the quality of beautiful pleasure. Sex is cuddling and being close.*

*The sex itself is not so important but the closeness is.*

*It's nothing now.*

***Now I appreciate how much we have got and how much we could lose.***



Most women prior to being immediately terminal expressed some interest in retaining attractiveness, desirability and keeping relationships involving intimate care and sexuality present. Women feared loss of those aspects in their daily living:

*Now I appreciate how much we have got and how much we could lose.*

*I still live in fear of my body decaying even further. I don't want anyone else to be as lonely as me travelling along this road.*

*Everything at home is a bit out of control...By withdrawing, everyone becomes less attached. Leaving my partner, the kids, everyone behind will have been smoother.*

## **Coping Strategies during Palliative care**

The five dominant Coping Strategies chosen by women at Post-treatment were:

- Compliance – conforming or complying with an authority, doing what is expected or advised (COPE Strategy No 14)
- Shared concern – talking with significant others to relieve distress; finding consolation with significant others and/or carers (COPE Strategy No 2)
- Fatalism – stoic submission to and acceptance of the inevitable; resignation to a view of ‘nothing I can do about it’ (COPE Strategy No 8)
- Displacement – keeping busy; distracting yourself (COPE Strategy No 5)
- Confrontation – confronting the issue; acting according to present understanding of the problem (COPE Strategy No 6).

**Compliance**

**Shared concern**

**Fatalism**

**DisplacementConfrontation**

***My kids are grown up now. I'm still alive and after all this time with my illness rely on their support. I take the medication I'm given and do the right thing.***

**Coping by conforming and complying with an authority; doing what is expected or advised**

The profound support of the doctors and associated comprehensive cancer care staff cannot be underestimated during Post-treatment, in particular palliative care:

*I asked for help to get me through. I tell the nurses how I am and what I need. Then I keep in touch with the specialists and check on that angle.*

And for those with hope of long-term survival:

*Now I go to the hospital every 3 months for check-ups. This illness has been just another big job to do. I've achieved it with the help of the Professor, other doctors and my friend H.*

*My kids are grown up now. I'm still alive and after all this time with my illness rely on their support. I take the medication I'm given and do the right thing.*

***They got smaller and smaller, like dots on a horizon. From 12 floors up, you have a bird's eye view. My heart broke that day. They were walking away and I wasn't with them. I thought, 'Is that what our family will look like in the future'?***



**Coping by shared concern; talking with significant others to relieve distress, finding consolation with significant others and/or carers**

Some patients relied primarily on spousal support:

*My husband has remained my consistent support. I have lived on the love and support he has continued to give. I am worried about what I am doing to him, what all this is doing to his life. I'm sorry for that.*

*'We have faced things head on together. He is very anxious to get me home. He can't face losing me and I can't face losing him. We are going to fight this together with all our positive thinking'.*

Some were emotionally reluctant to rely on their children during the course of palliative care:

*Neither of the kids know my long-term prognosis and that I'm going to die. I'm too scared to tell them.*

*I fear talking about it, of breaking down and crying a dam full of tears. I want to plan that fishing trip instead. I want to do that, like we used to, the boys and I.*

*I worry about my son because he's only 8. He hates it when I have to go into hospital and cries every time he knows I will be leaving, he worries about being away from me.*

*I just want another 25 years to stay and bring my children up myself...The other day my husband brought the kids in to visit me. After he left, I saw him walking away from the hospital with the boys and my daughter. They got smaller and smaller, like dots on a horizon. From 12 floors up, you have a bird's eye view. My heart broke that day. They were walking away and I wasn't with them. I thought, 'Is that what our family will look like in the future'?*

***The only time I've tolerated other people during this illness is when they have had cancer themselves: 'Unless they've been there and done that, they don't really know. That is true. No one who hasn't had cancer ever does.***

Whether patients were supported by spouse and family or not, patients looked to cancer survivors for support:

*The only time I've tolerated other people during this illness is when they have had cancer themselves: 'Unless they've been there and done that, they don't really know. That is true. No one who hasn't had cancer ever does.*

*When I think about my body I get sad. I am like a little ship on a sea. I realise that I am going to die.*

**Coping by Fatalism: resigning to the view of ‘nothing I can do about it’**

For those faced with acceptance of the inevitable, resignation to a view that ‘there is nothing I can do about it’ is a choice intended to acknowledge forces **beyond one’s control – resignation to forces which seem to be incomprehensible.**

**Certainly for women with dependent children the very thought of leaving families who are still dependent on them irreplaceably for guidance, developmental direction and daily nurturance, the journey of departure offers irreparable and irretrievable breakdown. It is not a given aspect of justice at its most natural that mums die early, leaving dependent children to the care of another.**

**Young women confronting palliative care with children routinely revisit the lost potential of their most critical life relationships:**

*I’m just giving in to it. I have to. Death means no choice.*

*Our family has slowly shut down feelings for each other. It’s really too painful any other way. I don’t want to make it any harder to leave than I have to and leaving is inevitable.*

*When I think about my body I get sad. I am like a little ship on a sea. I realise that I am going to die. .*

*My husband has taken over my old role as mum. He cooks and cleans and finds my daughter’s dollies for her when she loses them.*

***Things live and die and that includes me.***



**For those with older independent children:**

*You might say that I've pulled the plug on all of this now. I've had my turn. It's Saturday, Tattslotto night and my numbers are up. In some ways I think, Thank God; in others, I despair.*

**Single women with no children**

**For women with no supportive partner or children, grief related to lost life potential not having a 'meaningful partnership,' life and death concepts are marginally easier to confront:**

*No expert in the world can cure me. I'm not Pollyanna, I've faced it.*

*Things live and die and that includes me.*



*I cope by thinking of the grandchildren, that I love them and that I want to watch them grow up.*



**Coping by Displacement; keeping busy, distracting yourself**

Distraction and keeping busy with a sense of purpose and dedication to another or collective activity is often good when used to gain a sense of perspective, but poor when used to completely avoid facing a problem. In the RWH study, the needs of a significant other/support person were routinely registered by patients during palliative care:

*I cope by thinking of the grandchildren, that I love them and that I want to watch them grow up. I take the medication I'm given and do the right thing. The kids keep me busy and up.*

*I am not really coping. I'm keeping going of sorts. I'm not communicating with anyone except the doctors. I'm just trying to rest and accept what has to be. My other half and I are struggling too much to talk a lot. I am so worried about him.*

**We are working on my health by positive thinking. It's the only thing that we can rely on now. I'm not having any more hospital treatments now that the disease is in my liver**

#### **Strength of belief gleaned from desperate hopefulness**

Desperate hopefulness existed in the palliative phase of the study where no room for realistic hope remaine:

I am really frightened of not getting better, of dying. I can't stand to look at that. What would be left of my life and my dream?

We are working on my health by positive thinking. It's the only thing that we can rely on now. I'm not having any more hospital treatments now that the disease is in my liver. Being in touch with the Gawler Foundation and being told that things are normal both help us with a natural attack on the Cancer. I want to go one day at a time and keep hoping to turn this thing around.

We've had a few parties, drunk Tia Marias and the rest. I've been sick afterwards. I've loved my friends from the Primary School coming around. The parties are fun and distract me from the pain.

***The nurse told me the other day, 'Darl, you know you are not going to get better.' I thought about that but I'm believing that I'm getting better.***

### **Denial: Continuing that special form of coping into Palliative care**

While distracting oneself from the risk of illness failure and the darker realities associated with a cancer prognosis, denial is in evidence:

*Mostly I switch off and when people come, we stick to talking about normal things. Anything else upsets me and I can't cope.*

*The nurse told me the other day, 'Darl, you know you are not going to get better.' I thought about that but I'm believing that I'm getting better.*

*When the doctors told me how bad my health was, and is, I tried to change the uncertainty into hope. I felt numbed by hearing that my body wouldn't get better.*

*I couldn't understand this outcome because I had felt cured. The medical Professor told me that they couldn't offer me any more treatments but I knew I had to be cured somehow. I know that I can do it if I work on my body hard enough.*

*I will find a way to cure myself. I believe that one never knows what the mind and body can do, that in fact my mind can cure my body. I've got to get this cure going.*

***Would it be fair on you if I died in the bed you are going to sleep in for the rest of your life?'***



**Coping by Confrontation; confronting the issue, acting according to present understanding of the problem**

This strategy calls upon the best judgement one can summon with the aid of opinion sought from an acknowledged medical expert.

*I cope by talking the big things over with my family and the doctor, by coming into hospital for a rest and pain management, and by telling the girls what we are all facing ... a funeral, a burial, life without mummy in this body.*

*Poor G, my husband, it's hard for him to cope with the things I say to him. I say shocking things like, 'Do you want me to die in hospital or at home here in bed? Would it be fair on you if I died in the bed you are going to sleep in for the rest of your life?'*

## **ADDITIONAL COPING STRATEGIES IDENTIFIED IN THE FINDINGS**

All patients in the study found it impossible to imagine beyond the now, that life could continue into the future without their physical presence, at least registration of their feelings about living and being alive. Study findings indicate however that surrendering to the universe is easier as the body subsides and engagement with the matters of the world becomes a past tense interest.

The following new strategies emerging from results of this study are detailed overleaf. Clinging to the last lifebuoy of hope; facing the very real anticipatory grief of potential loss of one's own physical life and its key relationships; and the lost potential of what one could become if life could have been extended have been key themes in confronting life's most perilous question when one's body 'no longer exists.'

***How can I plan to leave all I know and all I really value?***

**Coping by Crossing the bridge of uncertainty/clinging to the last lifeline/  
lifebuoy**

For patients encountering the huge quagmire of uncertainty and change during palliative care, an emerging, absolute, desperate search for emotional lifebuoys exists— to hold onto positive hope in spite of recurrent personal fear, emotional distress, life insecurity and existential aloneness:

*This is killing me. It is making me weaker, taking away my passion and determination to keep going. My mind is alert and okay at this stage. It's my body that is slowing me down.*

**Coping by expressing anticipatory grief of the loss of one's life and key relationships**

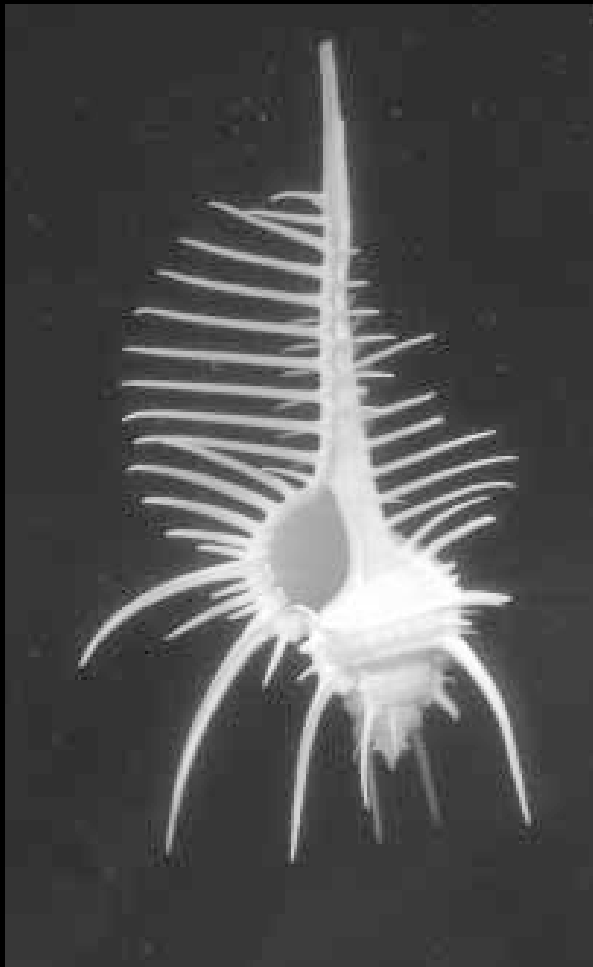
*I didn't want to leave. We had a happy life planned, B and I.*

*We are very close which of course makes leaving harder and full of so much pain. What and who I leave when I die is another issue. I have to face it though. I know I am dying, gradually leaving. But still I am trying to stay close to mum and my daughter. That is so hard.*

*I value my life more than I ever have before. I value everything more because I know it is ending.*

*I'm past history. I am no longer able to be E's wife or the kids' mum. That has all ended. So in the same way I am ended... How can I plan to leave all I know and all I really value?*

***I'm allowing my time to close naturally. Then I will be ready.***



## **Coping by expressing anticipatory grief in the form of lost physical life and lost potential for what could have been**

Patients registered significant trauma in attempting to conceptualise human life without them, when their body 'no longer exists':

*I've come to terms with death as best I can. I've found out as much as I can about dying and after death. So it doesn't matter any more about my body. I leave behind a body that has battled cancer and I am resolved about my soul. I've asked the mortician about the process of bodily decay. I want to know as much as I can.*

*I've tried to adjust to the changes forced on me by my illness. In a word, it's sad; in three, I'm melancholy, nostalgic and depressed. I've been reacting normally as everyone probably does, to leaving every personal joy they have known behind. ...I'm allowing my time to close naturally. Then I will be ready.*

Continuing into the future without one's physical presence is unimaginable:

*Death is now inevitable and I've nearly finished my last project, my book. Now we are writing up my life story to distribute at the funeral.*

*I want to have this poem on record, a sonnet I've lived my life by. Shakespeare was such a truthful man. The poem will outlive us both: 'When forty winters shall besiege thy brow And dig deep trenches in thy beauty's field...'*

But after all, surrendering to the universe is easier as one's body surrenders and the world becomes past tense:

*I have no choice to resist or ignore dying because things have already captured me and simply it's a matter of time and body energy. I'm allowing my time to close naturally then I will be ready.*

*I just feel so lonely, distant and helpless. I lie here in a dead quiet room. No sounds, looking into empty space and seeing nothing. That's all I do.*

***I am sort of more mellow, I'm preparing not to recover. It's the next step and one that I'm prepared to take now.***



The concept of God offers an enduring emotional guide while one concludes and tidies up 'what was':

*I leave behind a body that has battled cancer for 4 years. God has promised there will be no sickness, sorrow or sadness in Heaven. I'm looking forward to finally having rest in a tranquil place. I've coped by relying on shared religious beliefs with the Pastor and a missionary friend.*

*I am sort of more mellow, I'm preparing not to recover. It's the next step and one that I'm prepared to take now.*

*Now I just want to be remembered for being a good mum and for holding onto my faith and being true to myself. Having tidied up happy and sad feelings with the girls and my ex-, I want to have a clean slate. Everything is just about in order.*



*to have your hopes dashed at the last minute,  
and to have to share the pain with your despairing husband.*

## **SURVIVORSHIP: THE OTHER ARM OF POST-TREATMENT**

The experience of surviving cancer has been an interesting and unexpected one in that patients in the study who overcame active disease evidenced a struggle to survive up to, and including the Survivorship interview. Three adaptive directions, influenced by the Little paradigm<sup>6</sup> detail the way cancer survivors attempt to rebuild their lives after the active onslaught of cancer treatment is over:

1. Some patients chose to externalise fears by blaming others and situations around them.
2. Others returned to a former lifestyle without making any reflective change.
3. Still others, in confronting the course of their disease, continued to acknowledge the uncertainty of potential recurrence, reporting their ongoing struggle to survive the vulnerability of survival and adapting new life meaning as a result.

### **Reacting against Illness by Externalising Blame**

Some patients relied on externalising fears by blaming others, making their fears part of faulty situations around them:

*I was so distressed about wearing a colostomy bag. The worst part was the social side. Whenever we had visitors I would get stressed because the bag would rumble loudly and fill. Everyone could hear.... There were always the bags during sex, during any closeness.... I don't think the doctors understand what it's like to have sex with a plastic bag gurgling all the time, or to have your hopes dashed at the last minute, and to have to share the pain with your despairing husband.*

***The cancer took away my zest for life. The way I am now is not me. I'm very cautious and anxious that things will go wrong again.***

### **Returning to a Former Lifestyle without Change**

For some patients the relief of recovery blocks fears associated with confronting mortality. Return to past habits and patterns were a safe escape from the harshness of cancer, a chance to block the event and put it 'to bed' as an event now past:

*Like an exhibition, you work on it, and then it's over.*

*What I had been aiming for pre-cancer hasn't changed. E and I can now save for a house. Then after I am clear of the cancer for 5 years we can adopt children...I'm involved with people, working and saving money for our home. It is all in place, as I like to see it.*

*I'm 31 in October and the cancer has put a lot of life experience my way. I'm happy to be entering a new and different phase.*

## **Incorporating the Cancer Experience into a New Adaptation and Life Meaning, Acknowledging the Vulnerability of Life and One's Body**

Patients who used this strategy clearly acknowledged and began to deal openly with residual fears:

*It's just a frightening feeling a human gets...that it comes back.*

*There's only like one thing and it's being honest with myself, and this is how I'm really feeling. Is I am still scared that the cancer will come back.*

***It's just a frightening feeling a human gets...  
that it comes back.***

The learning curve is profound for some survivors. The ability to confront a new experience oftentimes brings healthy change, a capacity to juggle and create newly affirmed goals and life purpose:

*I tried originally to go back to the same life I was doing. But the cancer had changed me. I no longer spoke the language that they, we were speaking before.*


Patients report a new capacity to evaluate life and death priorities so that life takes on a new way of seeing life challenges and meanings:

*The awareness that it took ... had to come to me as a result of the illness, the threat on time that I might have left to live.*

*I still see myself as a better person for the experience with a better set of values but I am tired and fatigued with the pain and really managing it alone.*

*The cancer freed me. I have learnt how to live and to count each day. And to value that day.*

*I take some risks now and again, that I just wouldn't have done before...Well I got me belly done, pierced. I thought, yeah.*



***Since cancer sex is not just a physical act,  
it's compassion, care, feeling, affinity, and spiritually  
connecting with a person.***

## **SEXUALITY ISSUES FOR SURVIVORS**

Throughout the course of the illness, patients identified a profound need for reassurance, and increased emotional and tactile touch:

*I tell my husband and the boys every day now how much I love them. They are everything to me.*

'Being touched and being in touch' was persistently identified as a key coping tool for families and individual members. One 7 year old:

*... did a drawing with everything in the house, all the furniture was lined up around the square of the page so that it was clinging to the 4 edges. There was a bed and some furniture, in grey lead only, no coloured pencils at all. He seemed to be drawing everything around the edge of the page trying to hang onto something because mum's hand wasn't there at the time.*

*I'm getting more support now than I've ever had but then I need more support now than I ever needed.*

*I'm still learning, and I think one day I can sit down and say, 'Well, I know what love is, to receive it and accept it, than rather give it all the time'. I'm trying to learn that.*

### **Let's talk about sex**

In surviving beyond active treatments for gynaecological malignancy, issues of sexuality and body image continue to form an integral part of one's most critical sharing and satisfying life relationships:

*Since cancer sex is not just a physical act, it's compassion, care, feeling, affinity, and spiritually connecting with a person.*

*Cancer has affected the way I feel as a woman. I feel lousy about how I look.*

***Illness gave me clarity on my life. It made it important to be happy. I know now that there are no dress rehearsals.***



### **Younger women and lost potential**

For younger women surviving gynaecological malignancy, life without an intimate partner left them with damaged feelings concerning their own femininity and sexuality. With irretrievable missing parts, and evidence of symptoms of premature ageing, the experience was a hard one. Yet there is a way forward to a new style of future relationships:

*Now I'm looking for quality. I want a caring exchange. After all this I'm not going to short change myself in a relationship again.*

*Yes, sex is totally important but the scar reminds me that it must be with the right person. It's my war wound and I now choose with whom and when I want to.*

*Illness gave me clarity on my life. It made it important to be happy. I know now that there are no dress rehearsals.*