



WELCOME TO THE CANCER JOURNEY  
WHERE THE NIGHT IS DARK AND FULL OF TERRORS

Michelle Davey

# OVERVIEW

- ▶ Introduction to Cancer
- ▶ Psychological distress and models of the adjustment to cancer
- ▶ Case study Jack
- ▶ Case study Jill
- ▶ Questions at any time

# THE CONFRONTING NATURE OF THIS WORK AND CONFIDENTIALITY



42,079

new cases of cancer were diagnosed  
Total population of NSW was 7.3 million

1 in 2 people  
will be diagnosed with  
cancer by the age of 85



There has  
been a  
**significant  
increase  
over 10  
years**  
for both  
men and  
women

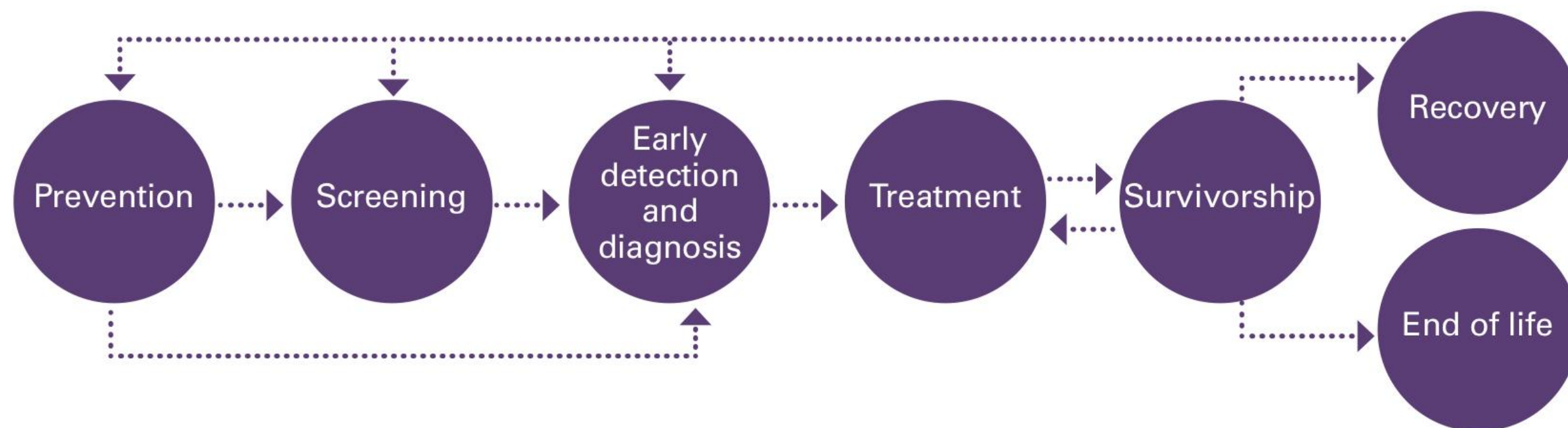


# CANCER IS COMING!

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# UNDERSTANDING THE PROCESS ....

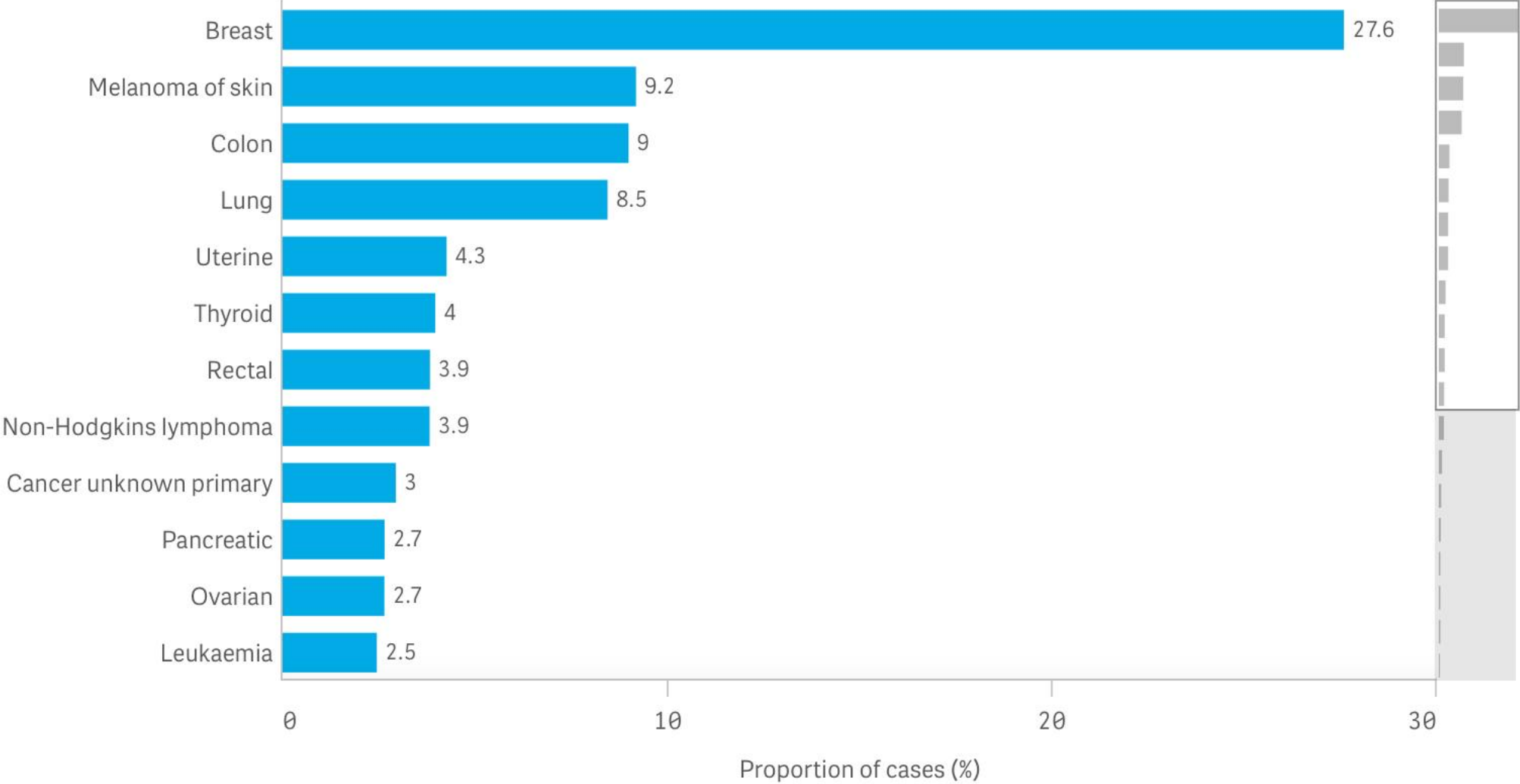


# NSW CANCER SUMMARY

- ▶ 41,888 cases of invasive cancer diagnosed in NSW in 2013
- ▶ Men are 1.3 times more likely to be diagnosed with cancer than women
- ▶ The most common cancers were (which accounted for 60.4 % of all new cases)
  - ▶ Prostate
  - ▶ Bowel
  - ▶ Breast
  - ▶ Melanoma
  - ▶ Lung

Most common cancer types, females

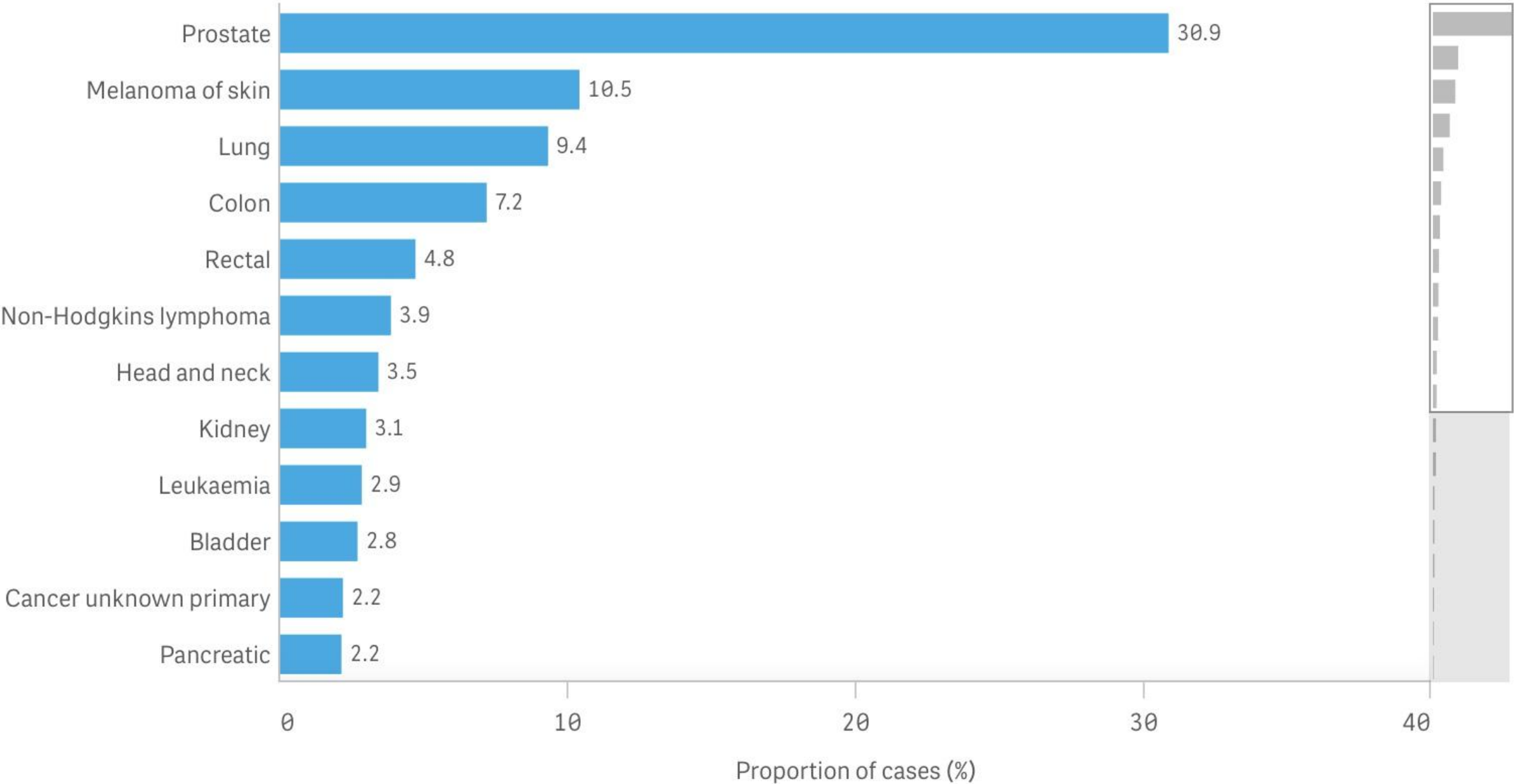
Proportion of cases, NSW, 2009 - 2013





Most common cancer types, males

Proportion of cases, NSW, 2009 - 2013



# NSW CANCER SUMMARY CONTINUED ....

- ▶ In 2017 there were 48,458 projected new cases of cancer
- ▶ 15,719 cancer deaths expected in NSW (Predicted in 2017)
- ▶ Some people are more affected by cancers than others, including;
  - ▶ Aboriginal communities
  - ▶ Culturally and linguistically diverse communities
  - ▶ Rural and remote communities
  - ▶ People from lower socio-economic backgrounds
- ▶ Greater survival rates increase needs for follow up treatment, ongoing rehabilitation and improved palliative care

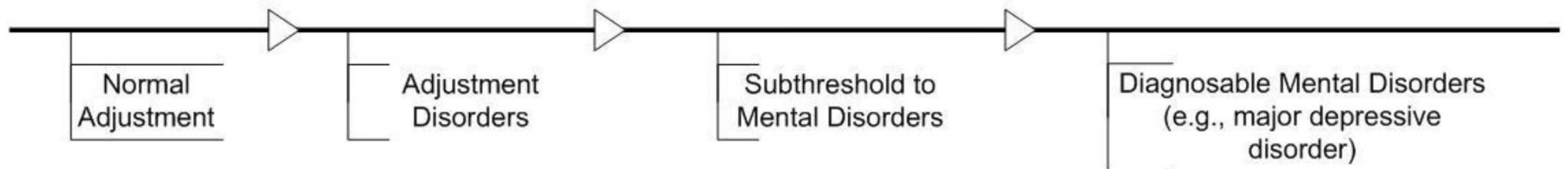
# PSYCHOLOGY AND CANCER

# PSYCHOLOGICAL DISTRESS IN CANCER

as defined by the National Comprehensive Cancer Network  
(NCCN)

“a multifactorial unpleasant emotional experience of a psychological, social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment.”

Distress extends along a continuum, ranging from normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crises.



# PREVALENCE RATES OF PSYCHOLOGICAL DISTRESS

- ▶ 20 – 66% patients with cancer experience significant levels of distress
- ▶ However pooled average of studies indicates it's about 40%.
- ▶ Patients with lung, pancreatic, and brain cancers seem more likely to report distress, but in general, type of cancer is only modestly associated with distress.

Carlson, et al (2012 ).



# DEPRESSION AND ANXIETY PREVALENCE RATES

- ▶ Significant uncertainty about prevalence of mood disorders
- ▶ Mitchell et al (2011) meta analysis
- ▶ 70 studies with 10,071 patients in oncological and haematological care
  - ▶ Major depression 14.9%
  - ▶ Minor depression (NOS) 19.2%
  - ▶ Adjustment disorder 19.4%
  - ▶ Anxiety 10.3%
  - ▶ Dysthymia 2.7%
  - ▶ Depression or Adjustment disorder in 31.6%
  - ▶ Any mood disorder 38.2 %

# DEPRESSION AND ANXIETY PREVALENCE RATES

- ▶ Mitchell et al (2011) meta analysis
- ▶ 24 studies with 4007 patients in palliative care
  - ▶ Major depression 14.3%
  - ▶ Minor depression (NOS) 9.6%
  - ▶ Adjustment alone 15.4%
  - ▶ Anxiety disorders 9.8%
  - ▶ All types of depression combined 24.6%
  - ▶ Depression or adjustment 24.7%
  - ▶ All types of mood disorder 29.0%

# UNDER IDENTIFICATION OF DISTRESS

- ▶ Under recognition of distress among cancer patients can lead to several problems
- ▶ Emotional, cognitive, behavioural challenges
- ▶ Poor quality of life
- ▶ Difficulty in making decisions about treatment
- ▶ Adherence to treatment\*\*
- ▶ Not attending / extra visits to medical providers
- ▶ Greater stress for oncology teams
- ▶ Negatively impacts survival

(The National Comprehensive Cancer Network, 2010 Distress Management Clinical Practice Guidelines in Oncology)

# THE DREAM VERSUS THE REALITY

Whilst a focused discussion checking psychosocial needs should ideally be an integral part of all clinician-patient consultations

Time pressures and lack of interest/ knowledge of psychosocial needs often resulted in physical symptom issues and discussions regarding treatment options taking priority.

# REALITY ..... AGAIN

Less than half of the patients with cancer who are experiencing significant distress were referred for psycho-social support

*Kaddan- Lottick et al 2005*

*Sharpe et al. 2004*

# HOW TO CHECK DISTRESS IN PATIENTS ....

► The distress thermometer

NCCN

National  
Comprehensive  
Cancer  
Network®

NCCN Distress Thermometer and Problem List for Patients

NCCN DISTRESS THERMOMETER

Instructions: Please circle the number (0–10) that best describes how much distress you have been experiencing in the past week including today.

Extreme distress

10  
9  
8  
7  
6  
5  
4  
3  
2  
1  
0  
No distress

PROBLEM LIST

Please indicate if any of the following has been a problem for you in the past week including today.

Be sure to check YES or NO for each.

YES	NO	Practical Problems	YES	NO	Physical Problems
<input type="checkbox"/>	<input type="checkbox"/>	Child care	<input type="checkbox"/>	<input type="checkbox"/>	Appearance
<input type="checkbox"/>	<input type="checkbox"/>	Housing	<input type="checkbox"/>	<input type="checkbox"/>	Bathing/dressing
<input type="checkbox"/>	<input type="checkbox"/>	Insurance/financial	<input type="checkbox"/>	<input type="checkbox"/>	Breathing
<input type="checkbox"/>	<input type="checkbox"/>	Transportation	<input type="checkbox"/>	<input type="checkbox"/>	Changes in urination
<input type="checkbox"/>	<input type="checkbox"/>	Work/school	<input type="checkbox"/>	<input type="checkbox"/>	Constipation
<input type="checkbox"/>	<input type="checkbox"/>	Treatment decisions	<input type="checkbox"/>	<input type="checkbox"/>	Diarrhea
			<input type="checkbox"/>	<input type="checkbox"/>	Eating
			<input type="checkbox"/>	<input type="checkbox"/>	Fatigue
			<input type="checkbox"/>	<input type="checkbox"/>	Feeling swollen
<input type="checkbox"/>	<input type="checkbox"/>	Dealing with children	<input type="checkbox"/>	<input type="checkbox"/>	Fevers
<input type="checkbox"/>	<input type="checkbox"/>	Dealing with partner	<input type="checkbox"/>	<input type="checkbox"/>	Getting around
<input type="checkbox"/>	<input type="checkbox"/>	Ability to have children	<input type="checkbox"/>	<input type="checkbox"/>	Indigestion
<input type="checkbox"/>	<input type="checkbox"/>	Family health issues	<input type="checkbox"/>	<input type="checkbox"/>	Memory/concentration
			<input type="checkbox"/>	<input type="checkbox"/>	Mouth sores
			<input type="checkbox"/>	<input type="checkbox"/>	Nausea
			<input type="checkbox"/>	<input type="checkbox"/>	Nose dry/congested
<input type="checkbox"/>	<input type="checkbox"/>	Depression	<input type="checkbox"/>	<input type="checkbox"/>	Pain
<input type="checkbox"/>	<input type="checkbox"/>	Fears	<input type="checkbox"/>	<input type="checkbox"/>	Sexual
<input type="checkbox"/>	<input type="checkbox"/>	Nervousness	<input type="checkbox"/>	<input type="checkbox"/>	Skin dry/itchy
<input type="checkbox"/>	<input type="checkbox"/>	Sadness	<input type="checkbox"/>	<input type="checkbox"/>	Sleep
<input type="checkbox"/>	<input type="checkbox"/>	Worry	<input type="checkbox"/>	<input type="checkbox"/>	Substance abuse
<input type="checkbox"/>	<input type="checkbox"/>	Loss of interest in usual activities	<input type="checkbox"/>	<input type="checkbox"/>	Tingling in hands/feet
<input type="checkbox"/>	<input type="checkbox"/>	Spiritual/religious concerns			

Other Problems: \_\_\_\_\_



# THE DISTRESS THERMOMETER

- ▶ Distress over a 4 is clinically significant
- ▶ Psychometric properties are sound.
- ▶ Validated against the HADS in multiple languages for multiple populations ( in adults )
- ▶ Scores of 7 or above used in immediate referral to clinical psychology (Lambert et al 2014)
- ▶ Does not take place of common sense / clinical judgment

# COGNITIVE MODELS OF ADJUSTMENT AND COPING

*A diagnosis of cancer threatens a person's sense of survival and threatens their sense of self*

*Moorey and Greer 2002*

MICHELLE DAVEY

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# THREAT TO SURVIVAL

# THREAT TO SURVIVAL

From a cognitive perspective; the core beliefs held about the self, the world and the future are challenged.

After the initial shock reduces patients and families start to ask:

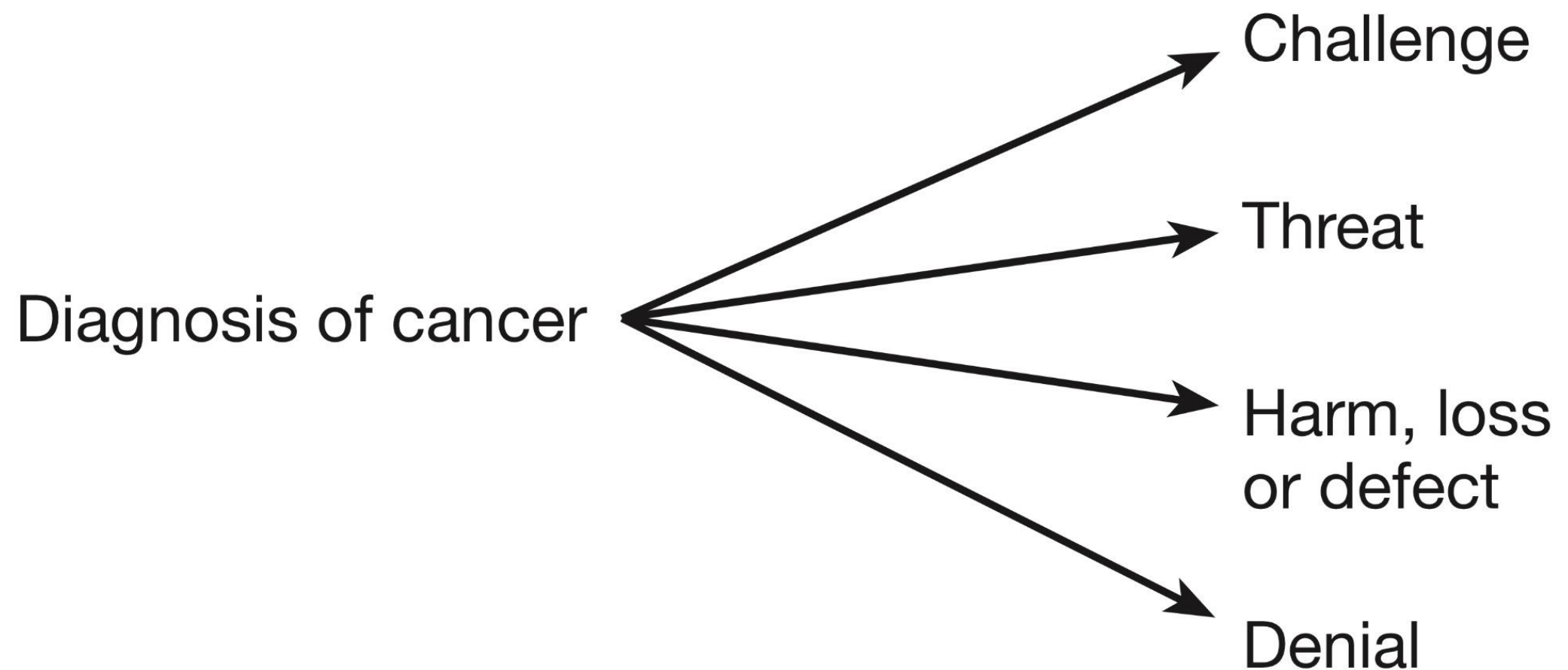
How great is the threat?

What can be done about it?

What is the prognosis?

# THREAT TO SURVIVAL AND ADJUSTMENT STYLES

Greer and Watson (1987)



# FIGHTING SPIRIT

- sees the illness as a challenge
- positive attitude towards outcome.
- appropriate, but not excessive, information seeking about the disease
- taking an active role in recovery
- attempting to live as normal a life as possible.
- the individual can exert some control over the stress, and the prognosis is seen as optimistic.

- Typical statements of a patient with a fighting spirit might be:

‘I don’t dwell on my illness.’

‘I try to carry on my life as I’ve always done.’

‘I see my illness as a challenge.’

‘I keep quite busy so I don’t have to think about it.’



# AVOIDANCE OR DENIAL

- ▶ denies the impact of the disease
- ▶ threat from the diagnosis is minimized
- ▶ the issue of control is irrelevant and the prognosis is seen as good
- ▶ accompanied by behaviour which minimizes the impact of the disease on the patient's life.

Patients make statements such as:

‘They just took my breast off as a precaution.’

‘It wasn’t that serious.’

“It is treatable” (when it is not)

# FATALISM

- diagnosis represents a relatively minor threat
- there is no control that can be exerted over the situation
- attitude of passive acceptance
- active strategies towards fighting the cancer are absent.

‘It’s all in the hands of the doctors/God/fate.’

‘I’ve had a good life, what’s left is a bonus.’

# HELPLESSNESS AND HOPELESSNESS

- Overwhelmed and engulfed by the enormity of the threat of cancer
- Focus of attention may be on the impending loss of life
- Diagnosis is seen as a major threat, loss, or defeat
- There is a belief that no control can be exerted over the situation,
- Perceived negative outcome is experienced as if it has already come about.
- No active strategies for fighting the cancer are absent
- Reduction in other normal activities.
- Basically, the patient gives up.

'There's nothing I can do to help myself.'

'What's the point in going on?'

# ANXIOUS PREOCCUPATION

- Anxiety is the predominant affect
- Compulsive searching for reassurance
- Much of the time is spent worrying about the disease coming back, and any physical symptoms are immediately identified as signs of new disease
- Reassurance is sought by self-referral, use of alternative medicine, and excessive searching for information about cancer.
- The diagnosis represents a major threat
- Uncertainty over the possibility of exerting control over the situation
- The future is seen as unpredictable.

‘I worry about the cancer returning or getting worse.’

‘I have difficulty believing this happened to me.’

‘I can’t cope with not knowing what the future holds.’

# THREAT TO SURVIVAL AND PSYCHOLOGICAL ADJUSTMENT

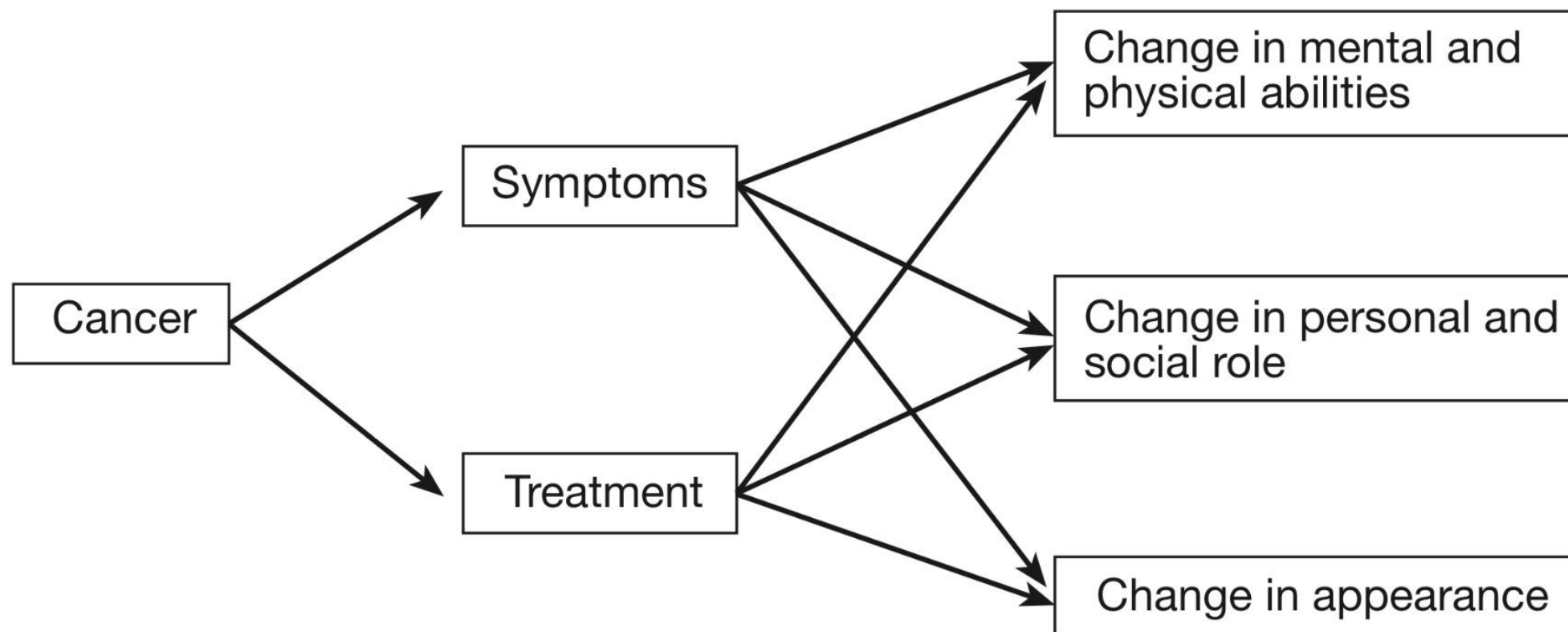
Fighting spirit is linked to lower levels of anxiety and depression

Helplessness and hopelessness and anxious preoccupation adjustment styles are linked to greater levels of depression and anxiety long term

# THREAT TO SENSE OF SELF



# THE THREAT TO THE SELF



**Fig. 2.2** Negative consequences of the diagnosis of cancer.

CASE  
STUDY :

JACK

# THREAT TO SURVIVAL

- ▶ Immediate admission after falls, ICU stay, very very unwell
- ▶ Distress elevated for all in family
- ▶ Threat to survival activated when informed it was cancer
- ▶ Threat to survival activated on multiple occasions with serious side effects of complications
- ▶ Treatment outcomes and rising PSA

# PSYCHOLOGICAL TREATMENT STRATEGIES - THREAT TO SURVIVAL

- ▶ Phase one
  - ▶ Allowed space for hearing concerns / worries / complaints
  - ▶ Psycho education on emotional experiences in the oncology world
  - ▶ Consistency with appointments
  - ▶ Family meeting
  - ▶ Supporting medical team to understand behaviours from psychological perspective

# PSYCHOLOGICAL TREATMENT STRATEGIES - THREAT TO SURVIVAL

- ▶ Phase two:
  - ▶ Introduced linked between thoughts, feelings and behaviour
  - ▶ Behavioural strategies (PMR, breathing, change of environment, sense of self efficacy)
  - ▶ Communication with family/friends and medical team

## PSYCHOLOGICAL TREATMENT STRATEGIES - THREAT TO SENSE OF SELF

- ▶ Changes in physical and mental abilities:
  - ▶ Physically and cognitively significant changes in functioning
  - ▶ Expectations reviewed and challenged gently
  - ▶ Provided skills for developing measurement of skills in both areas to enhance self efficiency
  - ▶ Expressing need for help
  - ▶ Explored allowing others to provide help

## PSYCHOLOGICAL TREATMENT STRATEGIES - THREAT TO SENSE OF SELF

- ▶ Changes in social and personal role
  - ▶ Explored change in role (doctor - patient)
  - ▶ Explored changes in role as husband / father (provider)
  - ▶ Communicating with employer and various professional bodies
  - ▶ Return to work (anxiety elevated and strategies reviewed)

# PSYCHOLOGICAL TREATMENT STRATEGIES - THREAT TO SENSE OF SELF

- ▶ Changes in physical appearance:
  - ▶ Hair loss
  - ▶ Weight gain



# SIDE STEP - MANAGING CALM

## MANAGING CANCER AND LIVING MEANINGFULLY (CALM) OVERVIEW

- ▶ Between three and six sessions
- ▶ Advanced disease with more than six months prognosis
- ▶ Delivered over a 3 -6 month timeframe
- ▶ Invites significant other into one session
- ▶ Significant decrease in depressive symptoms in RCT

# THE BACKGROUND....

- ▶ There is no systematic approach: Calm was developed to integrate already known techniques.
- ▶ Combination of practical approaches while being oriented to exploring the profound existential situation
- ▶ Predictable problems:
  - Physical symptoms
  - Self concept
  - Intimate relationships
  - Social roles
  - Physical activity
  - Sense of autonomy
  - Grief and loss of meaning ( present and future )
  - Threat of dying and death

# SHIFTING THE FOCUS

"Everyone is focused on tasks, things aren't being unpacked"

- ▶ Based in a psychological frame work with includes:
  - ▶ Self psychology ( empathy based subjective experience being understood)
  - ▶ Relational theory
  - ▶ Attachment theory (especially with therapist )
  - ▶ Existential theory
  - ▶ Adult developmental theory
- ▶ Goal of reducing distress and increasing psychological growth

# RATIONALE FOR CALM

- ▶ Predictable problems
- ▶ Pressure of time
- ▶ Crisis of meaning
- ▶ Need for a psychological road map
- ▶ Significant psycho-social distress
- ▶ Therapeutic opportunity

The most motivated patients are around the "tipping point" of becoming aware the disease isn't curable

# PARADOX OF CALM

- ▶ Reflective and structured
- ▶ Brief and deep
- ▶ Practical and profound
- ▶ Living and dying
- ▶ Taking time and time limited

The hidden aspects of CALM is about developing the reflective space....

**"We enter into their world we do not correct their world"**

# MENTALIZING

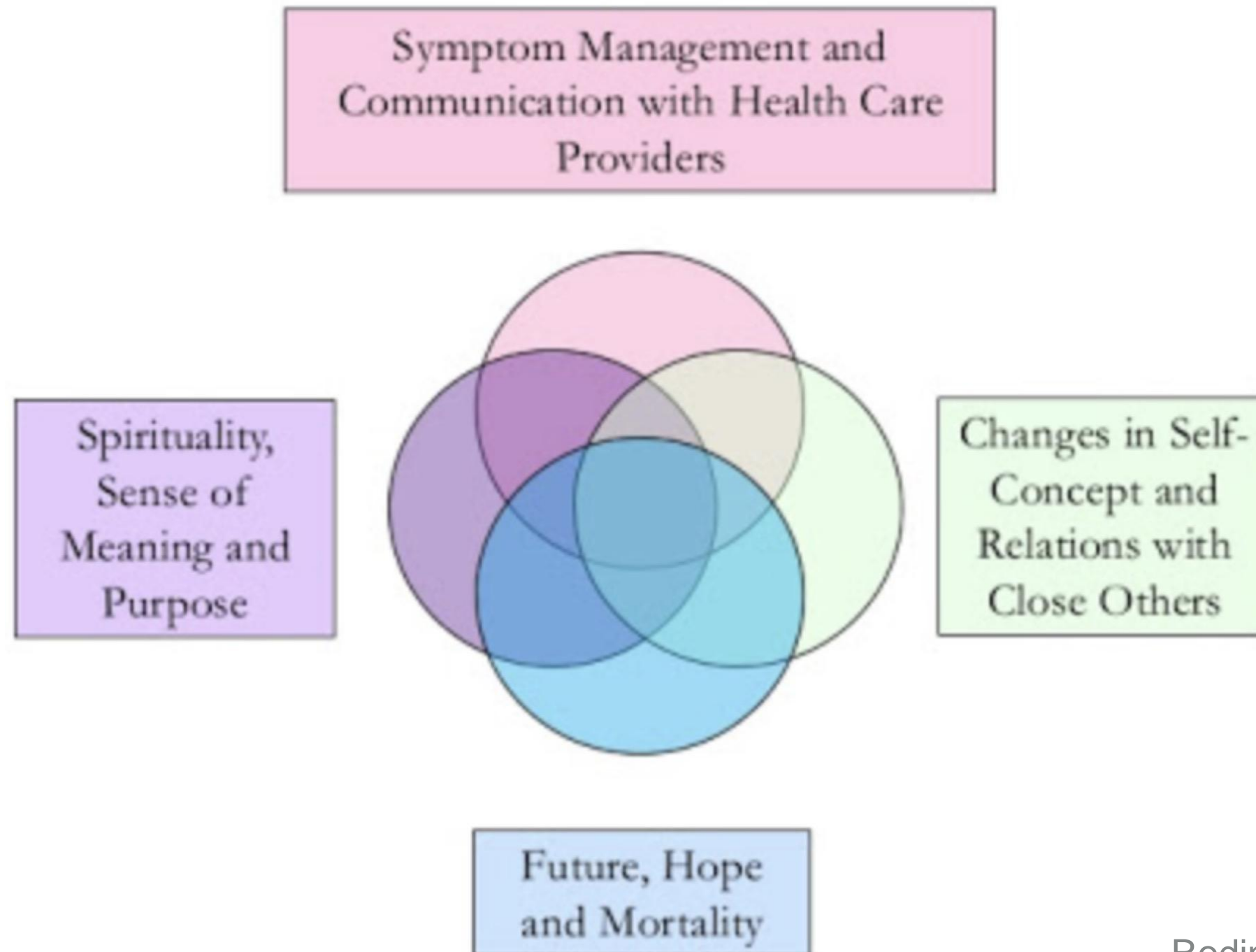
- ▶ Opening up of ones thinking, being open to alternatives
- ▶ "Understanding that our emotions and behaviours may influence that of others"
- ▶ Capacity to mentalizing depends on the experience of a secure attachment base.

# DOUBLE AWARENESS

- ▶ "Success in facing advanced disease / death depends upon the ability to sustain a "double awareness" of the possibilities for living and of dying".



# DOMAINS OF CALM



# DOMAIN 1 SYMPTOM MANAGEMENT AND COMMUNICATION

Themes :

Advocating for patient while part of the hospital / oncology team

Knowing the disease course which patients may not want to explore / prepare for

- ▶ Eg: communicating desire to be treated like patient (not as medical profession not as a guinea pig), expressing wishes to radiology team each time attended scan, fatigue management

## DOMAIN 2: CHANGES IN SELF CONCEPT

Themes :

Supporting needs of both patients and caregivers

Facilitating change while recognising unresolvable disappointments of the past

- ▶ Eg: discussing relationship difficulties when wife unwell

## DOMAIN 3: FUTURE, HOPE AND MORTALITY

### Themes:

Introducing painful topics surrounding dying process while supporting and respecting the patients defences.

- ▶ Eg: family time together building relationships with children,

## DOMAIN 4: SPIRITUALITY, SENSE OF MEANING AND PURPOSE

Themes:

Being useful despite potential feeling uselessness

Finding meaning with patient rather than imposing meaning of traditions, events or experiences.

- ▶ Eg: new approach to work, challenges with limitations in career progression and the type of work he is now doing

# QUESTIONS RE JACK

# CASE STUDY: JILL

# PSYCHOLOGICAL TREATMENT STRATEGIES - THREAT TO SENSE OF SELF

- ▶ Changes in social and personal role
  - ▶ Patient role
  - ▶ Expectations of others (family)
  - ▶ Expectations of self
  - ▶ Explored changes in role as wife / mother
  - ▶ Expressing needs regarding help
  - ▶ Return to work (change in hours, perception of capacity)
  - ▶ Wishing to help others



# PSYCHOLOGICAL TREATMENT STRATEGIES - THREAT TO SENSE OF SELF

- ▶ Changes in physical and mental abilities:
  - ▶ Physically and cognitively changes in functioning - roller coaster post three treatment modalities
  - ▶ Expectations of capacity of functioning
  - ▶ Pacing for pain and fatigue
  - ▶ Expressing need for help
  - ▶ Explored allowing others to provide help
  - ▶ Fertility uncertainty

# PSYCHOLOGICAL TREATMENT STRATEGIES - THREAT TO SENSE OF SELF

- ▶ Changes in physical appearance:
  - ▶ Hair loss
  - ▶ Weight gain
  - ▶ Change in body - grief of loss of femininity (with removal of breasts )
  - ▶ Change in sensation
  - ▶ Intimacy concerns

# PSYCHOLOGICAL TREATMENT STRATEGIES - THREAT TO SURVIVAL

- ▶ Not primary concern at presentation (fluctuated during different treatment modalities )
- ▶ Post surgery fear of cancer recurrence

# SIDE STEP - FEAR OF CANCER RECURRENCE

# FEAR OF CANCER RECURRENCE

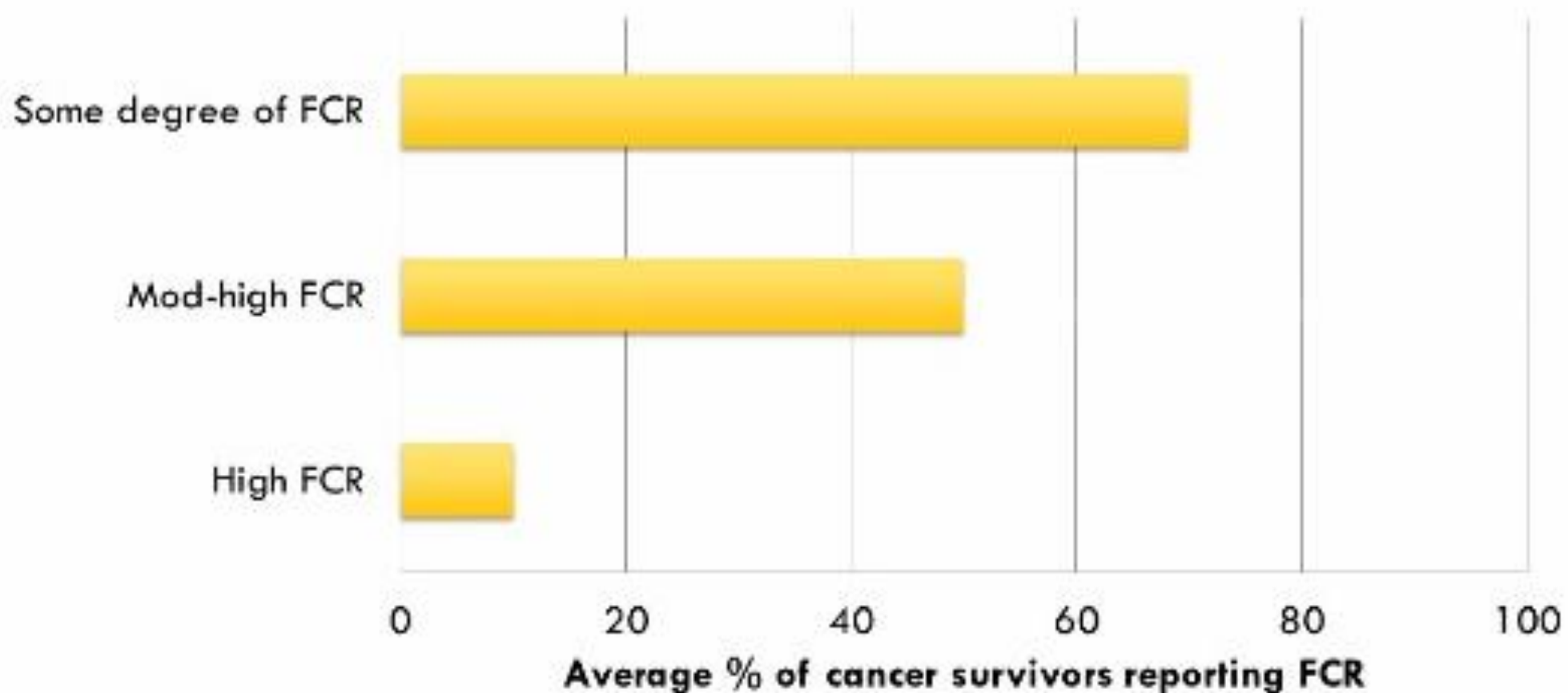
- ▶ Fear of cancer recurrence is the fear or worry that cancer could return or progress in the same place or another part of the body (Lebel et al. 2016)
- ▶ Occurs at any disease stage
- ▶ Patients and carers can experience FCR and it does not resolve over time (Butow 2017)

# FEAR OF CANCER RECURRENCE

- ▶ Constant and intrusive thoughts about cancer
- ▶ A conviction that cancer WILL return
- ▶ Inability to plan for the future (in case cancer interferes)
- ▶ Avoidance of or excessive screening
- ▶ Interpretation of symptoms as sign of cancer recurrence
- ▶ Excessive visits to the doctor
- ▶ Anxiety, distress, feeling trapped
- ▶ Poorer quality of life

# FEAR OF CANCER RECURRENCE

— Patients, survivors and carers experience fear of cancer recurrence (FCR)



Butow (2017) Can you really “Conquer” Fear of Cancer Recurrence. Ingham Institute presentation.

# FEAR OF CANCER RECURRENCE

- ▶ This is not irrational
- ▶ Linked to existential issues
- ▶ Goal is not to remove FCR , but to live with it.
  - ▶ Give less importance and attention to it
  - ▶ Develop goals for the future
  - ▶ Give life purpose, meaning and direction



# FEAR OF CANCER RECURRENCE CONTRIBUTORS

- ▶ Treatment and prognosis seem unrelated to FCR (Simard et al. 2013)
- ▶ Risk perception is related to FCR (Simard et al. 2013)
- ▶ Symptoms are related to FCR (Simard et al. 2013)
- ▶ GAD related to FCR in some studies (Thewes et al. 2013)
- ▶ Meta cognitive beliefs significantly higher in breast cancer patients (Butow 2015).

# FEAR OF CANCER RECURRENCE

- ▶ A recent study “CONQUER FEAR” conducted by Butow demonstrated the benefit of intervention that utilized aspects of Meta Cognitive Therapy .

# SIDE STEP OF A SIDE STEP - META COGNITIVE THERAPY

# META COGNITIVE THERAPY

- ▶ The approach is based on a specific theory proposed by Wells and Matthews (1994) initially to treat Generalised Anxiety
- ▶ Based on metacognitive processes in psychopathology, specifically the self regulatory executive function (S- REF) model. This model proposes all forms of emotional disorder are maintained by the cognitive attentional syndrome (CAS) which includes: perseverative thinking, inflexible self focused attention and counter productive coping strategies that impair cognitive and emotional regulation.
- ▶ The CAS is activated and guided by positive and negative metacognitive beliefs.

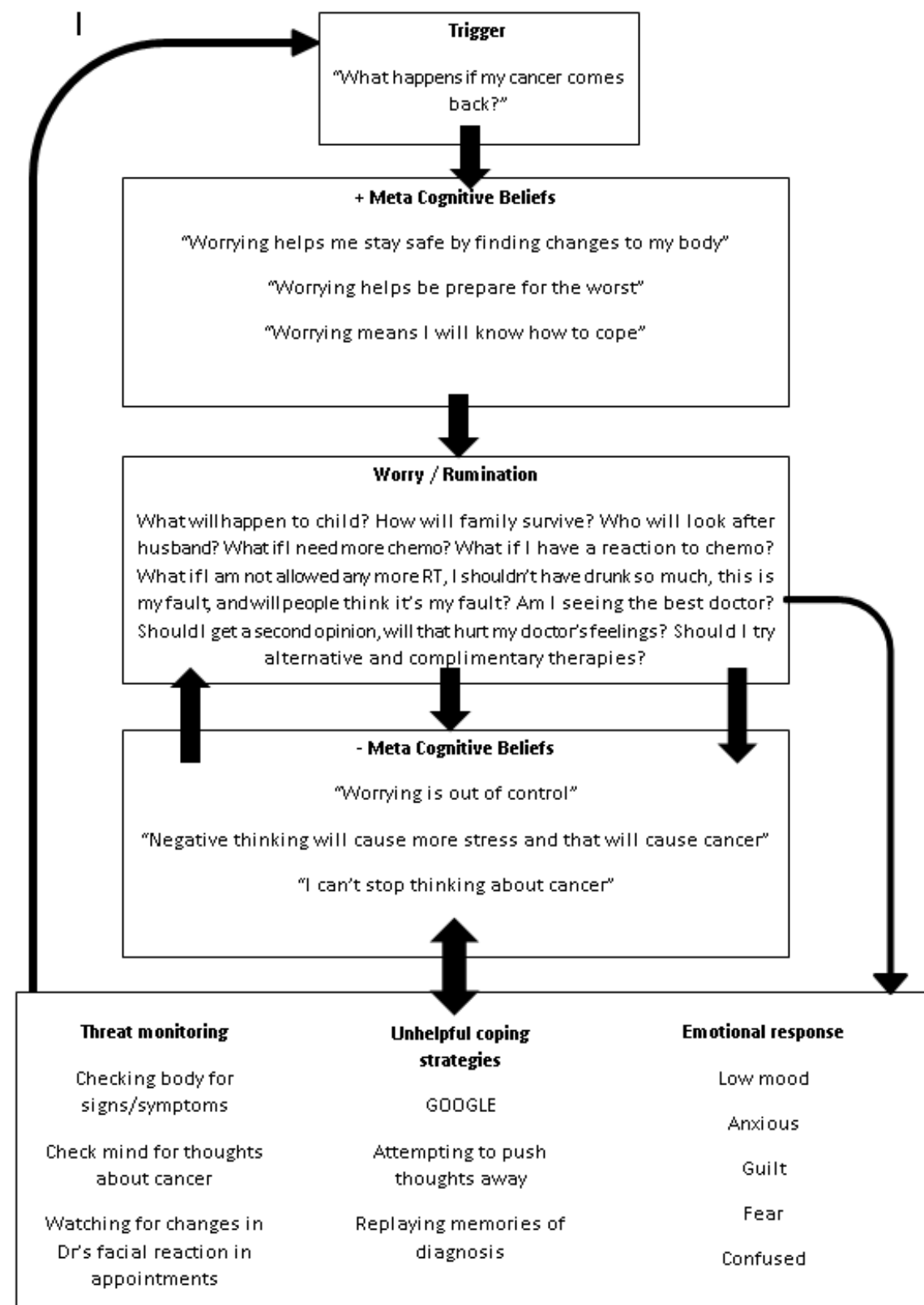
# META COGNITIVE THERAPY

- ▶ Considerable evidence supports association between metacognitive beliefs and emotional distress in a wide range of anxiety and depressive disorders (Wells 2013)
- ▶ Emerging evidence in physical health populations
  - ▶ Chronic fatigue (Maher-Edwards et al 2011)
  - ▶ Epilepsy (Fisher et Al. 2016)
  - ▶ Parkinson's Disease ( Brown and Fernie 2015)

# META COGNITIVE THERAPY

- ▶ MCT literature in oncology emerging
  - ▶ AYA young adult survivors of paediatric cancer (Fisher et al. 2015). Reduction in trauma symptoms, depression and treatment gains maintained at 6 month follow up
  - ▶ Fisher et al (2017) demonstrated significant reductions in anxiety, depression, FCR, worry/rumination and metacognitive beliefs. Gains maintained at 3 months for all patients and maintained for 3 out of 4 patients at 6 months.

# MCT MODEL



# MCT STRATEGIES

- ▶ Case formulation and socializing to the model
- ▶ Modify negative beliefs about worry (uncontrollability, danger challenging, detached mindfulness)
- ▶ Attention training
- ▶ Modify positive beliefs about worry
- ▶ Review advantages and disadvantages of threat monitoring and coping strategies



# QUESTIONS RE: JILL

# WHERE TO GET MORE INFORMATION

- ▶ Cancer council for any information
- ▶ Disease specific support agencies
- ▶ Come and meet us at the "Psychologists in oncology" bi-monthly meetings
- ▶ Contact me - any time !!