

## The personal side of survivorship

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## The treasure

- Each of us has skills and knowledge from our past that can be used with our present and future problems.

## Overview

- Prevalence of distress
- Managing problems and distress
- Anxiety about health
- Emotional support
  - Support groups
  - Relationships
  - Intimacy

## Prevalence of distress in the RCTS region

## Sample

- Sample: 400 patients
- Response rate: 50%
- Questionnaire:
  - CRDSA
  - HADS
  - Demographics

- Maori 10.1%
- NZ European 86.8%
- Other 7.1%
- PI and Asian 0.5%
  
- Male 48%
- Female 52%

### Stage in the Journey

- Diagnosis 16.6%
- Treatment 35.9%
- Post Treatment 35.9%
- Disease Recurrence 2.6%
- Palliative Care 6.4%
- Hospice 2.6%

### Problems experienced



### Problems: Spiritual & Practical

Spiritual	11.5
Practical	
Child care	2.5
Housing	7.6
Financial	20.3
Transportation	11.7
Work/school	15.7
Cultural obligations	2.5
Hospital Processes	11.7

### Problems: Family (Whanau)

Dealing with children	9.6
Dealing with partner	17.3
Other family members	14.7
Family/whanau dealing with the situation	12.7

### Problems: Emotional (Hinengaro)

Depression	17.8
Fears	25.9
Anxiety	32.5
Sadness	25.9
Worry	40.1
Loss of interest in usual activities	33.5

### Problems: Physical

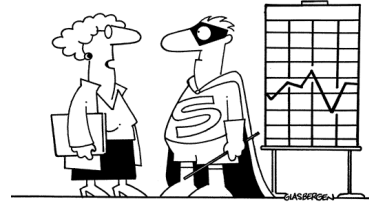
Appearance	21.8
Fatigue	66.5
Pain	25.4
Sexual	23.9
Sleep	45.7

## Family / Whanau

- Small unrepresentative sample
- More indications of problems in all areas except physical

## Prevalence of distress

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"Fear of public speaking is quite common. If dressing up as Speaker Man makes you feel more confident, then so be it."

## Prevalence

	HADS Anxiety	HADS Depression	BSI-18 Distress
Overall	27.2 %	20.3 %	34.3 %

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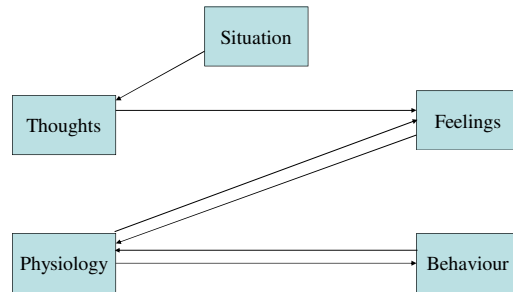
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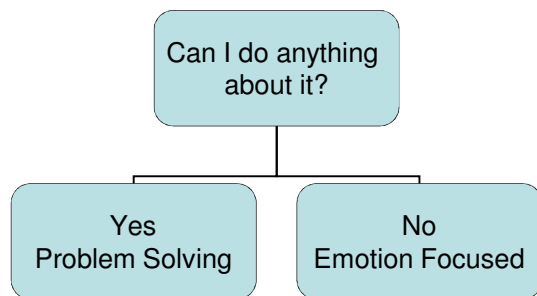
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Advanced Disease	33.5 %	52.4 %	44.4 %

## 5 Part Model



## Worry tree: an approach to problems



## Problem Focused

For when the problem can be solved

### Control what you can

- Seeking information
- Making decisions
- Resolving conflicts
- Setting goals, prioritising
- Requesting help (e.g. with activities)

## Emotion Focused

For when the problem cannot be solved

- Recognising and accepting negative emotions
- Managing stress
- Being aware of your thoughts
- Health anxiety
- Emotional support

## Emotions

- Sadness and grief are not negative emotions
- Expressing feelings

## Stress

- Feeling overwhelmed natural at times like this
- An overloaded boat?
  - Chucking stuff out of the boat
    - Does it need to be in the boat now?
  - Not making the load bigger than it need be



## Stress reduction

- Relaxation, meditation - ways to quieten the mind
- Music, dance, art,
- Exercise
- Sharing stories
- Laughter, funny movies, comedy cds, jokes etc.

## Thoughts

“I am an old man and have known a great many troubles, but most of them never happened.”

-Mark Twain-

## Thoughts

- Learn to be aware of your thoughts
- Learn to step back from your thoughts
- Recognise that thoughts are not necessarily ‘truth’
- Develop the ability to choose what you think about

## Meaning making

- Positive reinterpretation of events in terms of benefit to values, goals, beliefs.
- Looking at life in a new way, reflecting on spiritual values, the purpose of life, what is most valued

## Learning by association

- Pairing of a neutral stimulus and one of significance
- Pavlov's dogs pairing of bell and presentation of food, conditioned response salivation. Over time salivation in response to the bell in the absence of food
- Negative associations, chemotherapy related nausea occurring not in response to chemotherapy, but when sometime later entering the hospital to visit a friend

## Displace and replace

- Patrick McCarthy's Glasgow Bouncer. Vital to practice and cement the associations
- Association different digits and thumb and different images.
  - Image of loving memory
  - Compliment
  - Feeling of healthy tiredness
  - Image of beauty

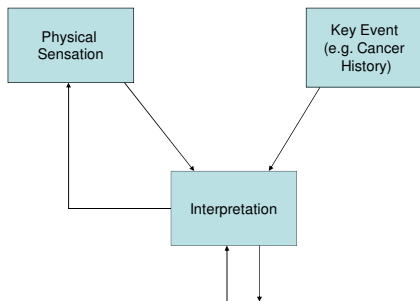
## Worrying about your health

- Worry about the cancer returning is normal
- Even years later events can trigger anxiety
- It's a problem when it's a problem
- Fine balance



## Health Anxiety Model

(Salkovkis, Warwick & Deale, 2003)



Over focus on bodily sensations  
 •sensations detected at lower levels  
 •increases number of sensations detected

Selective attention to illness information  
 •See more negative information

Checking (e.g. continual palpating, pressing, manipulating)  
 •Can lead to bodily changes (e.g. redness and soreness)

Thinking a problem over and over  
 •Increases belief that its real  
 •Increases body awareness  
 •Increases anxiety and depression

Anxiety and low mood  
 •Clouds thinking  
 •Increases belief it is real  
 •Can produce bodily changes (e.g. due to stress)

Seeking reassurance  
 •Keeps focus on health  
 •More information that can be misinterpreted

## Support

- Your usual support: family, friends, colleagues, community, marae, church or other
- Non governmental agencies such as Leukaemia and Blood Foundation, Cancer Society and Child Cancer Foundation
- Maori Cancer Coordinators
- PHO based cancer nurses
- Oncology Social Workers
- Adolescent and Young Adult Service
- Psycho-oncology
- Hospital based specialist nurses
- Chaplains and others
- Local support groups
- Online support

## Support groups

- An opportunity to meet others who have had similar experiences to you
- Research endorsing facilitated support groups
- A chance to talk about your feelings
- An opportunity to look at practical problems
- A place to share ideas about things that have helped
- Different types for e.g., a group for men (very successful one in the Manawatu), a group for women with breast cancer etc.

## What is right for you, find out about the group

- How many people attend?
- How long are the sessions, and how frequent?
- Who leads the group?
- What is the format?
- What is the main purpose?
- Can I just sit and listen?

## Social support

- Very important, but quality not the quantity counts
- Individual variation on being under/over supported
- What are you used to?
- What do you need?

## Social support

- Ideas about social equity from Social Psychology point to the importance of reciprocity, being able to give and receive.
- After a cancer diagnosis, there can be a disruption in what a person is used to, in terms of giving or receiving, (benefiting).
- It can be distressing not be able to give as much as usual.

## Social support

- Remind yourself that you have been caring towards others in the past and that your present situation is most likely temporary
- Some research shows there are gender differences in terms of comfort around who is benefiting
  - Women less bothered by under benefiting
  - Men less bothered by over benefiting

## Communication: potential pitfalls

- Poem from Anthology "Playing God" Glen Colquhoun
- At a medical appointment where key information is provided we are likely to lose 75% of what we are told, if we don't take steps to retain it, (notes, recording etc)
- What we mean to say isn't communication, what is heard is the communication
- Language and intonation 7 possible meanings of:
  - "I didn't say you stole her purse"

## Relationships

- It is commonly reported that relationships change during and after cancer, this is to be expected, but can be disconcerting.
- Many report greater closeness and understanding, but some can experience difficulties with communication and can feel disconnected. Stress can put strain on relationships at various times, be active in doing what you can to put things right (see later slides)

## Relationships

- Expectations and role changes can provide challenges in a range of relationships
- Little and Sayers (2002) point out that friends and family may want to have back the person they knew before cancer. This expectation may be difficult for the person recovering as they adjust to many changes resulting from cancer.
- Role changes in close relationships are not necessarily problematic, but there is a process of adjustment in becoming a carer even if temporary for your partner/lover.

## Friends/work colleagues

- Communicate needs/wishes to friends be clear and specific about what friends can do to help
- Onion layers of relationships. You may want to keep detailed and personal information for those closest. Think about what you might say to those not quite so close, and to those in the outer layers (acquaintances)

## Friends/ work colleagues

- Quite often people are distressed by friends seeming to avoid them, or avoiding the topic of cancer.
- Although it is difficult when you are vulnerable yourself, if you can, help them out. Name it when you get chance. For instance: "I don't know how it is for you but often people say it is hard for them to begin a conversation about cancer when a friend is diagnosed. I would find it helpful, if it is ok with you, just to tell you a little about what is going to happen with my treatment."

## You and your partner

- An earlier slide drew attention to the impact of stress on couples. With a diagnosis of cancer comes much change, uncertainty, sense of loss of control, financial pressures etc
- Cancer can affect how a person feels about themselves and this together with natural emotional responses such as anxiety, depressed mood, guilt, and distress can all potentially lead to some difficulties with communication and with intimacy

## Physical changes and intimacy

- Treatment effects, such as scars, skin changes, chemotherapy, medication, alteration in body weight can have physical and psychological effects. For e.g., antidepressants can lead to lack of desire and lack of orgasm. 50% patients on antidepressants cannot have an orgasm. Physical changes affect self image.
- Even the less visible or invisible bodily changes are often troubling, and people may not be prepared for changes in their sex life.
- Not feeling good about your body can impact on sex life, in terms of willingness to be sexual with your partner and can also impact on desire

## Main concerns

- Worry about intimacy after treatment
  - Appearance, discomfort, performance,
- For men difficulty getting or keeping an erection
- For women discomfort/pain related to sex,
  - Menopausal symptoms

## Women

- For women: loss of oestrogen, hot flashes, genital changes, cystitis. Testosterone also important for women for mood and ovaries stop producing during menopause. (Also comes from the adrenal glands). In women loss testosterone can lead to low mood, fatigue, lack of desire/fertility

Trajectory of sexual activity over cancer experience  
Information from Confrontation and Challenges in Oncosexology IPOS 2009  
Woet Gianotten

- Pre diagnosis: reduction with fatigue
- Treatment : for many almost complete cessation
- Recovery: increase in activity but for most not getting back to baseline
- Palliative: some physical affection, cuddles only, some continue as usual, others increase

## What to expect?

- There is data for a range of cancer types that shows difficulties with sexual life can be experienced, such as reduced desire, arousal, erections, orgasm, satisfaction
- Some differing data on whether pre treatment levels of sexual activity/satisfaction attained
- If there are difficulties, don't suffer in silence, talk to your partner, read some books together, and/or get professional advice

## Sexual problems

- If you and your partner both decide that a reduction in, or stopping sex is ok, that isn't a problem
- Potential problems relate to mismatch in terms of desire, and wishes re frequency of sex
- However, it is useful to avoid the idea that we are getting older, so it doesn't matter

## Sexual problems and media myths

- The media encourage people to associate sex with youth and beauty
- As Robyn Salisbury notes in her book "Staying in Love" many couples have the most satisfying sex of their lives when they are more mature in years

## Intimacy

- Be the best you can be and aim for the best relationship you and your partner can have
- In her book "Staying in Love" Robyn Salisbury sets out some reasonable expectations for an adult intimate relationship:
  - "Sexual pleasure
  - Times of cherishing the unique individual that is your partner
  - Times of enjoying feeling loved" (p.16)

## Intimacy continued

- "Some arid times when there may seem little to cherish
- Day-to-day practical caring for and from each other
- Moments of intimacy and appreciation, which sustain, comfort, and delight
- That change will occur as you grow
- Pleasure and satisfaction from the ongoing process of getting to know each other" (p.16)

## What can you do?

- Work at staying in touch with your life partner, maintain connection
- Keep communication channels open.
- If you have cancer let your partner know what you need, what you are able to do as you recover
- Mary and Ian Grant in their new book (see later slide) talk about:
  - "Emptying your pockets with each other" time
  - Three things that happened during the day and how you felt about these things
- Make time for you and your partner
  - "dates" things you will enjoy so that your time together isn't dominated by cancer appointments etc.
  - Keep hold of what makes you, you.

## What can you do?

- For women talk to your oncologist about what options might be available to assist with menopausal symptoms. Some women are told they definitely cannot use any oestrogen preparations, others might be able to use a local cream, but it is vital to check.
- Use a good personal lubricant such as "Sylk" made from kiwi fruit vine, water soluble, available in most chemists. Replens is another non hormonal lubricant. Both partners can use the lubricant and enjoy the slipperiness.

## What can you do?

- Men also experience some changes in sexual function over time. As part of normal ageing erections may not be as prompt or as firm. It may also take longer to reach orgasm.
- This doesn't have to mean a reduction in sexual pleasure for either partner. It may mean a shift in focus from intercourse to other ways of being sexual and some flexibility, and adjustment.
- It is also important for men undergoing cancer treatment to remember that penises are also susceptible to effects of treatment, to fatigue, and the emotional and psychological aspects of cancer. There is value in recognising this is normal, and expecting it to be recoverable.

## What can you do?

- Allow yourself some time to adjust, to mourn your losses but also to celebrate your gains
- Be proactive in enhancing your appearance
- Value yourself

## What can you do?

- Make use of some of the good resources available e.g.,
  - “Growing great marriages” Mary and Ian Grant (2009)
  - “Staying in love” Robyn Salisbury (2009)
  - “Fighting for your marriage” Howard Markman, Scott Stanley, Susan Blumberg (2001)
- It can work very well to each read a section or chapter and talk about what you have read
- If you don't think you are making progress seek some professional advice or assistance

## Professional help

- Talk to your general practitioner, oncologist or oncology nurse about a referral to the Psycho-Oncology Service. In this Service Clinical Psychologists work with people with cancer and/or their family/whanau, on their concerns, and what they want to change. Referrals can be for individuals, couples, families. The Service is free and for those resident within the MidCentral Health area.

## Professional help

- Family court provides free relationship counselling for couples, and this isn't only for those who are at the stage of needing the family court. Phone family court and they can explain the process to you. A free service.

## Professional help

- Sex Therapy NZ is a private referral network. Our therapists are extensively trained to deal with all issues of sexuality and intimacy. Contact can be made by calling 0800 sex therapy (0800 739 843) or emailing [admin@sextherapy.co.nz](mailto:admin@sextherapy.co.nz) or via our website [www.sextherapy.co.nz](http://www.sextherapy.co.nz)

## Other useful books

- Here for now Living well with cancer through mindfulness
- Elana Rosenbaum (2005 – 2007)
  - Author diagnosed with non-Hodgkin's lymphoma
- Coming to grief Pam Heaney (2002)