RESPONDING TO THE IMPOSSIBLE QUESTION

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MEET MARION

63-year-old woman treated for early breast cancer

Prognosis good

No other medical history

Frequent attendance with vague symptoms:

- Lack of energy
- Fatigue

Repeatedly always asks “if the cancer has come back”

Requests blood tests, imaging “to make sure”

Does not respond to reassurance

FEAR OF CANCER RECURRENCE

"The fear that cancer could return or progress in the same place or another part of the body" ***Vickberg 2003***

Transient FCR almost invariable, however:

- **40 to 70% of cancer survivors report *clinically significant* FCR**

  Thewes et al 2009

- **FCR identified as one of the greatest unmet needs of cancer survivors**

  Hodgkinson et al 2007

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Web-based survey completed by 218 women diagnosed with early stage breast cancer at least one year earlier

70% reported clinically significant levels of FCR

High FCR associated with:

- Higher frequency of unscheduled visits to GP
- Higher frequency of breast self-examination
- Not having mammograms or ultrasounds or other forms of screening in the past year
- More use of CAM
- More use of counselling and support groups

Thewes et al 2012

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DEVELOPMENT OF FCR

Precise mechanism unclear

Likely to be contributions from:

- **Past experiences of loss and grief**
- **Personality style**
- **Current caring and social roles**
- **Information or misinformation**
- **Circumstances of the diagnosis**
- **Experience of treatment**

A NOTE ABOUT REASSURANCE

Health professionals have a strong desire to reassure

Our roles focus on doing and fixing

We want to help

We are concerned about increasing distress

We worry about “opening a Pandora’s box”

We feel uncertain about how to help

But:

- Premature reassurance inhibits disclosure of concerns
- Patients do not expect us to fix their distress
- They want to be seen and heard for who they are

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RESPONDING TO MARION

Listen

Allow her to articulate her concerns

Efforts to “reason” typically do not help

Trying to avoid thinking about it typically does not help

Help to clarify:

- ✓ ***“What worries you the most about…”***
- ✓ ***“What would be the worst thing if….”***

Master the art of the “two-fold message”

- ✓ ***“The evidence we have is that….” AND***
- ✓ ***“Although we have said that, I know that in your heart it is hard to believe, and it is really very distressing”***

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EMERGING EVIDENCE

MEET FRAN

32 year old woman with glioblastoma

Married to Doug

Two children:

- **Eliza aged 6**
- **William aged 4**

Has struggled with treatment and wants to stop

Doug pleads with you to make her keep going:

- **“*She can’t just give up – she’s got to fight it*”**

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SMILE OR DIE: HOW POSITIVE THINKING FOOLED AMERICA AND THE WORLD

Ehrenreich: ‘In the lore of the disease, chemotherapy smoothes and tightens the skin and helps you lose weight, and, when your hair comes back it will be fuller, softer, easier to control, and perhaps a surprising new colour.’

http://www.theguardian.com/lifeandstyle/2010/jan/02/cancer-positive-thinking-barbara-ehrenreich

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SANITISED RESPONSES TO DEATH

The entire population is:

- Much-loved
- Cherished
- A devoted mother/father/aunt/uncle etc.

No-one dies - they “pass away”, a process which is:

- Peaceful
- In the presence of loving family

Occurring after:

- A courageous fight against cancer
- A brave struggle

All deceased will be:

- Sadly missed
- Forever in our hearts

RESPONDING TO DOUG

Listen

Don’t assume

Be generous

Acknowledge the grief:

- ***“It feels as though the whole world is falling apart”***

Appeal to “better self”

- ***“One of the bravest things you can do is be prepared to support her decisions even though that is so painful for you”***

MEET IVAN

52 year old man with mesothelioma

Second marriage - one child aged 5 years

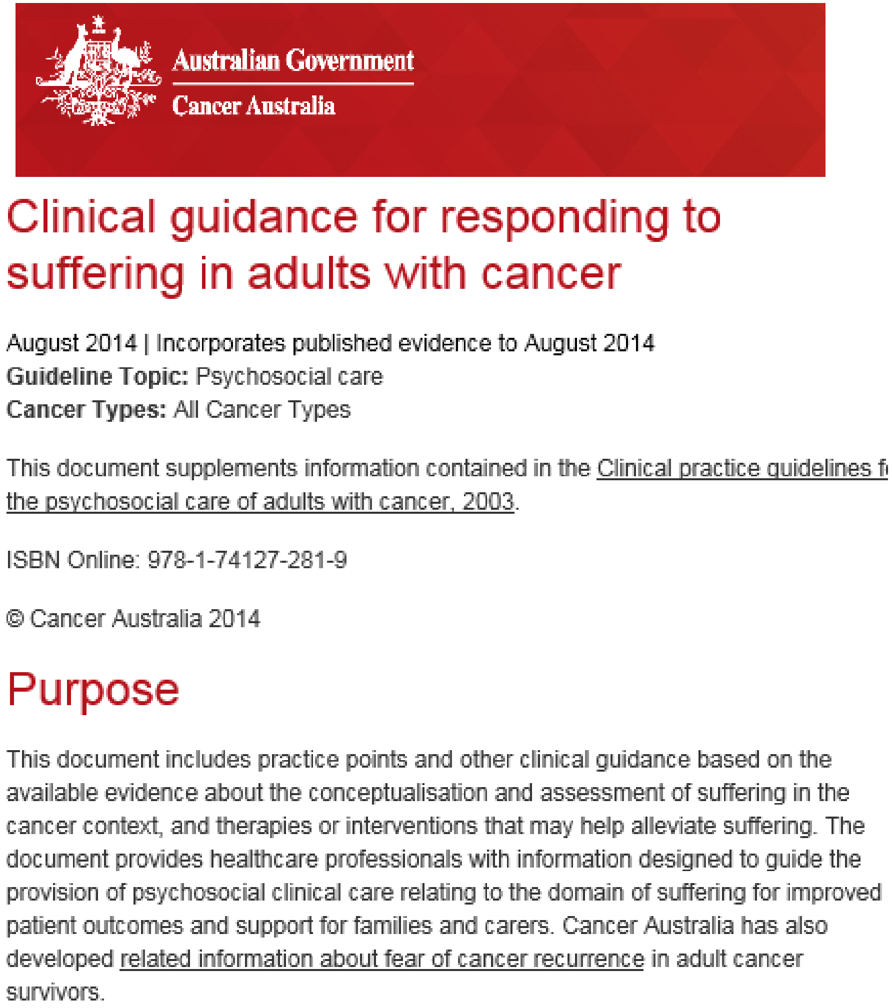
Estranged from adult children from first marriage

Distressed by dyspnoea

Difficulty achieving pain control, worst at night

Repeatedly asks:

- ***“How long have I got?”***
- ***“What’s going to happen?”***



Australian Government
Cancer Australia

Clinical guidance for responding to suffering in adults with cancer

August 2014 | Incorporates published evidence to August 2014
Guideline Topic: Psychosocial care
Cancer Types: All Cancer Types

This document supplements information contained in the Clinical practice guidelines f the psychosocial care of adults with cancer, 2003.

ISBN Online: 978-1-74127-281-9

Purpose

This document includes practice points and other clinical guidance based on the available evidence about the conceptualisation and assessment of suffering in the cancer context, and therapies or interventions that may help alleviate suffering. The document provides healthcare professionals with information designed to guide the provision of psychosocial clinical care relating to the domain of suffering for improved patient outcomes and support for families and carers. Cancer Australia has also developed related information about fear of cancer recurrence in adult cancer survivors.

http://canceraustralia.gov.au/publications-and-resources/cancer-australia-publications/clinical-guidance-responding-suffering-adults-cancer

Suffering is complex, and can include physical, psychological, social and spiritual reactions

Although suffering causes unique experiences of distress for the individual, it has many common features particularly associated with loss or perceived loss

These include loss of meaning or hope, loss of physical or emotional strength, loss of independence, isolation or changed relationships

Patients who are suffering may:

- **Ask existential or spiritual questions about the meaning of life and death, their place in the world, and why the cancer occurred**
- **Question their religion or religion in general, or seek spiritual answers**
- **Voice a deep concern for their family**
- **Try to equate past wrongdoing with the cancer, asking “*What have I done to deserve this*?”**
- **Talk of their “struggle”, “battle” or “loss” which could be:**
  - **Physical, as in a body part**
  - **Emotional, as in the loss of autonomy or identity**
  - **Spiritual, such as a loss of meaning**
- **Make “desire to die” statements**
- **Avoid talking about it**

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STARTING A CONVERSATION

“What should I know about you as a person to help me take the best care of you that I can?”

“What has been the hardest part of this experience for you?”

“Who else or what else will be affected by what is happening with your health?”

FAITH, HOPE AND MEANING

“Do you consider yourself spiritual or religious?”

“Do you have spiritual beliefs that help you cope with stress?”

“What gives your life meaning?”

“What are your sources of hope, meaning, comfort, strength, peace, love and connection?”

“What do you hope for?”

Lo et al. Discussing religious and spiritual issues at the end of life. A practice guide for physicians. Journal of the American Medical Association 2002;287:749-754.

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RESPONDING TO IVAN

Feelings and meaning before explanations and words!

- ***"What is the worst thing about your situation?"***
- ***"What is the thing that worries you the most?"***

Be prepared to explore unresolved issues of grief and loss

Regrets and recriminations – is it too late to reconcile?

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MEET INGA

41 year old woman with metastatic breast cancer

Two daughters, aged 14 years and 12 years, son aged 8 years

Progressive disease despite therapy

Investigating going to Germany for non-proven treatment

Refuses to consider referral to palliative care

Difficulty with pain relief but reluctant to take morphine

Husband becomes angry when results discussed:

- *“I won’t have any of that negative talk here”*

Refuses to believe that scans demonstrate progression:

- *“I have faith, I know that God will heal me”*

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HOPING FOR (EXPECTING) A MIRACLE

Is the belief compromising care?

Is the person competent to make decisions?

Are the patient and the family "on the same page"?

AMEN:

- Affirm the patient's belief: "*Yes. I am hopeful too*"
- Meet the patient or family where they are: "*I join you in hoping for a miracle"*
- Educate from your role as a medical practitioner: "*And I want to speak with you about some medical issues"*
- No matter what – assure the patient that you are committed to them: "*No matter what happens, I will be with you every step of the way"*

Cooper et al Journal of Oncology Practice 2014;10:e191-e195)

JUST ONE DAY……

Study of 83 women:

- Had completed adjuvant chemotherapy for breast cancer 3 - 4 months earlier
- Mean age 55 years
- More than half of women judged a benefit of *one day* sufficient to make adjuvant chemotherapy worthwhile

Duric et al 2007

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WHY?

To minimise regret

Doubts about information provided (doctor could be wrong, I could get more)

Difficulty interpreting quantitative information

Every day counts – especially because of my children

I don’t have a choice (if I don’t do this, I am doing nothing)

I might get more than one day

Duric et al 2007

RESPONDING TO INGA

Is this compromising care?

Who else is affected?

Children trump parents

Talking in the world of possibilities within the patient's idiom:

- ***"None of us knows the mind and will of God fully"***
- ***"I know that people sometimes pray for things that they don't receive"***
- ***"We don't know if God's plan for you is the one you hope for yourself"***
- ***"IF God's plan for you is not what you are hoping for, what would be important to think about and do?"***

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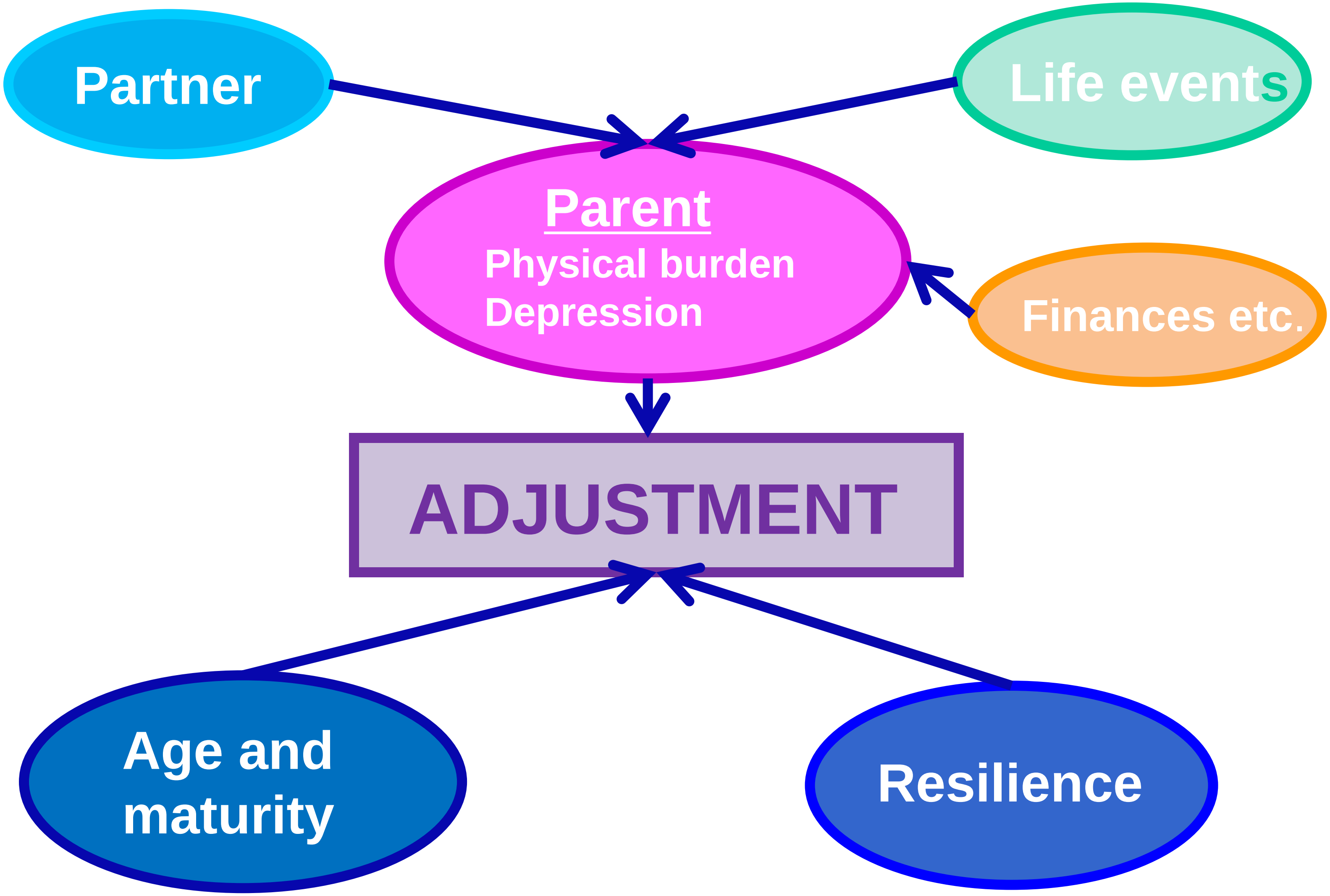
CHILDREN'S ADJUSTMENT



Partner

Life events

Parent

Physical burden

Depression

Finances etc.

ADJUSTMENT

Age and maturity

Resilience

AGE-SPECIFIC NEEDS

Young children:
- Information which is staged and updated over time
- To be told they will always be safe and cared for
- To be told it is not their fault
- Opportunities to ask questions and express feelings

Middle-age children:
- Information appropriate to understanding
- Social and sporting activities
- To be told it is OK to be sad, not exhorted to “be brave”
- Opportunities to ask questions and express feelings

Adolescents:
- Information
- Negotiation not imposition of tasks
- Social relationships, leisure activities
- Opportunities to ask questions and express feelings

CHARACTERISTICS OF RESILIENT CHILDREN

- ✓ Strong connectedness to at least one adult with unconditional positive regard
- ✓ Perceived area of self-competence e.g. sport, academic
- ✓ Belief that they can control their lives, but able to see what is not in their control
- ✓ More likely to discuss problems at home and be encouraged to face up to difficulties
- ✓ Chores and tasks for the good of the family
- ✓ Seen and respected for who they are
- ✓ Positive school experiences
- ✓ Fewer delinquent peer associations

Note the concept of chain reactions

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WHEN A CHILD ASKS THEIR PARENT IF THEY ARE GOING TO DIE

"Well, some people with cancer live for a very long time, and I hope I am one of them. But sometimes people with cancer only live for a short time. That makes me sad – is that something you want to talk about?"

"I am doing everything I can to stay well but there are no guarantees"

"I guess that is possible. But you will always be safe, no matter what"

Turner et al., Palliative and Supportive Care 2007:5:135-145

FACTORS AFFECTING ADJUSTMENT

Gender of parent:

- Fathers more likely to make unilateral rules *Boerner & Silverman 2001*

Gender of child:

- Boys more vulnerable *Downey et al 1999*

Support from family and friends

Qualities of surviving parent:

- Good communication *Raveis et al., 1999*
- The way the surviving parent continues to parent

Ability to connect with the dead parent:

- 81% experience the deceased parent as watching over them
- 57% speak with their deceased parent *Silverman et al., 1992*

COMPASSIONATE CARING

Sharing and connecting

Bearing pain

Seeing the humanity

Resisting the urge to try to make it better

Being prepared to work within the patient’s idiom

Recognition of the variety of empathic and human connections beyond just words

Seeing the potential for endurance and courage beyond what is endurable

Being generous