

Coping with fear of cancer recurrence

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Today we will cover

What is fear?

Fear, worry & cancer: remembering diagnosis and treatment

Fear, worry & cancer: after treatment ends

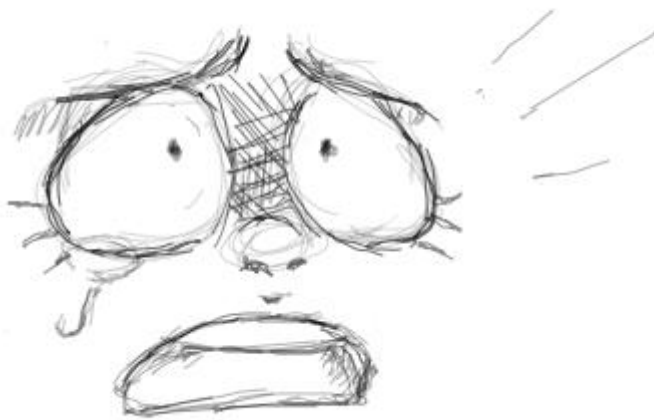
Fear, worry & cancer: when fear persists

Fear of cancer recurrence

How to cope with fear of cancer recurrence

When to seek additional support

What is fear?



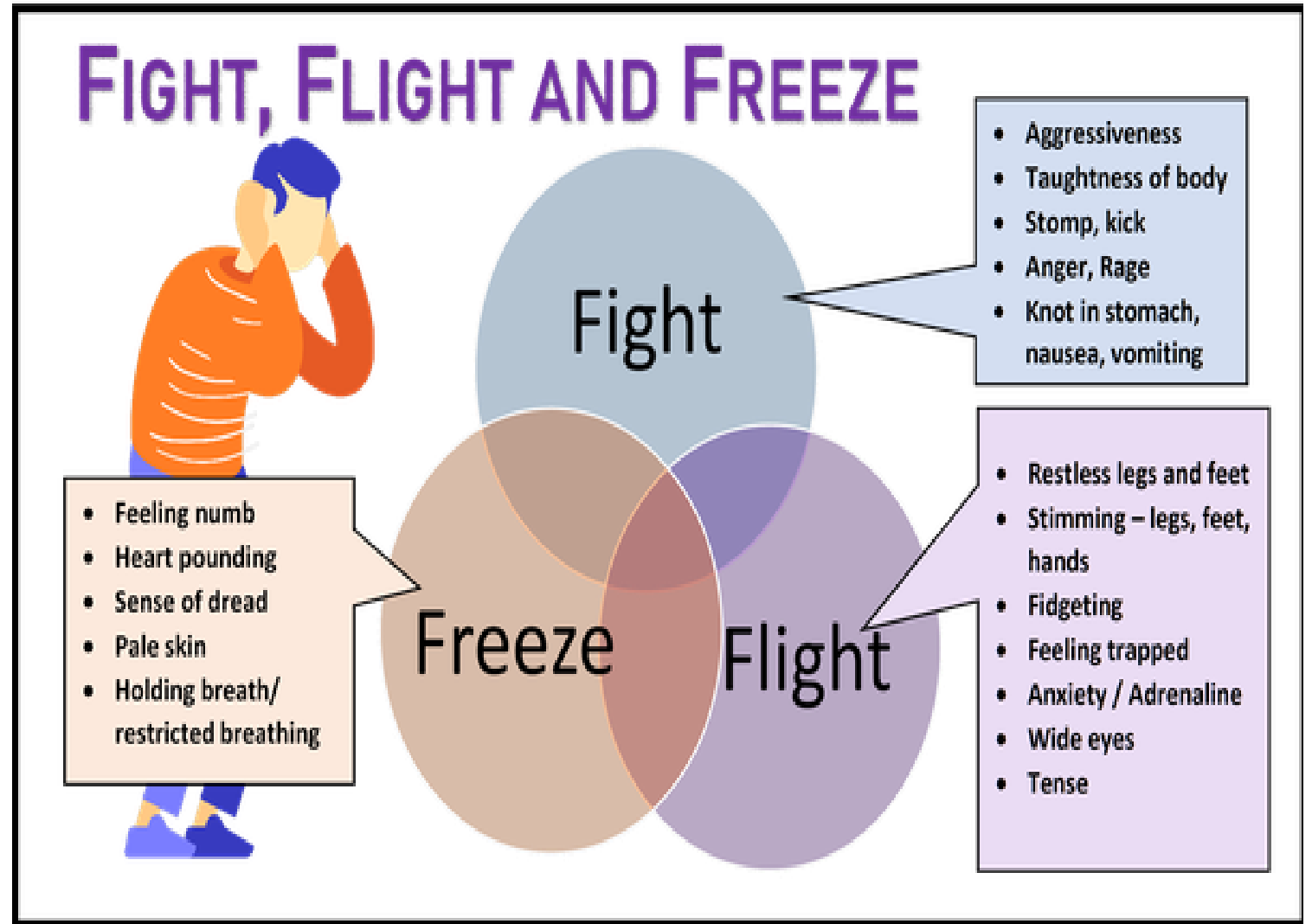
It is a natural intense emotional response to real or imagined physical or psychological threat/danger

It is adaptive and helps to keep us safe

Fear usually reduces once the threat/danger passes

Sometimes fear doesn't reduce which makes it hard to feel safe and impacts our daily life

Common responses to fear



Fear, worry & cancer: remembering diagnosis and treatment

Wide range of experiences that affect feelings of fear and worry at time of diagnosis & treatment

- Delayed diagnosis- quick diagnosis
- Shock/disbelief- confirms what you thought or relief after multiple investigations
- Fearful of treatment- grateful for treatment options
- Lots of side effects- minimal side effects
- Lots of delays with treatment- no delays with treatment
- No/little support- supported
- Personal knowledge or experience of cancer
- Capacity to cope with stressful events

Fear, worry & cancer: remembering diagnosis and treatment



Some common causes of worry and fear

- Life plans are interrupted
- Impact on identity, body image & sexuality
- Impact on job/financial status
- Emotional and psychological impact
- Loss of independence
- Loss of control
- Navigating a health system
- Experience of family members and friends
- Worry about “what if.....?”

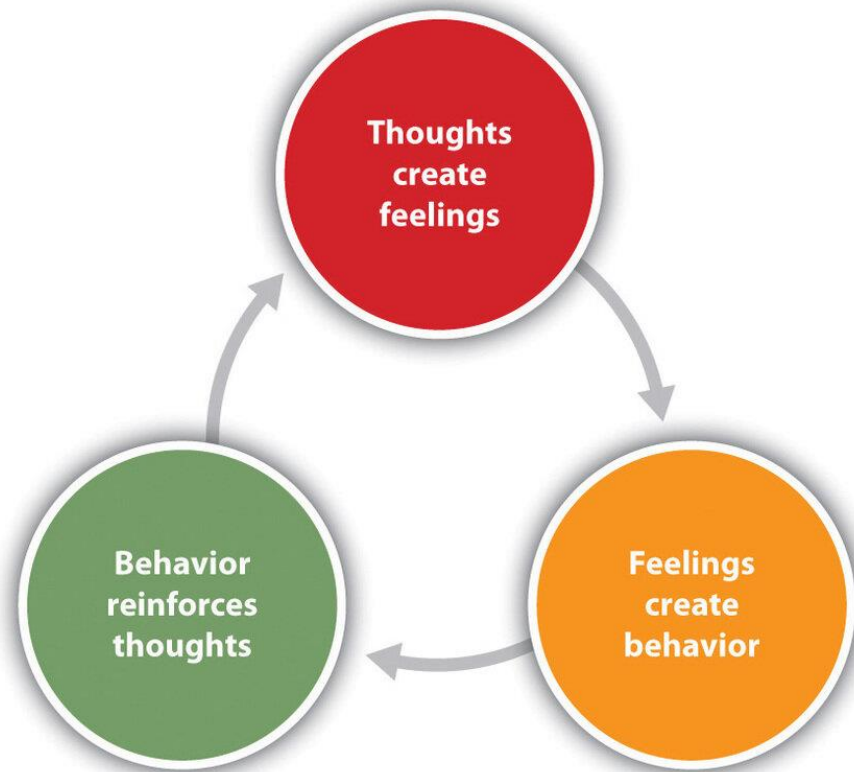
Fear, worry & cancer: after treatment ends

Wide range of experiences that affect feelings of fear and worry

- Relief-fear
- Adjust to physical changes- difficulty adjusting to physical changes
- Return to normal life- worried about return to normal life
- Regain independence- difficult to regain independence
- Reassess meaning of life- frightening to think about meaning of life
- Less medical appointments- would prefer more appointments
- Looking to the future- frightening to look to the future

Fears typically reduce naturally as time passes and you feel physically better and are reassured by positive outcomes from review appointments, scans, blood tests

Fear, worry & cancer: when fear persists



Remember:

We feel fear as it helps to keep us safe

However.....

Fear is an unpleasant feeling

Fear causes us to worry

We try to avoid this feeling or we can try to plan for every possible outcome which can increase our feeling of fear

Fear of cancer recurrence (FCR)

Fear or worry that cancer could return or progress in the same place or another part of the body

Approximately 97% of cancer survivors experience some degree of fear of recurrence

On average 49% of cancer survivors experience a moderate level of fear

On average 7% of cancer survivors experience a high level of fear

(Simard S., et al., 2013)

“It just doesn't look the same once you know how fragile your life is. That fear, of the past and of it coming back, can haunt you for the rest of your life after cancer” (Yahne, 2017)

Factors that can influence FCR

Experience of diagnosis

Age at time of diagnosis

Life stage at time of diagnosis

Pre-existing anxiety

Experience of treatment & side-effects

Long term effects of treatment

Experience of health care system

Missing regular checks with team

Experiences of family & friends

Previous cancer related loss

Caregiving role

Social support

Coping style

Psycho-social stressors

Constant level of uncertainty



(Lebel et al., 2013; Simard et al., 2013; Thewes et al., 2013)

Impact of FCR

Thoughts

Preoccupied with thoughts of cancer

- How will I.....
- Will I need more treatment?
- How will they cope?
- I should.....
- What if.....



Worry about thinking about cancer

Avoid thinking about cancer

Difficult to think about the future

Emotions

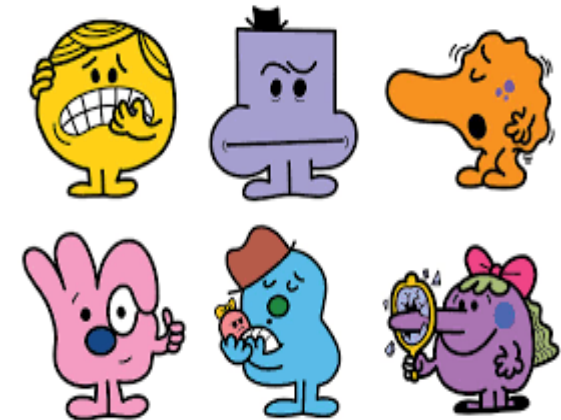
Fear

Anger

Worry

Sadness

Tearful



Impact of FCR

Behaviour

On alert

Change health behaviours

Seek reassurance

Avoid following up about concerns

Cancel appointments

Avoid talking about cancer

Avoid meeting family & friends

Body

Monitor for symptoms

Difficulty trusting how you feel

Difficulty managing long term side effects

Avoid self-care



How to cope with fear of cancer recurrence

Learn to **recognise & acknowledge**:

- **Physical** and **emotional** impact of cancer and treatment
- Your **thoughts** by writing them down, diarising and talking to others about them
- **Expectations**- yours and those of family and friends
- Your **triggers for increased fear** - appointments, scans, ads, TV shows, birthdays, special occasions
- Your **fears will fluctuate** over time



How to cope with fear of cancer recurrence

Take **control**:

- Consider new ways of **coping with your emotions**- be kind to yourself, learn to describe your emotions, know what helps when your fear increases
- **Lifestyle** choices & **stress management**
- **Expectations**- yours and those of family and friends
- **Support** needs-practical & emotional



How to cope with fear of cancer recurrence

Be **informed**:

- Know **symptoms** of concern
- **Dates**, times & frequency of **appointments, scans, bloods**
- Know **who** to follow up with and their contact details
- Know **how** to complete self-examination
- Ask where to find **reputable information** resources



How to cope with fear of cancer recurrence

Incorporate **relaxing self-care** activities into your daily life

- Allow yourself to **time** to do **enjoyable** activities
- Be **kind** to yourself
- **Mindfulness** & meditation
- Deep **breathing** exercises
- **Exercise**
- **Creative** outlets
- **Complimentary therapies**



How to cope with fear of cancer recurrence

Connect & share:

- With **family** and **loved ones**
- With other **cancer survivors**
- **Groups**- online or in person
- **Individual** support



When to seek additional support

Change in mood- increased worry, fear sadness, low mood, tearfulness, overwhelmed

Change in sleep pattern

Change in appetite

Change in behaviour (keeping busy v little or no motivation for activities)

Avoid meeting family & friends

Difficulty being on your own

Difficulty planning for the future

No reduction or increased pre-occupation with thoughts of cancer

Who to speak to

ICS helpline

Local cancer support Centre

Speak with your treating team

Speak with your GP or attend your local emergency department if it is after hours

Seek referral to specialist services from your GP or treating team



Resources

The Irish Cancer Society- Coping with cancer- Information booklets on the **emotional effects of cancer** and **life after cancer**

<https://www.cancer.ie/about-us/cancer-resources-publications/coping-with-cancer-resources>

Macmillan Cancer Support- **Worry about cancer coming back:**

<https://www.macmillan.org.uk/cancer-information-and-support/after-treatment/being-aware-of-symptoms>

Cancer Council NSW- **Managing fear of cancer recurrence:**

<https://www.cancercouncil.com.au/cancer-information/living-well/after-cancer-treatment/fear-of-the-cancer-returning/managing-fear-of-recurrence/>

HuffPost article- **5 things they don't tell you about life after cancer:**

https://www.huffpost.com/entry/5-things-they-never-tell-you-about-life-after-cancer_b_10012552