

Finding the hope whilst facing the reality: The psychological challenges of living with pancreatic cancer

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Introduction

- **Dr Lucy Davidson, Counselling Psychologist**
 - Over a decade of experience supporting patients and relatives in oncology, haematology, palliative and bereavement settings including charities, the NHS and private sector
 - Leaders in Oncology Care, HCA hospital – inpatient and outpatient support
 - Royal Marsden Hospital
 - Trinity Hospice – managing bereavement service
 - Independent practice and consultancy
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What I am not...

I am not an expert.

- Patients are the experts in their own experience
- I am a curious, interested and active participant
- The 'expert' paradigm is a challenging concept in healthcare
- As is the concept of being a 'patient' (they are also a person)
- All I need to do is ask a question, listen to the response and be able/prepared to hear what they are saying...

**IN THE BEGINNER'S
MIND THERE ARE MANY
POSSIBILITIES, BUT IN
THE EXPERT'S MIND
THERE ARE FEW.**

SHUNRYU SUZUKI

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An initial concept to think about...

***Finding the hope whilst facing the reality:
the psychological challenges of living with pancreatic cancer***



**LIFE IS NOT A
PROBLEM TO BE
SOLVED, BUT A
REALITY TO BE
EXPERIENCED.**

Soren Kierkegaard

PICTUREQUOTES.COM

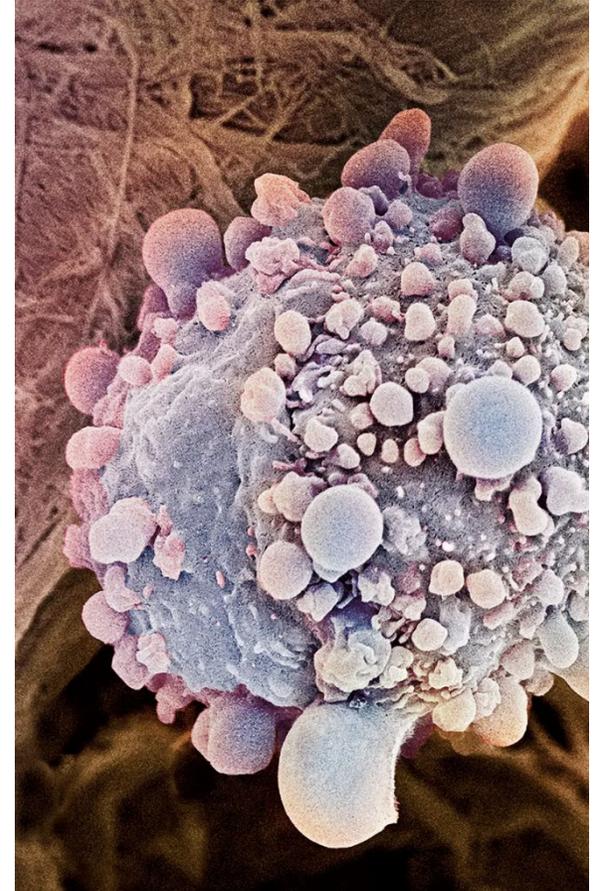
Aims

Aims:

- To consider the psychological impact of a pancreatic cancer diagnosis on patients, their relatives and us
 - To understand our role in supporting someone emotionally with their disease
 - To consider any blocks we may have in addressing emotional issues
 - To provide tips and tools to support you in your work
 - What you can do and when to refer on
 - Questions
-
- Introduce some themes, ideas, thoughts for you to reflect on, to encourage reflection, development and critical thinking/self awareness

Pancreatic cancer context

- Prognosis/survival rates
- Less diversity of disease trajectory
- Fewer treatment options (anxiety of recurrence after surgery)
- Media portrayal of disease – googling
- Stigma – everyone knows something about it
- Fear, sense of hopelessness
- *Will I die?*



British Medical Journal 2018:361, Pitman et al.

NICE estimate that 1:4 patients experience psychological distress or anxiety following diagnosis

BMJ study indicates that depression could be 4x prevalent in general population.

Highlighted that some cancers and treatments are thought to cause depression (inc. pancreatic ca)

Depression prevalent regardless of disease trajectory

Poor recognition = poor QOL

thebmj

Research ▾

Education ▾

News & Views ▾

Campaigns ▾

Archive

What you need to know

- Depression affects up to 20%, and anxiety 10%, of patients with cancer, compared with figures of 5% and 7% for past-year prevalence in the general population
- Poor recognition of depression and anxiety is associated with reduced quality of life and survival
- Some cancers, such as pancreatic and lung, can release chemicals that are thought to cause depression, and certain cancer treatments, such as chemotherapy and corticosteroids, are associated with depression
- Depression in cancer patients receiving end-of-life care is no more prevalent than in patients living actively with cancer
- Be aware that antidepressants can worsen existing cancer symptoms and interact with chemotherapy agents: sertraline and citalopram tend to have the least interactions and are generally well tolerated as first line agents

Advances in cancer treatments mean that half of people now diagnosed with cancer can expect to survive for at least 10 years,¹ defining many cancers as long term conditions. Psychiatric illnesses such as depression and anxiety are common, but often neglected, complications of cancer, influencing quality of life, adherence to treatment, cancer survival, and treatment costs.²⁻³ Depression and anxiety affect up to 20% and 10% of patients with cancer respectively, regardless of the point in the cancer trajectory, and whether in curative or palliative treatment.⁴ Geographical variations in the diagnosis and treatment of depression or anxiety in cancer settings implies under-recognition of these problems.⁵ Depression is associated with poor adherence to cancer treatment and poor cancer survival,⁶ and the increased risk of suicide in all patients with cancer⁷ is a concern.

This clinical update outlines the prevalence, aetiology, and management of depression and anxiety in patients with cancer to raise awareness among doctors of the need to address the psychiatric consequences of cancer.

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Prevalence of psychological distress in individuals diagnosed with cancer

- Over 4000 patients surveyed
- 14 different cancer diagnoses included
- Overall prevalence of distress was 35.1%
- Pancreatic patients produced the highest mean scores for symptoms of anxiety and depression
- Failure to detect and treat elevated levels of distress jeopardises the outcome of cancer therapies, and decreases quality of life



Research Article

The prevalence of psychological distress by cancer site

James Zabora, Karlynn BrintzenhofeSzoc, Barbara Curbow, Craig Hooker, Steven Piantadosi

First published: 26 January 2001 |

[https://doi.org/10.1002/1099-1611\(200101/02\)10:1<19::AID-PON501>3.0.CO;2-6](https://doi.org/10.1002/1099-1611(200101/02)10:1<19::AID-PON501>3.0.CO;2-6) |

Cited by: 1113

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Abstract

Purpose:

The goal of this project was to determine the prevalence of psychological distress among a large sample of cancer patients (n=4496). In addition, variations in distress among 14 cancer diagnoses were examined.

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What do we mean by depression and anxiety?

Anxiety

- Feeling of panic, worry
- Easily upset, tearful
- Low mood
- Irritable
- Loss of concentration
- Fatigue, insomnia, nightmares
- Physiological – shaking, headaches, digestive issues, loss of appetite, aches and pains, sweat
- Social anxiety

Depression

- Low mood
- Sleep disturbance
- Tearful and emotional
- Loss of interest in activities
- Hopelessness about the future/demotivated
- Low self esteem/loss of confidence
- Rumination and regret
- Suicidal feelings

Enduring & significantly impactful



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Cancer and loss

There are differences between grief and depression/anxiety – even though the symptoms often feel the same...

- Grief is natural and understandable
- Emotion impacted by an external situation or experience
- Multiple losses and changes that impact mood – adapt and adjust
- Anticipatory grief – existential anxiety
- Loss of meaning in life – searching for new meaning
- Yearning to go back to how things were
- Profound sadness
- Hyper alert and hyper vigilance – fight of flight
- A process rather than something with an end point
- **Tolerate rather than accept**



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Psychological concerns in a cancer context

- Multiple losses and changes: roles, employment, identity, hair, body parts, independence, **life plans, future**, mobility, body image, **choices & control**, jobs, **meaning**, relationships, sexual function...
- Existential anxiety – unknown, uncertainty, the desire for an equilibrium, unsettled
- Control and communication – knowledge, communication with medical team, clear plans, proactivity, controlling what you can (diet, exercise etc.)
- Different coping strategies within a family – denial, information, facing fears, emotional/rational, plan ahead/live in the moment, calm/anxious, anger/resignation, different ways of coping with change, and managing the expectations of others
- Physical side effects and hospital admissions – emotionally impactful, traumatic
- Other stresses – work, family life, finances, other illness/loss in family, mental health challenges, illness burden



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Is this 'normal?'

'natural'

'understandable'

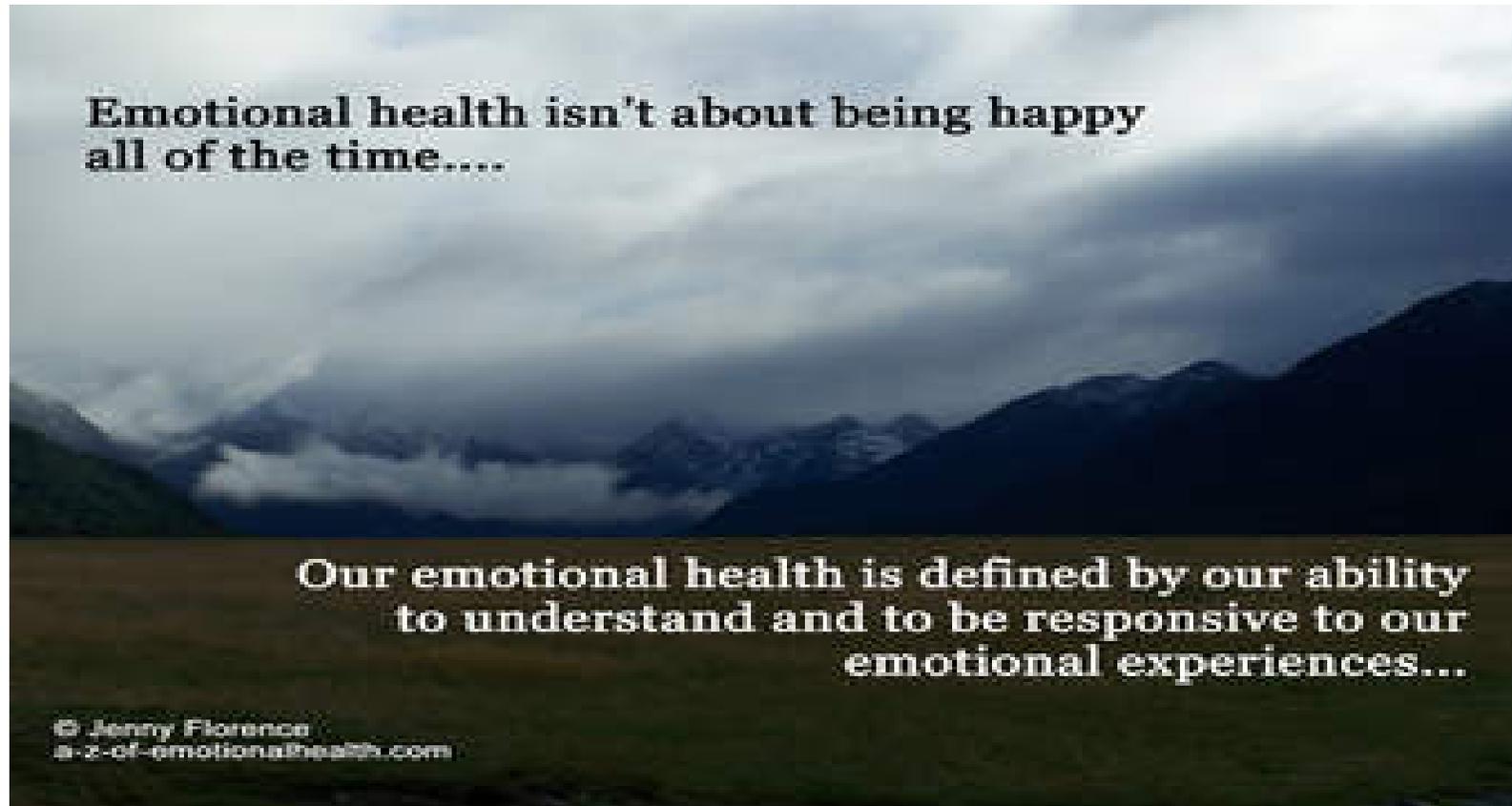
'usual'

**Fear of not
coping**



Often we see a 'normal' reaction to an 'abnormal' situation...

What does emotional wellbeing mean to you?



Experience every emotion every day...



You've got to go through it...

A process...

A constant challenge to maintain...

Won't always feel great

Sometimes easier to avoid or ignore

But important to pay attention to regularly



Permission not to always feel positive...

- It is ok not to feel positive all the time – trying to can be exhausting.
- Often others encourage positivity in us, even if we don't feel particularly positive.
- Positivity is not the same as emotional strength.
- Positive/negative is a value that we place on our thoughts – why not think of them as just thoughts?
- Thoughts perceived as 'negative' can't hurt us.
- Important to feel a spectrum of emotions, approach with curiosity rather than judgement.

'I *should* be more positive'

'these negative thoughts are detrimental to my health'



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The expert/human practitioner

Often put in a position by patients of knowing things and being able to fix them

- They are scared, vulnerable, dealing with uncertainty
- We are trained to 'do' things, we alleviate symptoms, we find solutions
- Their expectations and easier for us to do something than nothing
- **What would it be like to do nothing but listen?**

The human part of us is often the part that is harder to engage with

- Desensitised by overwork, long hours, lack of time
- Emotional part – incompatible with being professional?
- Can feel overwhelming, impactful to us, hard to tune into
- But, is also the **hopeful, engaging, connected and genuine** part of us
- **Empathy is a human trait...**

Key aspect of psychological therapy is finding an empathic understanding – **sharing and understanding the feelings of another**, listening, talking through, not solving the problem but identifying and sharing it



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Brene Brown: Empathy <https://www.youtube.com/watch?v=1Evwgu369Jw>



Containment

How do we contain a patient's overwhelming feelings?

- Time frame
- Start & end
- Sense of safety
- Trust
- Listen
- Our openness and availability
- Break it down for them



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Cancer is not a mental health condition...

But it does have mental health consequences

“You are telling me about the things you are doing to optimise your physical wellbeing, but **what are you doing to support your emotional wellbeing?**”

- **Explore the patient’s emotional wellbeing**
 - Have they had counselling before? What type, when?
 - Are they taking any medication, and if so who is prescribing?
 - Who is supporting them emotionally?
 - What do they feel they need?
 - Risk assess
 - Arrange to revisit their concerns with them



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A challenging context/barriers to talking

- **Confidence in raising emotional issues**
- **Time**
 - Decide how much time you have, is it a good time for you/them
 - Have clear boundaries and remember how to end the conversation
- **Location/Privacy**
 - Ask relatives to step out
 - Check they are happy discussing things
 - Can you move elsewhere, arrange a time for later
- **Do they want to talk?**
 - What is your sense, too much to say? Nothing to say?
- **Do you want to talk?**
 - Be clear about your limitations – are you comfortable?



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Skillfully negotiating emotional conversations

- Clear time frame and boundaries
- Prepare
- Ask open questions: “tell me about how you are” rather than “are you ok?”
- Turn it back to the patient - **“what do you think?”**
- Acknowledge challenges and problems, you don’t need to solve them
- Contain the conversation – open and close it (with gravitas)
- Listen actively, don’t wait to speak
- Don’t fear silence
- Be honest about what you can achieve
- Signpost and suggest
- Summarise and conclude



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Benefits of addressing challenging issues

- Patient:
 - feels cared for, understood
 - has clarity and understanding of options
 - has reduction of fear and anxiety
 - feels more able to address further issues as they arise
 - realistic and hopeful
 - Prepared
 - Feels contained and supported

Clinician feels... ???

Self care and boundaries

- Understanding what has drawn us to a helping career (often carers at home, put others' needs before our own)
- Think about your own physical and psychological impact (headaches, anxiety etc.)
- Be mindful about self disclosure, sharing too much with patients – can be colluding and make us vulnerable. Privacy is a good form of protection!
- Identify and share any personal challenges at work or at home
- Put your oxygen mask on first
- Find a healthy distance from work and an ability to release concerns of the day
- Don't lose sight of your own wellbeing – leads to burn out
- Take an interest in your own self care
- Say no, prioritise work load, mindful of switching roles during the day
- Learn breathing techniques – mindfulness, relaxation and meditation
- Avoid self criticism
- Work out what helps you...



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What I tell patients!! (also relevant to us...)

- Mindful media use
- Healthy expression of feelings
- Relaxation and mindfulness – breathing
- Listening to your body, engage with it – trust
- Sleep, food and exercise
- Social interactions – who enriches you? Social interactions can be energising rather than draining
- Communication and relationships - connections
- Letting yourself off the hook – not lazy but unwell, unrealistic expectations
- Perspective and context
- Tolerance – of your situation and yourself
- Hope and reality



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When to refer...

- **Trust your clinical judgement and sense check**
- Does this feel like a natural reaction that they are having?
- Is there emotional movement over days, weeks – are their feelings evolving, or is it an enduring, significantly impactful state?
- Is there anything pre-existing to be aware of?
- Are they emotionally isolated or well supported?
- Is there something specific they need support with?
- Are there other challenges in their lives?
- Do they need containing? (multiple calls, repetition, out of hours...)
- Is supporting them feeling unmanageable for you?



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Key concepts to remember:

*“You are telling me about the things you are doing to optimise your physical wellbeing, but **what are you doing to support your emotional wellbeing?**”*

CONTAINMENT EMPATHY

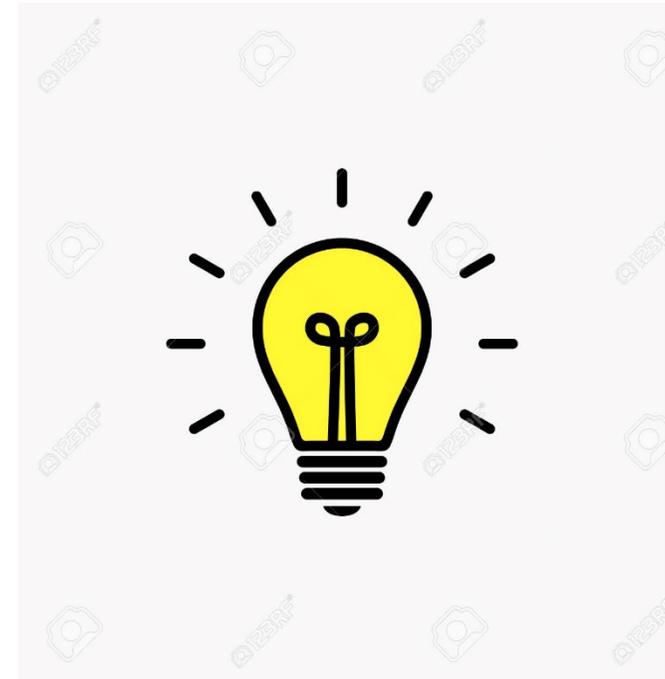
Think about the language you use

A spectrum of emotions is ok - validate

Human/expert – be open, listen, don’t assume

Look after yourselves

... Hope and reality are not incompatible



Questions

