

End of Life Care and Assessing Capacity in People with Brain Tumours

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Balancing biology and meaning

“For the anonymous anyone, death is a fact of life and entirely unobjectionable.

*For the loved one, it is an offense,
and for oneself it is unthinkable.”*

“We have eminently good reasons for avoiding the matter altogether. It is the most disagreeable of subjects at the same time that it is inescapable...”

Overview

In people with brain tumours:

- Assessing mental capacity
- End of life care

**THE MENTAL CAPACITY ACT
2005 (ENGLAND & WALES) —
ASSESSING CAPACITY**

Five Principles

The fundamental goal of the MCA is decision making.

It has five principles:

- Assumption of Capacity
- All Reasonable Steps
- Unwise Decisions
- Best Interests
- Least Restrictive Option

Practical Decision Making

Three elements to decision making:

- Who is the decision maker?
- Determining capacity
 - Diagnostic assessment
 - Functional assessment
- Best Interest Process

Things to know

- The MCA applies to all citizens
 - Everyone is subject to this law
 - Any citizen (eg family) can be expected to assess capacity
- The MCA is supported by a *Code of Practice*. Some people have a legal duty to “have regard” to this eg
 - Professionals and anyone paid to care
 - Attorneys, CADs, IMCAs
- Capacity decisions should be made by the person who is “directly concerned” with the implementation of any decision eg the surgeon who will operate, the nurse delivering care (role of MDT)

Capacity assessments are:

- Decision-specific
- Time-specific
- Made when the person is most likely to be able to demonstrate capacity – “all practical and appropriate support”
 - If time allows
 - All efforts must be made to try and enable capacity before a decision is made on somebody else’s behalf

More things to know

- Presumption of capacity (1st principle)
 - Disagreeing with you is not a capacity criterion!
- A competent adult can refuse any treatment, even if his/her life is at risk as a result
- Generally the more serious the decision the greater capacity required to make it
 - And the greater expectation that the capacity assessor is skilled at assessing capacity
- You must have a “reasonable belief” that the person lacks capacity in order to be able to act on this conclusion

Assessing capacity

- **“Diagnostic” Assessment:** Impairment or disturbance of the mind or brain
 - This is not enough to determine capacity
 - Whether the person can or cannot make the relevant decision is the point of the functional assessment
- **“Functional” Assessment:**
 - Understand the relevant information
 - Retain the information
 - Use or weigh in the balance to make a decision
 - Able to communicate

Functional assessment in practice

In relation to the specific decision to be taken:

- Understand
 - “What would happen if you said Yes to the decision, or No to the decision, or you choose to not decide?”
- Retain
 - For long enough to make a decision
- Use or weigh in the balance to make a decision
 - “Tell me your rationale for that answer.”
- Able to communicate it by any means
 - Work with your SLT colleagues

In people with brain tumours

- The common combination of functional impairment, cognitive impairment and mental illness makes capacity assessment challenging
- The keys are
 - Time: allowing enough and choosing the optimum time
 - Ensuring appropriate support for the patient (eg family member)
 - Ensuring appropriate support for you (eg SLT, a senior colleague)
 - Recognising that mental illness (eg anxiety, depression) may be affecting capacity and knowing how to assess for the impact of this

Capacity assessment in the context of mental illness

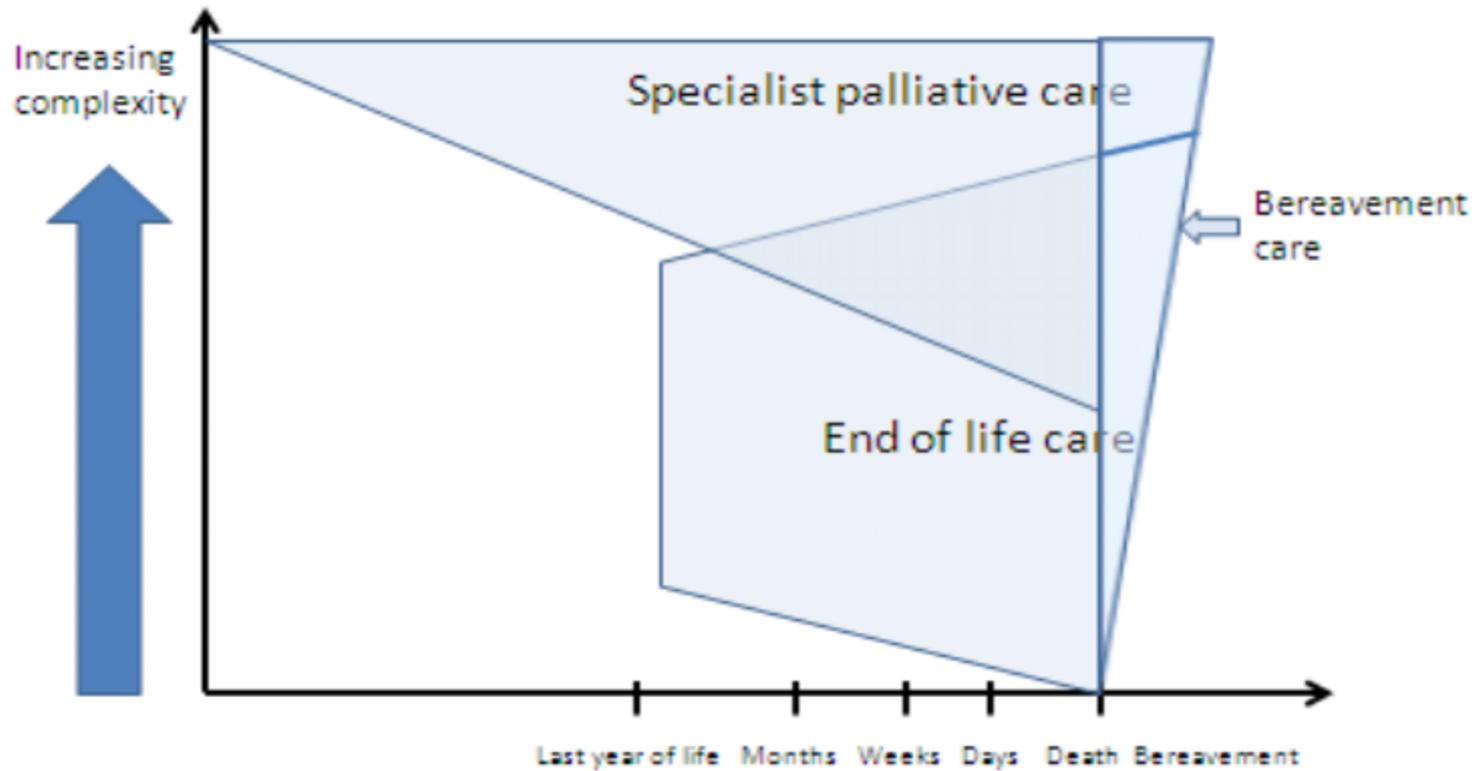
- The “test of authenticity”
 - This is not a recognised element of the MCA or Code of Practice
 - The question to try to answer is: *How consistent the current decision is with the historical person?*
 - It has important limitations, so is not the whole answer:
 - The person may have had longstanding mental illness
 - A person is allowed to change their mind
- Seek senior advice

The role of the IMCA

- An Independent Mental Capacity Advocate must be instructed for people:
 - Aged 16 or over, and
 - A decision needs to be made about either a long-term change in accommodation or serious medical treatment, and
 - The person lacks capacity to make that decision, and
 - There is no one independent of services, such as a family member or friend, who is “appropriate to consult”

END OF LIFE CARE

The relationship between specialist palliative care and end of life care



Commissioning Guidance for Specialist Palliative Care: Helping to deliver commissioning objectives, December 2012.

Introduction to end of life care

- For the patient and his or her loved ones, being given the diagnosis of a life-limiting cancer is frequently shocking to the core. It usually involves some degree of suffering.
- Our patients are often highly vulnerable and desperate to find a cure, or if not then to live for as long as possible.
- Brain tumour patients may have the added problem of an early impact on their ability to think clearly and a sometimes profound impact on everyday functioning.
- It is into this context that we ask them to take serious and life-altering decisions.

Response to threat

- Patients and their loved ones respond to the diagnosis of a brain tumour in a multitude of ways:
 - Spectrum of denial at one end through to acceptance at the other
 - Denial is not usually absolute, but may simply be a choice to “live in a nicer place“
 - Strong emotions
 - Psychological reactions that may include a sense of hopelessness
 - A strong attraction to anyone who provides hope
 - A seeking of answers to the question of “Why?”

PALLIATIVE CARE - PHILOSOPHY OF CARE

Home truths

- Inherent in the fact of being alive is the fact that, one day, none of us will be. This simply a biological reality
- But we are more than our biological, physical selves; we are also thinking and feeling individuals with, many would say, spiritual aspects to our lives
- “Death anxiety” therefore becomes very important

Death Anxiety

- The fact that we must all, one day, die gives rise to varying degrees of anxiety, depending on personality but also on situation and time of life
- This is known as death anxiety and is present throughout our lives.
 - It is seldom explicit (it usually remains unconscious), but it bubbles up every time we twist an ankle or have a near-miss car accident
 - It is a powerful, often unseen, component of suffering

The palliative care approach

Palliative care is something that all practitioners should engage in. It is fundamentally an interdisciplinary approach – no one discipline of healthcare (including specialist palliative care), philosophy, religion, ethics or law has all the answers.

The principles are:

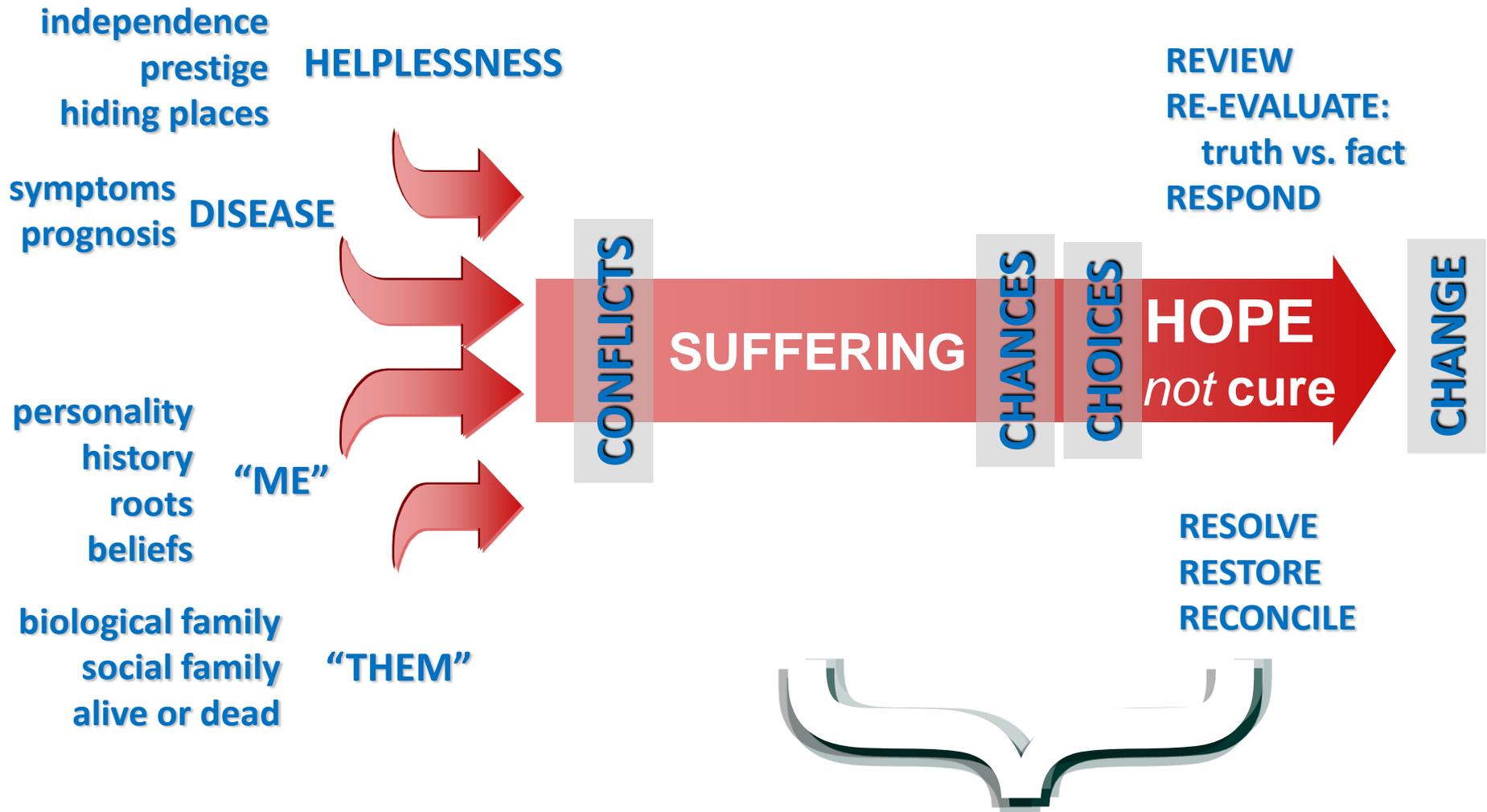
- The centrality of the whole person
- Optimal symptom control
 - It is difficult to process what is happening to you if you have symptoms, so we need to reduce these as far as possible.
- Stories are the containers of meaning:
 - Medical histories versus people's stories are like facts versus truth
 - Our stories contain the seeds of healing through meanings, rather than curing through healthcare

Suffering in the context of a medical system based on objectivity

- Suffering relates to conflict; our aim must be to promote an environment for patient and family in which choices and changes can be made to resolve any tensions.
- Suffering is something that happens to whole persons, not simply to bodies, which are the narrow purview of medicine:
 - Modern medicine invites the healthcare professional to “know”. But brain tumour patients expose, on a daily basis, the limitations of objective knowledge
 - Objectivity, even if it is truly possible, is a bias making us blind to mystery
 - “Answers” invite us to stop thinking; sometimes “questions” are the best travelling companions (and the more important questions don’t always have ready answers)

“Suffering”

a user friendly analysis



Attitude

- Uncertainty, hope and meanings all play into the therapeutic relationship
- A team approach is needed to achieve best symptom control in order to create “decision space”
- Individual attitude is critical to a person feeling valued and understood:
 - Generous listening

Uncertainty

- Acknowledging uncertainty can keep open the door to hope while allowing contingency planning
- Worrying about the future can impede enjoyment in the present
- Managing uncertainty entails: normalising the uncertainty; addressing any emotions that arise, including responding to distress; helping patients/relatives manage the impact of uncertainty about the future on their lives now.

Smith A et al. *NEJM*. 2013

- In terms of future symptoms, it may be better to concentrate on known consequences rather than on their unknown probability.

Latronico N. *Crit Care Med*. 2015

Hope

- Hope is multi-layered, but tends to be thought of only in terms of cure or longer survival; there can be adverse consequences to being fixed in this mode of thinking.
- The tension for healthcare professionals arises from the conflict between a beneficent desire to improve patient welfare through sustaining hope and an autonomy-based requirement not to deceive patients about their condition.

The adverse consequences of a fixed view of hope can be

- For patients and loved ones:
 - A tendency to spend time, money and energy chasing ultimately futile treatments
 - A lack of willingness to plan for an uncertain future and to reject any help that might encompass this as “negativity” eg memory boxes for children
 - A lack of willingness to engage in important conversations with loved ones eg “four things to say before goodbye”
- For healthcare professionals:
 - An assumption that death is always failure and therefore a continual resistance to admitting “defeat”
 - This approach sees dying as a problem to be solved (not a mystery to be engaged), even when everything reasonable has been done – this maintains people in a state of struggle and conflict
 - Burnout

Hope

- The standard account of hope pairs it with a belief that the specific hoped-for thing is possible, although not certain.
 - This contrasts with “wishing for impossible things” or optimism that always looks on the bright side, but has no definite objective.
- Different hopes can therefore be more or less rational, depending on the likelihood that the desired outcome is possible.

Hope

- There are alternative accounts of hope, which may allow hope to be maintained without recourse to deception, such as:
 - Hope as a process or activity (being hopeful)
 - Hope held as a “hope against hope”, maintained with an open-eyed grasp of the inevitability of the undesired, sometimes catastrophic, outcome (ie not false hope)
 - Hope as the notion that the future can be different and better, not that disease can be cured and mortality conquered
 - Hope for the well-being of those we leave behind

Hope

- While not ignoring the difficulties, these raise the idea that we might foster honest hope, even in the face of impossible odds, as an attempt to explore a range of goals - even if these are restricted by the limits of a person's life.

The role of meanings

“This world is above all a practical and moral one in which patients have life projects and everyday concerns, things ‘at stake’”

(Mattingly 1998)

We are meaning-seeking creatures who understand ourselves in relation to others. When illness breaks into our ordered, busy lives, it may be difficult to make sense of it. We can help patients to do so by hearing their story.

Meanings relate to issues arising in physical, psychosocial and spiritual domains.

Symptom meanings

- Physical suffering, while happening in the present, has both past and future associations:
 - Our past experiences may inform our understanding (correctly or incorrectly) of the meaning of a present symptom.
 - The present symptom, correctly or incorrectly evaluated, may give rise to fears about what the future is likely to hold.
- Symptoms thus have both universal and individual aspects – the wide-ranging nature of suffering.

PALLIATIVE CARE – A PRACTICAL APPROACH

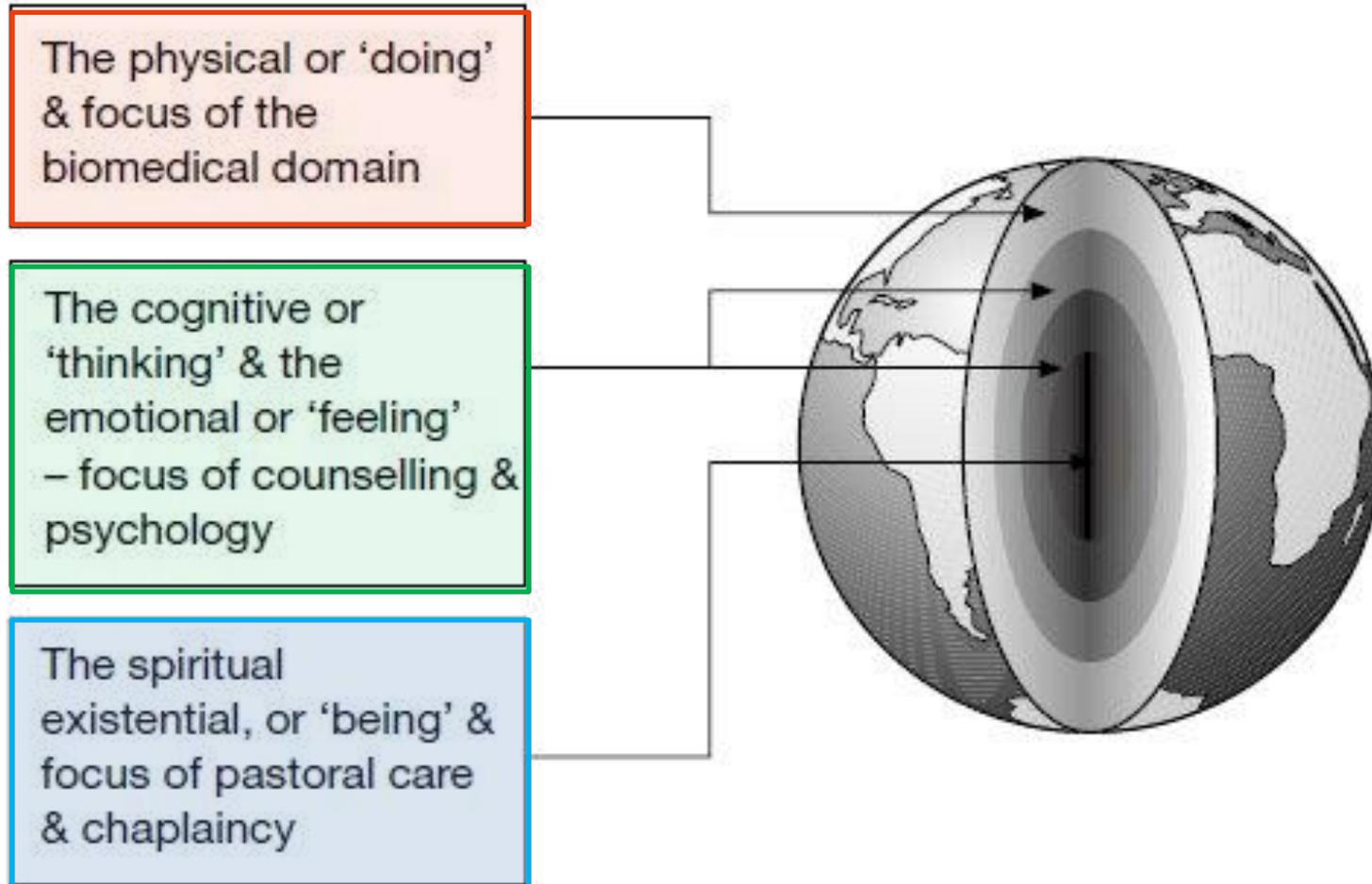
Many elements

- Who is in front of you? “What do I need to know about you as a person that will help me to help you?” (Harvey Chochinov)
- Authenticity: listening and being present – “turning up to the conversation”
- Human experience gains meanings in stories
 - Hearing, creating and sharing stories are core to relationships and reinforce mutual values
 - A patient’s search for meaning requires us to engage with the story through active listening and skilled questioning, to help the story make “good enough” sense for the dying person.
- Assuming a ‘not knowing’ position allows us to hear things that do not fit our preconceptions

Self care

- Integrity (what is true) is about wholeness and includes all our wounds and vulnerabilities, and through which we can sometimes connect with suffering people
- No one is comfortable with loss. The expectation that we can be immersed in suffering daily and not be touched by it is unrealistic (Rachel Naomi Remen)
 - Role of supervision

Using a framework for understanding suffering to guide conversation



The Physical or 'Doing' Domain

The surface of things. This includes

- Physical symptoms, such as pain.
- Uncertainties with regard to disability:
 - How much remaining useful time.
 - Aspirations to achieve goals.
 - The aspiration-achievement gap.
- Helplessness

The Physical or 'Doing' Domain

Helplessness

- The cardinal expression of this is the feeling of loss of control.
- The patient loses independence, prestige and privacy – the classical 'hiding places for the insecurities of our soul'.
- The patient can no longer dictate their own boundaries and find solace in *human doing* (rather than a *human being*).

The Psychological, Emotional or 'Feeling' Domain

Moves us deeper into the person, including as a social being.

- The emotional impact of the common experiences of living.
- The strains of particular psychosocial issues such as financial pressure.
- How symptoms are affecting those around the patient, and how this in turn feeds back to the patient.
- Does the patient trust the healthcare staff?

The Psychological, Emotional or 'Feeling' Domain

Relationships with significant others:

- Almost all relationships, and even the healthiest, need attention.
- Broken relationships within the patient's immediate family or friends, or may be more distant, in both space and time.
 - 'Dead' relationships are an essential and frequently neglected area to explore ie those where the person concerned has deceased: parents are the most obvious.
 - Sometimes more difficult are relationships that have failed, yet the person is still around. Examples are divorces or family estrangements.

The Spiritual/Existential or 'Being' Domain

- This domain encompasses the fundamental questions of life and death.
- Most patients do not wish to address these questions directly.
- Nevertheless these questions are likely to underlie the intensity of any suffering arising from the other two domains.

The Spiritual/Existential or 'Being' Domain

Anxiety (“death anxiety”) emerges from a person’s endeavours, conscious and unconscious, to cope with the harsh, uncomfortable facts of life – the ‘givens of existence’:

- The inevitability of death
- Freedom
- Ultimate aloneness
- Ultimate meaning
 - Resolving and integrating our personal meaning into the universal: is there meaning and order in the universe, or do we seek meaning and certainty in a universe with neither?

(Irvin Yalom, 1989)

Conclusion

- People, and their loved ones, when faced with a diagnosis of a brain tumour are often vulnerable, angry and in need of support
- Stories and meanings are important
- My thesis is that the philosophy of palliative care can be applied by anyone to infuse their own practice
- Pandora's box was not quite empty at the end...