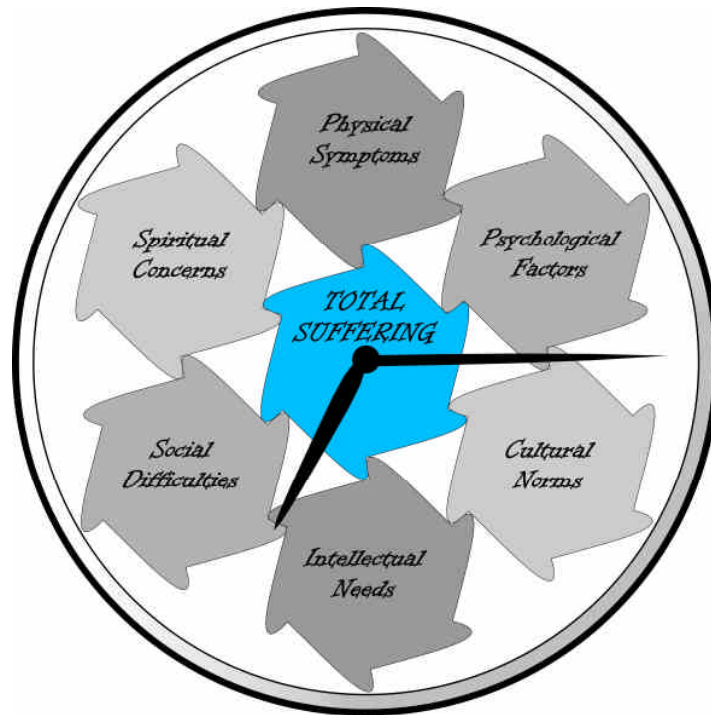


# THE CONCEPT OF TOTAL SUFFERING

Patients with life limiting illness may develop a number of symptom issues as their disease advances therefore as health practitioners anticipate and manage these problems awareness of the impact of total suffering is crucial.

## *The Concept of Total Suffering*



*The Concept of Total Suffering: Anne Morgan© 2004*

Each patient's journey with a life limiting illness such as cancer is unique. The concept of "total pain" or "total suffering" indicates that there are many factors which contribute to the experience of pain and other physical symptoms and each patient must be treated with the knowledge that physical symptoms cannot be treated in isolation.

Whatever symptom a patient is experiencing it is important to look at it in the context of the above diagram which describes the concept of *total suffering*. If we look at, for example, pain as the presenting issue for the patient as only a physical symptom then we negate the impact of all the other aspects of *total suffering*. We need to also look at the pain of leaving behind young children for example, the possible guilt of a previous lifestyle they have lived, cultural aspects of pain and the meaning of pain for this particular patient and the impact it may have on their life – all these aspects will contribute to the lived experience of **their pain**.

The concept of *total suffering* can be explained as a 'clockwork mechanism' in which various aspects of suffering interact with others. Each aspect of the above model is interdependent and must be viewed as a whole – just as with a clock if one cog is affected the clock can no longer

function effectively no matter how much we wind it. Contributing factors to symptoms may change with time so assessment needs to be done regularly and management of symptoms must be timely and medications regularly given on time.

All these aspects identified in the diagram must be considered when assessing symptoms in patients with advanced disease in order to provide the best quality of care and to plan goals of care. The patient and their needs are the centre of this concept and health professionals must actively engage in listening to their story in order to work with them in finding solutions. It requires a synergistic partnership, takes time and necessitates the building of a **therapeutic relationship**.

It is important to look at where the person is on this particular day at this particular time. It is their journey and their needs will be constantly changing and evolving over time. It is also important to realise that the choices that patients make may not be the ones that we would make for ourselves. We must above all respect our patients and work with them collaboratively to develop shared goals and realistic aspirations.

### Physical Assessment

- Accept patient's description
- Assess pain carefully – *history* (onset, course, site, radiation, severity, quality, frequency, associated factors, etc), *examination*, *investigations*
- Assess **each** pain
- Assess extent of disease
- Assess other factors which influence pain
- **Reassess**
- Examine the site/sites of pain having reviewed the extent of their disease impacting on these sites
- Palpate the areas for tenderness
- Observe for nonverbal cues such as grimacing, body posture, withdrawn behaviour, moaning, agitation or irritability
- Assess for fluid accumulation (eg: ascites or pleural effusions), abnormal breath sounds (eg: pneumonia or heart failure), bowel obstruction or neurological problems (eg: spinal cord compression or neuropathic pain syndromes)

### Psychological Assessment

- What pain experiences has this person had previously?
- What are the implications of their diagnosis?
- Guilt – do they feel they deserve pain?
- Fear?
- Vulnerability? Depersonalisation?

### Spiritual Assessment

- What are their beliefs?
- Conflicts in belief systems?
- Questions about strength of faith/loss of faith?
- Will they now be accepted?
- How is pain expressed?
- Culture affects how they understand health and illness and it also affects health professionals and their attitudes to their patients
- Gentle truth-telling

### Social and Intellectual Assessment

- Altered roles and relationships?
- Financial implications?
- Pain of leaving loved ones behind?
- How much do they wish to know?

### General Guidelines when Assessing Symptoms

(Modified from CME Resource: *Pain and Symptom Management in End of Life Care*, 2002)

- Symptom assessment should be performed at **regular intervals**, ie: on admission, if there is a change in symptom, after medication administration and if there has been a change in the symptom management plan
- Know the patient's medication history and what the patient has already tried, which medicines were effective and which were unhelpful.
- Ask about non prescribed medications (*over the counter medications, herbal products, homoeopathy, naturopathy, tonics, etc.*), complementary therapies (*acupuncture, massage, reiki, reflexology, etc.*) being used and non-pharmacological methods that they may find helpful (*massage, osteopathy, heat, cold, music, art, or distractions they use*)
- Discuss the meaning of their symptoms with them. What are their beliefs and knowledge about them, the reporting of symptoms and their fears about their disease?
- What are their spiritual and cultural beliefs around their symptoms eg; is it viewed as a punishment or do they believe they must suffer. Is reporting of issues culturally acceptable?