

**A SYNOPSIS OF DISEASE AND SYMPTOMS WHICH ARE AT BEST
DIFFICULT, AT WORST IMPOSSIBLE TO CONTROL WITH MODERN
PALLIATIVE CARE.**

Even with state-of-the-art palliative care many terminally ill patients will experience substantial physical suffering.

Hopelessness, futility, meaninglessness, disappointment, remorse, and a disruption of personal identity are frequently experienced. The ideal, therefore, to provide a pain-free, comfortable death with dignity is often unobtainable and should not be promised. It is a rhetorical myth that hospice and palliative care can relieve *a//* the suffering associated with the advance of diseases like cancer, AIDS, and motor neurone disease.

Over 90% of people with terminal illness will endure their situation, but around 5% find it intolerable and request euthanasia.

1. Difficult/Impossible to Control Pain Situations

Pain, particularly that due to infiltration by cancer of extremely sensitive nerve rich areas such as the head and neck, pelvis and spine, is commonly episodic and excruciating. aggravated by movement, and may be likened to a dental drill on an unanaesthetised tooth nerve.

Pain is not always adequately controlled by palliative medicine, 5-10% of cancer pain may be of this type and in some cases can only be “palliated” by producing a prolonged unconsciousness, coma or “pharmacological oblivion”. This may last for days until death occurs by dehydration and circulatory collapse or retention of bronchial secretions (“the death rattle”) pneumonia and pulmonary collapse. *This is not a dignified process.*

1.1 Raised intracranial pressure due to inoperable brain tumour

Severe head pain due to pressure on sensitive nerve structures by tumour expansion in a confined space, may be accompanied by loss of function e.g. blindness, paralysis, incontinence

1.2 Infiltrating head and neck cancers with/without ulceration

Some tumours fungate, hideously distort the face and produce foul odours.

1.3. Lung Cancer infiltrating the root of the neck or chest wall and damaging sensitive nerves.

1.4. Mesothelioma (associated with asbestosis utterly incurable) Producing severe chest pain with each breath, made far worse on coughing which may be chronic and persistent associated difficulty breathing and feelings of suffocation.

- 1.5. **Recurrent bowel obstruction due to widespread abdominal cancer.**
Diffuse deposits of cancer obstruct the bowel, causing pain, nausea and vomiting and abdominal distension. Surgery may be advised which may be either futile or of only very short term benefit. Vomiting and malnutrition lead to a kind of starvation until death.
- 1.6 **Pelvic cancer** (bowel, bladder, prostate, uterus, ovary) may infiltrate major nerve plexuses affecting the legs or genitalia and cause severe neuropathic pain (+/- paralysis of sphincters/legs). Incontinence of urine and faeces can occur.
- 1.7 **Severe chronic poly arthritis with joint disintegration** which renders most movements excruciating and severely limits mobility.
- 1.8 **Spinal cancer with nerve root pain; vertebral collapse**
+/- paraplegia. One of the worst situations possible, confined to bed with ... episodic excruciating neuritic pain with simple movement.
- 1.9. **Inoperable bladder cancer** with very frequent and painful urination, often with bleeding, blockage to flow and incontinence (hence the old medical saying "Please God, do not take me through my bladder")

2. **Non-Pain Syndromes Causing Extreme Suffering**

- 2.1. **Cachexia** Commonly associated with advanced cancer, involves severe loss of appetite and weight, loss of energy in extreme degree and severe psychological "pain" (distress) due to this gross debilitation and loss of independence. Malnourished bedbound patients are prone to develop ulcerating bedsores over bony prominences.
- 2.2. **Loss of appetite with intractable nausea and vomiting** due to either cancer itself or drug/other therapy including chemotherapy and radiotherapy.
- 2.3. **Obstructing oesophageal cancer** with inability to eat or even swallow saliva. Anything swallowed is vomited back.
- 2.4. **Chronic progressive difficulty in breathing.** Possibly with severe cough, perhaps with blood. +/- severe pain with each breath or cough. Fear of suffocation causes enormous anxiety.
- 2.5. **Incontinence of bowel and bladder** due to communication of these structures with the vagina, secondary to surgery/radiotherapy for cancer of the cervix or due to confusion and immobility. Producing gross indignity to some people.
- 2.6. **Chronic inexorably progressive neuropathic syndromes** leading to paralysis of all limbs, loss of speech, blindness loss of control of bowel and bladder, and perhaps inability to breathe or swallow. As in multiple sclerosis, motor neurone disease. The person's body functions disintegrate, yet trapped

within that shell may be a perfectly lucid mind.

- 2.7. **AIDS.** A potentially fatal disease, often of young persons, with an horrific dying process of cachexia immobility, incontinence and progressive loss of mental faculties.
- 2.8 **Total dependence syndrome** The loss of dignity due to loss of independence and control in the terminal decaying phase, particularly in hospital. *This is a major reason for euthanasia request.*
- 2.9 **Blockage of lymphatic or venous drainage of tissue** fluid causes swelling of limbs, genitalia and face. In severe cases fluid seeps through the skin which breaks down.

3. **Pen Pictures**

- 3.1 **Cancer in the spine with nerve root pressure and spinal collapse** Pain will be lancinating around the body, and also possibly into the legs (as in sciatica). The pain will be provoked by simple movements such as turning in bed, coughing, urinating, using bowels. Its intensity and unpredictability make routine analgesic measures inadequate. Bed sores are a common risk; Incontinence or inability to urinate highly likely. Every physical action, washing for example, is dreaded. Such a situation can last for months until the ravages of further cancer spread occur.

3.2. **Multiple sclerosis.**

Progressive loss of motor/sensory function in a haphazard way over many years leads to virtually total loss of movement. Initially wheel chair life, later bed bound. Total dependence, incontinence and if speech and sight are impaired, loss of even the ability to communicate. The intellect may remain unimpaired, the person is a prisoner in a body which cannot move or function in any real way.

This list was prepared for the former chief minister of the Northern Territory (Australia), Marshall Perron, who introduced the Rights of the Terminally Ill Act in 1995 – the first voluntary euthanasia legislation in the world – subsequently overturned by Federal Parliament in March 1997. The list was updated by a South Australian palliative care expert in March 2001.