

A Synopsis Of Disease And Symptoms Which Are At Best Difficult, At Worst Impossible To Control With Modern Palliative and Medical Care

This list was prepared for Marshall Perron, former Chief Minister of Australia's Northern Territory. He introduced the world's first voluntary euthanasia legislation, The Rights of the Terminally ill Act 1995. Four patients were assisted to die under the terms of the Act before it was revoked by Federal Parliament on March 25th 1997. The list was updated by South Australian palliative care specialist Dr Roger Hunt in 2001, further additions in 2003 and 2004, confirmed as accurate in 2012 by Dr Hunt..

Even with state-of-the-art palliative care many terminally ill patients will experience substantial physical and existential suffering. This is also the case with the best of medical care for hopelessly ill patients who may suffer for many years with incurable and unrelievable conditions; a much longer time frame than that defined under 'terminal illness'.

Hopelessness, futility, meaninglessness, disappointment, remorse, and a disruption of personal identity are frequently experienced. The hospice ideal, therefore, to provide a pain-free, comfortable death cannot always be realised and should not be promised. It is a myth that palliative and medical care can relieve all 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 between 5 - 10% find it intolerable and request euthanasia. A minority of those with a hopeless illness also suffer intractable symptoms 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.

- 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 - 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").
 - 1.10. Severe chronic spinal osteoporosis with vertebral collapse produces severe and unremitting pain.
 - 1.11. Recurrent carcinoma of the vulva with ulceration + or - invasion of bladder or urethra with loss of urine (usually acidic) across the ulcerated area.
- 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 bed-bound 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.
- 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.
- 2.10. Severe stroke (such as brain stem stroke or profound dense hemiplegia) can result in permanent paralysis, inability to communicate, inability to swallow (resulting in the necessity for tube feeding), commonly followed by muscle contractures, incontinence, and bedsores, and a state of total dependence which can last for years.
- 2.11. Primary or secondary cancer in the liver with vomiting and jaundice; at times painful.
- 2.12. Secondary cancer in bone (commonly prostate in origin) with pathological fracture of a long bone at the site of the secondary cancer. This will not heal (eg in a hip bone or arm).

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. Bedsores are a common risk. Incontinence or inability to urinate

is 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.