# Palliative Care was Everybody's Business

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#### Outline of lecture

- Mid-20<sup>th</sup> century awakenings
- The modern hospice-palliative care movement
- The palliative care paradigm
- The age of integration?
- Strengths, weaknesses, opportunities, threats

## The Practitioner 1948

LEAK, W.N. (1948). The care of the dying. *The Practitioner* 161(962), 80-87.

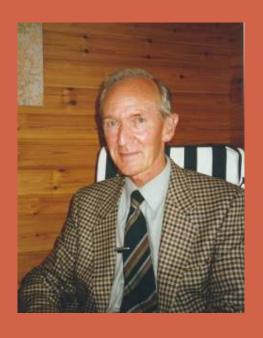
A paradoxical and awkward situation has been reached in which death is commonly occurring at advanced age (when dying is said to take longer) and also where medical and nursing skills are contriving to prolong life ... relatives are not available or willing to undertake care at home... However desirable it may seem to some that all old people should obtain the best skill and care in their dying moments, it seems pretty clear that this will remain an ideal for a long time to come

#### Joint National Cancer Survey Committee, 1952

- ... illness very far advanced when friends called a doctor ... In extreme squalor, resisting any attempt to wash or care for her.
- ... alone in a bed-sitting room, seldom visited by her married children, relying on the goodness of neighbours ... receiving very little nourishment.
- ... house was dirty as she was too ill to clean it, and her clothing filthy with neglect and discharge from the ulcer ... gave food to her pets which she needed herself.
- ... Loses faith in every possible way as he feels he is gradually worsening, and that no-one is taking any interest.

#### Scottish Highlands, mid 1950s

John Berkeley, GP – and first vice chairman of Scottish Partnership Agency (1991-93)



I can very clearly remember, within the first year or two of going into practice, a lady with advanced cervical carcinoma dying at home. And we were giving quite large doses of morphine. I mean they seemed lethal doses to us in those days. Now, looking back with hindsight, I think we were giving adequate doses but not frequently enough and they were intermittent. And my feeling of utter helplessness, of trying to help, not only this woman, but her husband and her daughters, and feeling that I had not got the skills at that time to actually deal with this situation. It made quite a profound impact. I can still now visualise the house, and the woman, and the many calls I made to that household. And I think it... stimulated me to read, to see what there was that one could do to help. And there was very, very little in the literature in those days to give any indication. But reading around in those days, reading the literature; there was nothing else to guide you.

### The Lancet, 1960

We must attack the problem on every side: hospital services must be improved and extended, staff in residential homes increased, and voluntary as well as profitmaking institutions helped in return for an approved standard of care

#### Cicely Saunders' first publication

Saunders, C. (1958). Dying of cancer. *St Thomas's Hospital Gazette*, 56(2), 37-47.

#### ST. THOMAS'S HOSPITAL GAZETTE

#### DYING OF CANCER

By Cicely M. S. Saunders, B.A., M.B., B.S., S.R.N., A.M.I.A.

REPORTS are given of four patients who have been chosen to illustrate some of the problems that arise in helping people with cancer to die comfortably and at peace.









#### 'Total pain'

Saunders, C. (1964b) The symptomatic treatment of incurable malignant disease. *Prescribers' Journal* 4(4), October, 68-73.

- Physical symptoms
- Mental distress
- Social problems
- Emotional issues



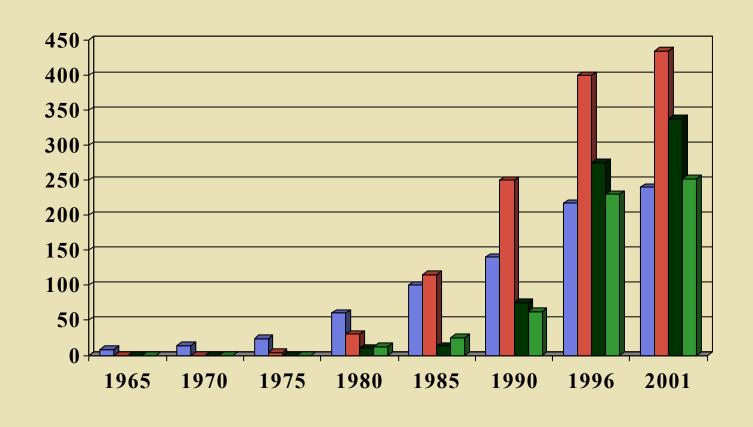




**■** Hospice

**■** Home support

### Growth rate of palliative care services in UK and Ireland 1965-2000



■ Hospital with palliative care service

■ Day care

### Key themes in UK hospice-palliative care development

- Arose in reaction to medical neglect of the dying
- Was a product of policy indifference within the post-1948 welfare state
- Influenced by the epidemiological transition to cancer and chronic diseases
- Institutional provision spearheaded by voluntary sector, NHS came later
- Growth and diversification went hand in hand
- Specialty recognition in medicine 1987; academic centres followed
- From 1980s considerable advocacy strength of national organisations (Help the Hospices; Scottish Partnership; National Council;; professional groups)

#### The palliative care paradigm

- Professor Balfour Mount, Montreal, 1974: applying hospice principles in the hospital and wider settings
- Multi-disciplinary and multi-facetted
- A move from 'modern' to 'postmodern' death?
- A philosophy of care regardless of disease, age, stage of life
- A specialty with generalisability
- An art and a science

#### The age of integration?

- Growing levels of policy recognition
- 'Mainstreaming' palliative care
- Standards and guidelines
- 'Preferred golden pathways'
- Palliative care on the basis of need, not diagnosis
- Signs of a research infrastructure
- Framing palliative care as a public health issue

#### Strengths and Weaknesses

- Unprecedented levels of interest in end of life issues
- Specialist workforce exists for education and clinical care
- Growing interest in 'rights' argument for palliative care
- Increasing level of global collaboration

- Low public recognition of palliative care
- Weak evidence at service level –esp. economic
- Inequitable access
- The medicalisation of dying?
- Global need vastly exceeds capacity to respond - eg access to opioids

#### Opportunities and Threats

- Innovative models –
   Hospice Friendly
   Hospitals;
   Neighbourhood
   Networks; Project on
   Death in America; social
   marketing
- Civil society and state partnerships
- Societal conditions for 'starting the conversation' may now be right

- Limited vision and preoccupation with health service solutions to cultural problems
- Philosophy of palliative care is reduced to technical procedures
- Assisted dying debate fragments effort and obscures public understanding of palliative care

#### Cicely Saunders, 1961

Saunders, C. (1961a) And from sudden death ... Frontier, Winter



'A society which shuns the dying must have an incomplete philosophy'