Medicine for Managers

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Care of the Sick and Dying

Providing care for someone as the end of their life draws near is often challenging. The period before death may have many presentations and carers may need to support those who are in pain, restless, distressed, anxious, or fearing the end or the suffering that may precede it. Carers will have common needs for their patients in their last days; support, good communication, maintaining fluid input, symptom management and medication.

The care of the sick and dying has been undertaken by families for thousands of years.

Following the birth of Christ and the dissemination of Christianity, religious establishments developed throughout Britain and these monasteries were inhabited by monks, canons or friars.

Nuns serviced the convents that also appeared.

By the Middle Ages, there were about a thousand such centres of worship and with a total population of between two and three million, there was a monastery for every 2-3,000 people. The power and reliance on religion was truly surprising in order that such lavish provision could be supported by the population.

The abbey, monastery, friary, priory or convent would have a religious community ranging from about twenty to hundreds of religious supplicants dedicated to lives of prayer and help for their fellow men and women. Such buildings were constructed throughout the country and nearly every one had an area where sick and dying people were tended. Cistercian monasteries had two infirmaries, one for the monks and one for lay brethren. In addition there were about 500 hospitals in Medieval England, again staffed by monks or nuns.

The hospitals and monasteries provided similar care. The monasteries were motivated to intercede for the souls of the living and the dead and provide spiritual care. The hospitals applied the emphasis more principally on practical relief of suffering.

Monastic and convent care was simple support and prayer. Cure was expected by the church, though not necessarily in this world, and much

of the church provision was directed to next world 'follow-up'.

Money was endowed for *Soul Prayers* and the wealthy could found a chapel or endow a whole monastery or hospital.

St Bartholomew's Hospital and Priory was founded in 1123 at Smithfield on the vow of a Royal Jester who had contracted malaria.

England suffered waves of bubonic or pneumonic plague insoluble by prayer or care. Priests would manage much of the illness including isolation.

Monastic design was the forerunner of ward based hospitals and such buildings were initially offshoots of abbeys or priories.

Hygiene was paramount and drains were stone lined and of a standard still acceptable today.

Buildings were often located near streams to obtain plentiful water for cleaning, with drinking facilities taken from upstream. Rain water was also collected from the roofs. Washrooms and flushing lavatories were added.

Most care was provided on the basis that illness was caused by God or an imbalance of the four humors (blood, phlegm, black bile and yellow bile) based on the ideas of Galen (129-216 AD) Prayer was a mainstay of treatment.

By the middle ages, hospitals were providing for leprosy. Lepers were isolated, often required to wear outfits rather akin to those of the Ku Klux Klan and have a clapper to warn anyone who came near. Even then there was pressure on beds, sometimes with sharing if necessary. However, care was taken to ensure clean linen at all times.

Accommodation in hospitals was commonly a mixture of long rooms with beds down each side, and multiple small rooms round a central cloister. As leprosy declined, beds were used increasingly for what is now geriatrics.

Early midwifery developed in medieval hospitals intermingled with other elements of care. In some cases, if the baby survived but the mother did not, the hospital would raise the child until age seven.

A list of admissions survives at St Bartholomew's Hospital from about the end of the fourteenth century, including;

> *'remedie of his akynge hede*', '*ryngyng of the eyrs*' and '*bleridness of eyen*'.

The data shows regular discharges, claims of cures for deafness and dumbness and remarkably small mortality figures. In York, the hospital had 13 canons, 4 chaplains, and 8 sisters in holy orders with 206 patients. One sister was responsible for babies and delicate children, and two cows were kept for their exclusive use.

St Mary of Bethlehem cared for the insane from 1247. The noise and confusion resulted in the name 'bedlam', the corruption of its name. It moved to its present site in 1814.

The mixed religious and secular care obtained for 400 years…

Hospice care for the support of end of life patients was one of the forms of management which developed from the monastic and hospital care, though in some form it had existed since the 4th century.

In 1843, a young widow, Mme Jeanne Garnier, founded the Dames de Claire in Lyon, France to provide care for the dying.

Dying was increasingly seen as a failure of the medical system and was not welcomed. Between 1874, 21 years after Garnier's death, and 1899, six similar establishments were created in France and New York. In 1879, a hospice was established by the Irish Sisters of Charity in Dublin and in 1905 St Joseph's Hospice was opened in Hackney, London.

Over the last sixty years in the UK patterns of late stage care have changed. The modern hospice movement was founded in 1967 by Dame Cicely Saunders (1918-2005), nurse, social worker, doctor and writer, with the opening of St. Christopher's Hospice in Sydenham in London.

She emphasised the importance of Palliative Care in modern medicine. She had been converted to Christianity in the late 1940s following which she worked part-time at St Luke's Home for the Dying Poor in Bayswater. This stimulated her to study medicine, qualifying in 1957. She recognised how little attention was devoted to the needs of the dying and the medical neglect of patients dying of cancer.

She worked to draw attention to the suffering and needs of the terminally ill and identified the importance of a new and dedicated approach to end-of-life care.

Crucial was the need to render patients pain-free and she described '***total pain***' as the sum of the patients' physical, psychological, social and spiritual pain.

St Christopher's became a centre of excellence and training of terminal care physicians.

The word '***palliative***' came into use, derived from the French "palliare" meaning to cloak or shield, suggesting protection from suffering for patients with life-threatening illness.

It developed rapidly and was recognised as a speciality in the UK in 1987. The WHO subsequently recognised palliative care as a speciality. It is defined as:

> *"An approach that improves quality of life of patients and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual".*

There are now about 220 hospices in the UK. National Charitable Organisations, ***Marie Curie Cancer Care*** and ***The Sue Ryder Foundation***

have also played an important part in provision of care for terminally ill patient and their families.

Today the UK can be proud of its end-of-life care and owes huge thanks to all those who have worked so hard to achieve it.

Cicely Saunders' legacy endures in hospitals, care homes and hospices throughout the UK and the world. One of her famous quotes summarises her ethos and her persistence

> *"You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die."*

Saunders' mantra is essential wherever death occurs. The most recent date shows that about:

- 28½% of people now die at home overall;
- nearly 5% in a hospice;
- about 44½% in hospital,
- nearly 21% in a care home and
- about 2½% in another place.

Perhaps unsurprisingly, of those dying at home, about 39% are under 65 whilst the number over 85 doing so is about 23%.

Wherever someone dies, it should be peaceful, comfortable, pain-free and with emotional support.

Although the hospice is specifically geared to providing this care and tranquillity, a death surrounded by a loving family or the caring staff in a care home can provide much the same support.

It is essential that the authorities commissioning such services in care homes and from other providers, should ensure that the specialist and generalist palliative care from employed staff is adequate and appropriately trained.

Family support and education, training and support for care home staff must also be provided and maintained.

In addition the specialist-trained palliative care nursing staff, working both in the hospital, in the care homes and in family homes, provide an essential component of the final period of life.

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