Medicine for Managers

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Palliative Care

Anyone facing life-threatening and life-limiting illness will need supportive care in addition to treatment for their condition. Where a cure cannot be achieved, supportive care is provided to ease symptoms and to help the patient and the family cope with any condition from its development and including treatment, support and encouragement during continuing illness, death and bereavement.

Palliative care really has its roots in the hospice service, the first purpose-built of which was founded by Dame Cicely Saunders in 1967.

Dame Cicely Saunders

In the UK there are now about 1,750 hospices for adults and children. However, increasingly comprehensive palliative care services are continuing to develop in the primary care sector.

Palliative Care includes many components of supportive care and may be defined as follows:

Palliative care is the active holistic care of patients with advanced progressive illness. It includes the provision of psychological, social and spiritual support. The goal of palliative care is the achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of an illness in conjunction with other treatments.

The deterioration in the health of someone is always distressing for family and friends and it is important that the patient has the best possible experience during their last illness. The key to effective palliative care is successful control of physical and psychological distress.

This will include the management of physical symptoms including pain, nausea, constipation, breathlessness, sleeplessness

and agitation. Drug therapy has become very skilled and palliative care teams can use powerful narcotics safely whilst maintaining the patient's full faculties and function.

The process is about helping the patient to find peace and to accept dying as a normal process. The management of the terminal care should be to help the patient to live as normally as possible until death. It is also important to try to support the family during the person's last illness and whilst they cope with their grief during the bereavement period.

At an administrative level the form DS1500 (issued when a patient is suffering from a potentially terminal illness, i.e. death will reasonably be expected to occur within six months) should be completed as soon as applicable to ensure that the terminal care allowance is obtained.

Palliative care may be provided in a hospice, in the patient's own home or a residential home, as a hospice day patient or in a hospital.

Hospice care is usually reserved for the last few days or weeks before death and provides a calm, relaxed atmosphere where the dying can receive support from a team of doctors, nurses, physiotherapists, occupational and complementary therapists.

Hospices are smaller and quieter than hospitals and they are designed to feel like home. Access to hospice care is organised by a patient's GP, hospital doctor or the Macmillan or district nurse.

MacMillan Cancer Support may be contacted at:

MacMillan Cancer Support
89 Albert Embankment
London SE1 7UQ
www.macmillan.org.uk
telephone 0207 840 7840
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These days most palliative care is provided at home and in residential homes, much of it by the GPs and the specialist palliative care teams.

These are often led by the MacMillan staff, who are highly trained specialist registered nurses and who provide leadership and expertise.

Many MacMillan nurses are non-medical prescribers who have considerable skill in managing the pain relief for those patients suffering intractable pain from malignant disease.

Many patients wish to spend their last days at their homes and to die with their families.

The management of the care of terminally ill patients is guided by the Gold Standards Framework, which is a standard of excellence to which clinicians should aspire in respect of communication, symptom control, continuity of care, carer support and, crucially, care in the dying phase.

For some patients a compromise is to continue to remain at home but to attend a hospice as a day patient where they can receive care including conventional medicine and complementary therapies, rehabilitation and nursing care. There they can also meet other patients.

For some patients the hospital provides a further option and palliative care teams, sometimes called MacMillan support teams or symptom control teams, may include doctors, nurses and a whole range of other medical staff, together with social workers and religious support.

Coping with a death may result in serious emotional strain particularly during the bereavement. Care will extend into the period following the death and bereavement counselling may be available through the MacMillan and other services.

The Quality and Outcomes Framework recognises the importance of Palliative Care and gives three points (PC001) if the practice has a complete register available of all patients in need of palliative care/support. A further three points (PC002) is available when practices have regular (at least three monthly) multidisciplinary case review meetings where *all* patients on the palliative care register are discussed.

Good palliative care, which derives its name from the Latin word *Palliare*, meaning to cloak, has dramatically reduced the suffering associated with severe symptoms of malignant and degenerative disease and has improved the quality of life for many people facing serious, complex or terminal disease.

It has truly revolutionised the quality of end of life care.

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