



Introduction

Palliative care is a term commonly associated in some peoples' minds with the end stages of diseases like cancer. For many it wrongly signifies a time of no hope where prognoses are whispered, eyes are downcast and heads are shaken.

In fact palliative care is much more widely applied than is commonly recognised and is not necessarily a notification of days or weeks to live.

Definition of palliative care

The popular on-line encyclopaedia "Wikipedia" defines palliative care as:

"Palliative care (from Latin palliare, to cloak) is any form of medical care or treatment that concentrates on reducing the severity of disease symptoms, rather than striving to halt, delay or reverse progression of the disease itself or provide a cure. The goal is to prevent and relieve suffering and to improve quality of life for people facing serious, complex illness. Non-hospice palliative care is not dependent on prognosis and is offered in conjunction with curative and all other appropriate forms of medical treatment. In the UK hospices and non-hospice-based palliative care teams both provide care to those with life limiting illness at any stage of their disease."

The World Health Organisation, meantime, defines palliative care as:

"Palliative care is an approach that improves the quality of life of patients and their families facing the problems

associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care:

- *provides relief from pain and other distressing symptoms;*
- *affirms life and regards dying as a normal process;*
- *intends neither to hasten or postpone death;*
- *integrates the psychological and spiritual aspects of patient care;*
- *offers a support system to help patients live as actively as possible until death;*
- *offers a support system to help the family cope during the patients illness and in their own bereavement;*
- *uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;*
- *will enhance quality of life, and may also positively influence the course of illness;*
- *is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications."*

The aim of palliative care is to make patients, and their families, comfortable in all departments of their life including the

MND Scotland is the working name of The Scottish Motor Neurone Disease Association and is the only charity registered and working in Scotland for the relief of Motor Neurone Disease. Scottish Charity number SC002662

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spiritual and psychological as well as physical, when little can be done to cure their illness.

The need for palliative care

In Motor Neurone Disease (MND) palliative care is often thought of as beginning at the time of diagnosis since the treatment of symptoms, or “palliation,” is the only option available to medical staff at present. Palliative care in MND does not, therefore, necessarily imply the patient is in the last days of life as is often the case with cancer patients.

Dr David Oliver is an MND palliative care specialist and Consultant Physician in

Palliative Medicine at Wisdom Hospice in Rochester, Kent. Dr Oliver reports that the symptoms experienced by MND patients are often on a par and sometimes more frequently occurring than the same symptoms in cancer patients; making MND patients every bit as deserving of palliative care and hospice care as are cancer patients.

He sees the role of palliative care in neurological patients as being to reduce the effects of the disease and maintain their remaining power in order to enable the patient and their family to live lives as full as possible.

Frequency of Symptoms in Each of the Groups

	MND	Cancer
Pain	94%	35-96%
Depression	44-75%	3-77%
Dyspnoea (Breathlessness)	85%	10-70%
Dysphagia (Swallowing problems)	56%	35%
Constipation	53%	23-65%

Table 1. A comparison of symptoms as experienced by groups of patients affected by either MND or cancer. (D Oliver 2007)

The providers of palliative care

In the UK both hospice care and non-hospice palliative care are generally provided by interdisciplinary teams consisting of physicians, nurses, social workers, physiotherapists, chaplains, occupational therapists, complementary therapists, and volunteers who specialise in working with the terminally ill. Missing from the above list, but probably the most important group in palliative care, is the family. This team's aim should be to optimise the patient's comfort.

Each hospice and palliative care centre has its own arrangements and not all services are necessarily provided from each centre as some coordinate with volunteer agencies or local health boards to provide some services.

Palliative care services are sometimes offered from hospitals as well as hospices and often offer respite services, in the form of inpatient care, home care and day care. Some also offer outpatient

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services. Hospital palliative care units usually work in close partnership with the mainstream hospital services while hospices often house a full range of their own palliative care services and professionals.

There are 14 hospices in Scotland which are run by voluntary organisations. As part of the independent healthcare sector, they are subject to regulation by the Scottish Commission for the Regulation of Care ('the Care Commission'). The hospices have charitable status and make no charge to the users of their services. They all receive part of their running costs from the NHS and all work in close partnership with local NHS services. Involvement doesn't necessarily have any health related significance for you. For example, the occupational therapists at St. Andrew's Hospice's in Airdrie recently ran a project to provide educational and occupational opportunities for people affected by terminal conditions, but still well enough to travel to local community and education centres to participate in activities such as art lessons.

The very nature of MND means that for much of their illness most people with MND will be cared for at home by relatives and local services such as their own GP, local district nurses, OTs and so on.

In the early stages of the condition this might not cause any problems, but as the disease progresses and more equipment is employed to help maintain mobility and quality of life the family's home life can

start to become lost amongst the specialist appointments and the equipment. Day care and respite care are intended to help families cope with this kind of situation by giving the family and carers some breathing space to re-organise themselves and by giving the person with MND the opportunity for specialist therapies that might not be available to those at home.

Accessing palliative care services

Your MND Care Team Member will usually have strong links with the hospice or palliative care unit closest to where you live and will know what services the staff there can offer to benefit you and your family and when the time is right to get them involved, however referral to a hospice is usually done by your GP or hospital consultant. See also our factsheet 42 'Being a Carer,' for information about "Carer Assessments" as a way of obtaining extra resources to help with caring at home and for information about organisations such as Crossroads Scotland which can also provide short periods of care at home for respite purposes.

If you feel you or your family might benefit from day care, day hospice or respite care speak to your MND Care Team Specialist, District Nurse or GP about what services are available in your area. All of the Scottish hospices have websites where you can find out about the availability of the services they offer. However there are many local palliative care units and teams attached to hospitals which do not have their own separate listings on the internet.

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Hospice Address and Phone Number	Web Site
Accord Hospice , Hawkhead Road, Paisley PA2 7BL Tel: 0141-581.2000	www.accord.org.uk
Ardgowan Hospice , 12 Nelson Street, Greenock, PA15 1TS Tel: 01475 726830	www.ardgowanhospice.org.uk
Bethesda Hospice , Springfield Road, Stornoway, Isle of Lewis, HS1 2PS Tel: 01851 706222	www.bethesdahospice.co.uk
Edinburgh Marie Curie Hospice , Frogston Road West, Edinburgh, EH10 7DR, Tel: 0131 470 2201	http://hospiceedinburgh.mariecurie.org.uk/ and www.mariecurie.org.uk/
Glasgow Marie Curie Hospice , 1 Belmont Road, Hunters Hill, Glasgow G21 3AY, Tel: 0141 531 1300	http://hospiceglasgow.mariecurie.org.uk/ and www.mariecurie.org.uk/
Highland Hospice , Ness House 1 Bishops Rd, Inverness, IV3 5SB Tel: 01463 243132	www.highlandhospice.org
Prince & Princess of Wales Hospice , 71 Carlton Place, Glasgow, G5 9TD Tel: 0141 429 5599	www.ppwh.org.uk
Rachel House Children's Hospice Avenue Road Kinross KY13 8FX Tel: 01577 865777	www.chas.org.uk/rachel-house and www.chas.org.uk
Robin House Children's Hospice 2 Boturich Road, Balloch Dunbartonshire G83 8LX Tel: 01389 722055	www.chas.org.uk/robin-house and www.chas.org.uk
St Andrews Hospice , Henderson Street, Airdrie, Lanarkshire, ML6 6DJ Tel: 01236 766951	www.st-andrews-hospice.com
St Columba's Hospice , Challenger Lodge, 15 Boswall Road, Edinburgh EH5 3RW, Tel: 0131 551 1381	www.stcolumbushospice.org.uk
St Margaret of Scotland Hospice , East Barns St., Clydebank G81 1EG, Tel: 0141 952 1141	www.smh.org.uk
St. Vincent's Hospice Midton Road, Howwood, Renfrewshire PA9 1AF Tel: 01505 705 635	www.svh.co.uk
Strathcarron Hospice Randolph Hill, Denny, Stirlingshire FK6 5HJ Tel: 01324-826222	www.strathcarronhospice.org
The Ayrshire Hospice 35 Racecourse Road, Ayr KA7 2TG Tel: 01292 269200	www.ayrshirehospice.org/

The information in this leaflet is believed to be accurate at the time of production, MND Scotland cannot give detailed medical advice, this leaflet should be regarded only as general background information.

Further Information

Help the Hospices is the leading charity supporting hospice care throughout the UK. Their website contains many useful educational materials and advice for family members providing palliative care

www.helpthehospices.org.uk

The Scottish Partnership for Palliative Care supports and contributes to the development and strategic direction of palliative care in Scotland and promotes improvements in service delivery at local level.

www.palliativecarescotland.org.uk

The Haven, a charity set up to provide a local 'drop-in' service to the people of Lanarkshire. (If you know of similar services local to you please let us know about them.)

www.thehavencentre.com

"Palliativecareglasgow" has been designed to help you find out about palliative care and who provides it in Glasgow.

www.palliativecareglasgow.info

Audit Scotland's review of palliative care services in Scotland (August 2008)

www.audit-scotland.gov.uk/docs/health/2008/nr_080821_palliative_care.pdf

Growth House is a subject gateway to palliative care and end of life resources on the Web, aimed at those with a life threatening illness. It is produced by Growth House, who aim to improve the quality of compassionate care for people who are dying through public education and global professional collaboration. The site includes a search facility, topic pages covering a range of subjects, and information for professionals.

www.growthhouse.org

Living and dying well : a national action plan for palliative and end of life care in Scotland is an action plan developed from the commitment made within the Scottish Government's 2007 action plan for health and wellbeing. 'Better health, better care' to the delivery of high quality palliative care across Scotland in a "consistent, comprehensive, appropriate and equitable manner across all care settings". This 46 page document was published by the Scottish Government in September 2008.

www.scotland.gov.uk/Publications/2008/10/01091608/0

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Factsheets

Factsheet 5A,	Assistive Equipment
Factsheet 5B	Maintaining Mobility,
Factsheet 5C	Getting the Best from Physiotherapy
Factsheet 5D	Aids to Maintain Mobility
Factsheet 6	Feeding Tubes
Factsheet 8	End of Life Issues
Factsheet 15A	Care at Home
Factsheet 21	Specialist Clothing
Factsheet 34	Adapting to Swallowing Problems
Factsheet 35	Breathing Matters
Factsheet 36	Oral Health
Factsheet 40	Ventilation in MND
Factsheet 42	Being a Carer
Factsheet 43	Useful Organisations