

# **REGISTRATION OF NURSING HOMES FOR PALLIATIVE CARE**

**Implications of the Scottish Core Standards**

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**The Scottish Partnership Agency for Palliative and Cancer Care  
brings together voluntary and statutory bodies concerned with palliative and  
cancer care services in Scotland:**

- Hospices and Specialist Palliative Care Services
- Health Boards and NHS Trusts
- National Charities & Support Organisations
- Professional Associations in Palliative Care
- Social Work Services

Through this partnership of 91 voluntary and statutory bodies the Agency promotes the development of palliative and cancer care provision, aiming to ensure that high quality care is available for patients and families throughout Scotland.

The Agency is an independent body with charitable status, set up in 1991.

For further information about SPA membership activities or publications:

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# **REGISTRATION OF NURSING HOMES FOR PALLIATIVE CARE**

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## **INTRODUCTION**

In 1994 the Scottish Partnership Agency published a Guide to Good Practice on Registered Nursing Homes and People with a Terminal Illness. It acknowledged the increasing role of registered nursing homes as a result of the policy of the Government of the time in relation to private health care and as a result of the growing elderly population. The guidance was drawn up for health boards, as registering authorities, on standards of care for people with terminal illness in nursing homes.

Core Standards for Nursing Homes in Scotland were issued by the Management Executive in 1997 which set out the minimum standards which all nursing homes would be required to achieve for all categories of resident, and for the first time introduced a registration category of Palliative Care. The SPA welcomed this development and undertook to review its Guide to Good Practice and to develop Core Standards for Nursing Homes Registered to Provide Palliative Care.

## **THE ROLE OF NURSING HOMES IN PALLIATIVE CARE**

### **The Total Spectrum of Care**

Palliative care is provided in a range of settings and the ultimate objective must be to provide a range of services capable of coping with and adapting to individual needs whether in the individual's own home, nursing home, hospital, specialist unit or hospice and to have in place the means to transfer and share skill and knowledge across these settings for the betterment of patient care.

### **All Nursing Homes**

Increasing numbers of people now spend the last months or years of their life in a residential or nursing home. Only a small proportion of them need the additional palliative care skills and facilities of a home registered for palliative care and the SPA envisages that only a small number of nursing homes will seek registration in the new category. All nursing homes however care for people dying from chronic and progressive conditions as well as from the multi-pathology of old age. Creation of the new palliative care registration category does not alter the need to ensure that all residents dying in nursing homes receive the best possible care for themselves and support for their families, respecting their dignity and privacy and rights to choice.

### **Nursing Homes Registered for Palliative Care**

The Core Standards make it clear that nursing homes registered in the new category will not be providers of specialist palliative care. Specialist palliative care is provided by hospices and specialist NHS units and teams and is delivered by a multiprofessional team led by clinicians with recognised specialist palliative medicine training. The nursing home's role will be to provide nursing care incorporating the palliative approach for residents admitted in the advanced stage of a progressive life-threatening condition. The Standards require that the nursing home

works in close consultation with the local specialist palliative care service and that arrangements are in place for access to specialist advice and for the transfer of residents if necessary.

Hospices in Scotland increasingly function as specialist palliative care units providing short term symptom management, respite or terminal care, rather than longer term care. This is reflected in an average length of stay for hospice patients of thirteen days. This change in hospice role, combined with the trend towards shorter hospital admissions and the reduction in availability of NHS continuing care beds, means that the demand for appropriate care in nursing homes seems likely to increase.

The ageing population and projected increases in the incidence of cancer will also affect the number of people likely to be needing palliative care in future. Whilst palliative care was developed largely for people with cancer it is equally applicable to people with a range of other progressive life-threatening conditions. Nursing homes registered for palliative care may have a particular part to play in the care of people with non-malignant disease who can benefit from the palliative approach.

Such nursing homes may be the place of choice for some when their continuing care needs cannot be met in the patient's home setting, and for those patients who no longer require continuing specialist palliative care input. They will have a part to play in respite and long term care and on discharge from hospital or specialist palliative care unit. The existence of homes registered for palliative care should increase the possibility for some people of being cared for nearer their home community. It should also increase the possibility of specialist palliative care beds being freed for those who require the expertise of the specialist team for management of physical, psychosocial or other problems.

## **Funding**

The cost of continuing care in a nursing home may in certain circumstances be met by the NHS. The criteria for eligibility for NHS funded continuing care are set out in Management Executive Letter NHS MEL (1996) 22 and include those who have finished acute treatment or in-patient palliative care in a hospital or hospice but whose prognosis is that they are likely to die in the very near future and for whom discharge from NHS care would be inappropriate. The Management Executive Letter makes it clear that where a patient meets the eligibility criteria for continuing NHS in-patient care but a bed is not available within the provision which has been contracted for, the agreement of the health board should be sought for an extra-contractual referral to another hospital, hospice or nursing home as close as is possible to the patient's own community. The health board will pay for such provision.

The ME criteria are open to local interpretation and the extent to which health boards and social work authorities have reached agreement locally varies around the country. Lack of agreement on local responsibility for funding the continuing care of palliative care patients continues, in some areas, to lead to delays and to significant distress for patients and families.

**\*\*All provisions within this section should be read with the general core standards for Nursing Homes set out in the Core Standards 1997 Guidance issued under cover of MEL(1997)34.\*\***

## **NURSING HOMES REGISTERED TO PROVIDE PALLIATIVE CARE**

### **Introduction**

The standards which follow set out the minimum required for registration for palliative care. They are supplementary to the Nursing Homes Scotland Core Standards and should be considered in conjunction with them.

The standards are for those nursing homes that currently provide care incorporating the palliative care approach, for residents admitted in the advanced stage of a progressive life-threatening condition and for those Homes considering that provision. Such homes will be assessed by these standards as part of the statutory registration and inspection process.

The new registration category of palliative care replaces the previous terminal illness category but it is not synonymous with it. All nursing homes provide terminal care but, depending on local circumstances, only a number of nursing homes in any Health Board area will be expected to apply for formal registration for palliative care.

This guidance adopts “will” in relation to many action requirements. Health Board registration and inspection teams should always have regard in this context that this does not limit the scope of the Homes to be responsive to individual residents’ needs.

The role of a Nursing Home registered for palliative care will be to provide basic palliative care, practising the palliative care approach, in consultation with local specialist palliative care services and with the patient’s General Practitioner. Nursing Homes registered in the new category will not be providers of specialist palliative care.

### **Definitions**

The World Health Organisation Definition of Palliative Care states;

Palliative care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and *help with* psychological, social and spiritual problems *are* paramount. The goal of palliative care is 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 the illness, in conjunction with anti-cancer treatment. Palliative care:

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- affirms life and regards dying as a normal process;
- neither hastens nor postpones death;
- provides relief from pain and other distressing symptoms;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death and;
- offers a support system to help the family cope during the patient's illness and in their own bereavement.

### **Forms of Palliative Care**

Basic palliative care: The palliative care approach, which should be practised by nursing homes registered to provide palliative care, aims to promote both physical and psycho-social well being. It is informed by a knowledge and practice of palliative care principles and supported by specialist palliative care. The key principles underpinning palliative care which should be practised by all health professionals caring for people with incurable progressive disease are:

- focus on the quality of life which includes good symptom control;
- a whole-person approach taking into account the person's past life experience and current situation;
- respect for patient autonomy and choice;
- care which encompasses both the person with life-threatening disease and those that matter to that person;
- an emphasis on open and sensitive communication, which extends to patients, informal carers and professional carers.

Specialist palliative care: is the active total care of patients with progressive, far advanced disease and limited prognosis, and their families, by a multi-professional team who have undergone recognised specialist palliative care training. It provides physical, psychological, social and spiritual support, including medical and nursing care, social work, pastoral/spiritual care, physiotherapy, occupational therapy, pharmacy and related specialties.

Specialist palliative care is provided by hospices and specialist palliative care units or teams.

### **Standards**

To provide palliative care a nursing home will need an appropriate staff/patient ratio, appropriately qualified staff, specialist equipment and good links with primary care and specialist palliative care services. At least one member of staff will have a Specialist Nurse

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Practitioner Qualification in Palliative Care or equivalent and be able to act as a co-ordinator/catalyst for the development and training of staff in palliative nursing care skills within the nursing home. Homes registered for palliative care have a place in the total spectrum of services by providing good basic palliative care, complementing specialist palliative care services and other NHS services.

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## **PHILOSOPHY**

1. A nursing home seeking registration for people requiring palliative care, will have a philosophy encompassing the following:
  - (i) Full recognition of the need for an holistic approach to palliation, including management of symptoms and psychosocial support. In this connection managers/owners will have regard to "Palliative Cancer Care Guidelines" published by the Clinical Resource and Audit Group and the Scottish Partnership Agency for Palliative and Cancer Care (1994), (see source documents).
  - (ii) An undertaking to make available core staff with knowledge and skills, to plan and co-ordinate care, recognising the need for the residents and their family/carers to be involved in this process. In this connection, the managers/owners will have regard to the "Report by the National Panel for the Dying and Bereaved - The Way Forward" (1997) and "Everybody's Death Should Matter to Somebody" A Review and Recommendations by a Working Group of the Scottish Health Service Advisory Council (1991), (see source documents).
  - (iii) An acceptance of and respect for the resident's social, emotional, religious, cultural, ethnic and personal needs, including where appropriate and requested arrangements for pastoral visits to the home by representatives of the residents' religious communities.
  - (iv) An undertaking to support residents and their family and friends throughout their stay and into bereavement, with appropriate skills and knowledge, and through liaison with local palliative care services and referral, where requested, and available, to bereavement counselling agencies. Links between the home and the local social work department and acute NHS Trust should also be established.
  - (v) A recognition that the GP has overall health care responsibility for the resident.

## **CARE STANDARDS**

2. **Nursing Assessment/Care Planning**
  - (i) For planned admissions of residents (or where there is a change of functional status of an existing resident) requiring a palliative care approach a pre-admission assessment will be carried out by a first level registered nurse from the nursing home in consultation as appropriate with the resident's GP and a

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member of the local specialist palliative care team. That assessment will as a matter of course take account of any care plan that was in place prior to admission or, in the case of existing residents before the change in the resident's functional status.

- (ii) On admission, an initial comprehensive assessment of each resident's needs will be made and documented by a registered nurse with the necessary skills, knowledge and experience to co-ordinate the provision of the palliative care required. (See 4(i)).
- (iii) Each resident will have an individual care plan initiated, wherever possible, within 12 hours but not later than 24 hours following admission (or where there is a change of functional status). The care plan will be completed and documented within 2 days. Where the patient's condition allows, the care plan will be developed by the multi-disciplinary team in agreement with the resident and, where the resident wishes, in consultation with his or her relatives/carers. The role of social work services will be taken into account in the preparation of the care plan. Written copies of the care plans will be available on request with the patient's consent, to the social worker or care manager involved in supporting the person, their family or carer, the GP, community nurse or professions allied to medicine involved in treating the person.
- (iv) Residents' care plans will be reviewed and documented at least weekly or more frequently in cases when the patient's functional status changes. Every effort should be made to conduct these reviews when the resident's named nurse is available to participate.
- (v) Residents will have access to specialist palliative care input in accordance with a policy agreed with the nursing home, the resident's GP and the local specialist palliative care services. Residents and their relatives will be informed about the policy agreed for referrals for specialist care.
- (vi) Specialist advice will be sought in those cases where the resident has a mental health problem.

### **3. Named Nurse**

- (i) All NHS patients in hospital or community settings will have a "named nurse", (paragraph 3.2.1, page 10 refers).
- (ii) The named nurse providing a palliative care approach, supported by the specialist nurse practitioner (see paragraph 4(i)) will be trained to such a level as to know when to seek advice from palliative care specialists and to initiate

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referral according to a pre-agreed policy with the resident's General Practitioner.

- (iii) The named nurse will maintain contact with relatives and offer ongoing support.
- (iv) The named nurse will be aware of other support available from the social work department (including for example welfare benefits advice, counselling etc) that may be able to assist the resident or their family and will keep a resource file available for consultation.

## **MANAGEMENT STANDARDS**

### **4. Staffing**

- (i) The registered person and person in charge will ensure that as a minimum, one member of staff within each home registered to provide palliative care has formal education and training in palliative care to specialist nurse practitioner level or equivalent, as defined by the UKCC\*. The person registered will provide evidence to the Health Board of the education and training undertaken. Where this person is not the person in charge, they will be directly accountable to the person in charge for the development of palliative care expertise.
- (ii) The specialist nurse practitioner will be the facilitator for assessments, for co-ordinating palliative care and for relevant in-house training of all staff (nurses, care assistants, ancillary and volunteers) on all aspects of the principles of palliative care. A record of the training programme (in house and other) and staff participation will be kept and be available for examination. (See paragraph 9).
- (iii) When residents are receiving palliative care within the home, the registered person must ensure that the staffing levels, skill mix, contingency and holiday cover arrangements meet those specified by the Health Board for the care to be provided.
- (iv) The staffing and skill mix at the home will reflect the additional workload entailed in providing palliative care.

(\*UKCC stipulate that all nurses are accountable for practice and that this has to be up-to-date)

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(vii) Recliner chair,

**And, as the needs of residents dictate;**

(viii) Oxygen,

(ix) Naso-gastric (NG) feeding pump,

(x) Intravenous infusion pump.

Specific recommendations on the availability of equipment in the community and about training and education is given in the document "Commissioning Cancer Services in Scotland - Primary and Palliative Care Services" (January 1997) (see source documents).

## **8. Source Documents**

- i. Cancer Pain Relief and Palliative Care. Report of a World Health Organisation Expert Committee. WHO, (1990).
- ii. Registered Nursing Homes and People with a Terminal Illness - A Guide to Good Practice. Report of a Working Group of the Scottish Partnership Agency for Palliative and Cancer Care, (1994).
- iii. Palliative Cancer Care Guidelines - Clinical Resource and Audit Group and the Scottish Partnership Agency for Palliative and Cancer Care (1994).
- iv. Management of Infusion Systems - SOHHD, (1995).
- v. Relief of Pain and Related Symptoms: The Role of Drug Therapy - Scottish Partnership Agency for Palliative and Cancer Care, (1995).
- vi. Palliative Cancer Care: The Integration of Palliative Care with Cancer Services. Report of a Working Group of the Scottish Partnership Agency for Palliative and Cancer Care, (1996).
- vii. A Report by the National Panel for the Dying and Bereaved in Scotland on Future Arrangements for the Care and Dying and Bereaved - The Way Forward, (1997).
- viii. Commissioning Cancer Care Services in Scotland - Report of the Scottish Co-ordinating and Advisory Committee Primary and Palliative Care Services, January 1997 - NHS MEL(1997)17, (1997).

**\*\*All provisions within this section should be read with the general core standards for Nursing Homes set out in the Core Standards 1997 Guidance issued under cover of MEL(1997)34.\*\***

- ix. Methicillin Resistant Staphylococcus Aureus in Community Settings (Scottish Office 16 May 1996).
- x. "Everybody's Death Should Matter to Somebody" - Review and Recommendations by a Working Group of the Scottish Health Service Advisory Council (1991).
- xi. NHS MEL(1997)66 - Commissioning Cancer Services in Scotland: Guidance on Pharmaceutical Services and Nursing Services (1997).
- xii. Standards of Care for Palliative Nursing - Royal College of Nursing (1993).

## **9. Postgraduate Courses**

Information on post graduate courses is available direct from the National Board for Nursing, Midwifery and Health Visiting in Scotland, 22 Queen Street, Edinburgh EH2 1JX.

## Appendix 2

### Membership of the Scottish Partnership Agency for Palliative and Cancer Care Working Party

Dr James Rodgers	Chairman Consultant in Palliative Medicine Borders General Hospital
Dr J Davie	Senior Consultant Geriatrician Stobhill General Hospital
Dr Catherine Dyer	Macmillan GP Facilitator Palliative Care Banknock Medical Centre
Miss Linda Easton	Nursing Home Inspector Forth Valley Health Board
Ms Anne Ferguson	Director Registered Nursing Homes Association
Mrs Lyn Forbes	General Manager Highland Hospice
Mr Paul Gibbons	Director of Corporate Assurance Argyll & Clyde Health Board
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