THE SCOTTISH OFFICE

Home and Health Department

PALLIATIVE CANCER CARE GUIDELINES

SCOTTISH PARTNERSHIP AGENCY
with the
CLINICAL RESOURCE and
AUDIT GROUP

SCOTTISH PARTNERSHIP AGENCY
FOR
PALLIATIVE AND CANCER CARE

The **Scottish Partnership Agency for Palliative and Cancer Care** brings together voluntary and statutory bodies concerned with palliative and cancer care to promote the enhancement and development of services for patients and families throughout Scotland. Its objects are

○ to establish and maintain effective links for communication among all those bodies involved with the provision of palliative and cancer care services in Scotland;

○ to facilitate the participation of voluntary sector groups and organisations in developing palliative and cancer care services in Scotland;

○ to facilitate planning, co-ordination, and consultation between the Partnership Agency's constituent members and the central departments of Government and related bodies; and

○ to encourage education and research to improve the quality of palliative and cancer care.

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FOREWORD

These guidelines on Palliative Cancer Care are concerned with the quality of care which should accompany the treatment of disease, and beyond. They should make a valuable contribution to the processes of purchasing and providing palliative cancer care with the goal of reducing the suffering of both patients and their families. They will also encourage and inform the proper audit and evaluation of the services provided.

The development of these guidelines has involved all the professions contributing to the partnership between the health service and the voluntary sector. They therefore reflect a broad consensus of opinion concerning good practice in palliative cancer care, and so can be used with confidence.

CRAG and the SPAPCC have enjoyed working together on this project. CRAG will maintain its interest in clinical provision holding, as it does, overall responsibility for monitoring use of the guidelines. The SPAPCC for its part will seek to facilitate discussion and implementation of these guidelines.

We commend these guidelines to purchasers, providers, and practitioners, so that by their use all who require palliative cancer care will have access to it and benefit from it.

T. J. Thomson.

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January 1994

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SECTION 1
THE GUIDELINES - PURPOSE AND PROCESS

> "You are entitled to the highest standards of care possible for yourself, your family, and your friends."
>
> The Patient's Charter

PURPOSE

1.1 These guidelines are published to facilitate the provision of palliative care so that it is available throughout Scotland, at the highest standards possible, to all those whose health and well-being can benefit from it. While it is true that palliative care is currently provided mainly for people suffering from cancer, it is increasingly recognised that people suffering from a range of other life-threatening diseases can also benefit from it.

1.2 These guidelines focus on palliative care for cancer patients, recognising that 1 in 3 people in the population in Scotland will develop cancer, and 1 in 4 will die from cancer. For this significant proportion of the population suffering can be reduced and quality of life enhanced by the provision of good palliative cancer care.

These guidelines should enable purchasers

- when undertaking needs assessment to recognise palliative care as an integral part of services appropriate for cancer patients and others;
- to recognise palliative cancer care as a potentially beneficial intervention for ensuring quality of life and reducing undue morbidity; and
- when negotiating contracts to ensure that the factors underpinning the effective provision of high quality palliative care, and the factors facilitating good practice in palliative care, are taken into account in contracts, and their implementation appropriately resourced.

These guidelines should enable providers

- ○ to recognise good practice in the nature, scope and standards of palliative cancer care currently provided by services and staff within their units;
- ○ to develop local protocols for palliative cancer care and secure matching resources; and
- ○ to ensure that organisational systems and resources are in place to allow the protocols to be implemented.

These guidelines should enable those who practice palliative cancer care

- ○ to become involved in the development of local protocols and their implementation;
- ○ to ensure, with provider management, that organisational systems, staff, and other resources are appropriate and sufficient for the implementation of the protocols; and
- ○ to establish mechanisms to monitor the application of the protocols and to evaluate their effectiveness.

PROCESS

1.3 The project was developed by a joint steering group of CRAG and the SPAPCC. Members are listed on Annex 1. The guidelines, and in particular the consensus statements in Section 4, were first developed at a workshop of professionals from all the relevant disciplines working in palliative cancer care (see Annex 2). Patients' views had been previously sought (see Annex 3) and are woven into the consensus statements. The method employed at the workshop is set out in Section 3.

1.4 The guidelines in draft form were then fully discussed and amendments made at a conference of 140 people from throughout Scotland (see Annex 4). Representatives came from health boards, NHS trusts, SOHHD, Royal Colleges, national charities, local voluntary organisations, consumer groups, and palliative and cancer care units and services. The Chief of Cancer and Palliative Care in the World Health Organisation acted as adviser and made a key presentation to the conference, bringing invaluable insights from a wider perspective.

1.5 The guidelines are now published jointly by the Clinical Resource and Audit Group of The Scottish Office Home and Health Department (CRAG) and the Scottish Partnership Agency for Palliative and Cancer Care (SPAPCC). They are commended to purchasers, providers and practitioners in order to facilitate

- needs assessments
- local protocols
- standard setting
- monitoring and review

1.6 Responsibility for the monitoring and maintenance of these guidelines will rest with CRAG. The SPAPCC will be available to advise those developing local protocols.

1.7 As with all clinical guidelines these should be seen not as the last word but as dynamic and evolutionary. Their overall purpose is to maximise the benefit for the greatest number of people and achieve the optimal standards of treatment and outcome, and the highest quality of care.

SECTION 2
PALLIATIVE CANCER CARE

2.1 DEFINITION AND FUNCTION

An Expert Committee of the World Health Organisation in 1990 drew up a definition of palliative care, stating its goal and indicating its function.

"Palliative care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best possible 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

- **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."**

It will be seen from this definition that palliative care is not somehow switched on at a particular point during the progression of the illness. Palliative care is provided across a range of settings and its functions are different at particular points.

- It may inform the approach to care in the early stages.
- Its knowledge and skills may benefit people's quality of life during curative treatment.

- It reaches its full potential when disease no longer responds to curative treatment.

These different functions of palliative care appropriate to the different stages of illness are set out in the consensus statements in Section 4.

Other terms used in relation to palliative care include

- palliative medicine - the medical practice of palliative care recognised as a speciality in the United Kingdom by the Royal Colleges of Physicians.
- palliative treatment - active treatment or intervention designed to relieve suffering resulting from disease. It may include treatment by radiotherapy, chemotherapy, or surgery.
- terminal stage - the stage when there is steady deterioration in the patient's condition and death is close.

2.2 HISTORY AND DEVELOPMENT IN SCOTLAND

2.2.1 The main period of development of units and services providing specialist palliative care began in Scotland in the 1970s. Before that the Marie Curie Memorial Foundation and the Order of the Sisters of Charity were providing care for people with cancer. Many of the initiatives in the voluntary sector led to the establishment of hospices. These initiatives received widespread and continuing support from local communities both in recruitment of volunteers and in financial provision.

2.2.2 Developments during the late '70s and early '80s in both the NHS and voluntary hospice sectors concentrated mainly on the provision of in-patient care during the terminal stage of illness. As it became clear that with effective pain control and sound support many people could be cared for at home, so home-care nursing services were developed by Cancer Relief Macmillan Fund and Marie Curie Cancer Care. In turn it was seen that home care nursing could be complemented by day care provision. Many hospices initiated day care and some offered day care prior to opening their in-patient units.

2.2.3 Specialist units for palliative care in the hospital setting were pioneered within the NHS with units in, for example, the Royal Infirmary, Dumfries.

Specialist nurses providing hospital support, liaison between hospital and community, or specialist breast care nursing are now developing the practice of palliative care in district general hospitals and regional cancer centres. Current palliative cancer care units and services in Scotland are set out in Annex 5.

2.2.4 The development of hospices, hospital units and palliative care services in the community required the recruitment of an increasingly wide range of professional staff. Many of the early initiatives in education and training were based in these units and services which also provided students with clinical placements. As a result the skills-mix of palliative care staff now includes clinical nurse specialists, consultants in palliative medicine, Macmillan and Marie Curie Nurses, clinical psychologists, social workers, chaplains, educators, physiotherapists, occupational and speech therapists and pharmacists. More education courses are provided or are being planned, to meet the increasing demand. More detailed reference to this is made at paragraph 4.1.5.

2.2.5 Accompanying this expansion in the number and range of professionals involved in palliative care has been the growth of support groups of people with cancer and their carers, and volunteer workers fulfil many roles. Although these early developments were largely unco-ordinated, leading to a wide variation in provision, all the bodies and organisations involved in palliative care are now seeking to collaborate through their membership of the Scottish Partnership Agency for Palliative and Cancer Care, established in 1991. The existence of the SPAPCC has helped to ensure that palliative care is on the agenda of the National Health Service in Scotland. The Scottish Cancer Co-ordinating and Advisory Committee, recently established by The Scottish Office Home and Health Department, recognises that palliative care services must be fully integrated as part of the total spectrum of services for cancer patients in Scotland.

2.2.6 When cancer services in Scotland were last the subject of a major review the report, published in 1979, acknowledged the need to include rehabilitation and terminal care within the spectrum of services. In a sense these two terms are today re-cast in the term palliative care and it is again recognised that palliative care is not an optional extra but a core component in cancer services.

2.3 Assessment of Need

2.3.1 Statistics available from Information and Statistics Division of the Common Services Agency provide details of the burden of cancer in the Scottish population, including geographic distribution and hospital of first treatment, for use in needs assessment and in developing strategies for care provision. Recent figures published jointly by the Cancer Research Campaign and the Scottish Cancer Registration Scheme show that in 1990 there were 31,000 new cases of cancer registered in Scotland. 15,000 people died from cancer in 1991. The 5 year survival rate for all cancers in Scotland from 1983-87 was 37% for men and 47% for women. Projected increases in the incidence of cancer during this decade are considerable.

2.3.2 Taken together, these statistics indicate that the need for increased provision of palliative cancer care must be carefully assessed and the resources required strategically planned. Selected statistics of cancer incidence in Scotland are set out in Annex 6.

SECTION 3
CONSENSUS GUIDELINE DEVELOPMENT

3.1 The method of approach to the development of consensus guidelines was planned by a steering group (see Annex 1) and the guidelines were initially drafted at a workshop attended by representatives of all of the professional disciplines working in palliative cancer care (see Annex 2).

3.2 Participants at the workshop were asked to consider and identify those factors which facilitate good practice in palliative care. To do this effectively discussion focused on the key points in a person's experience of cancer at which good practice in terms of active total care may be defined. These key points merge into 3 stages

- diagnosis and treatment
- discharge, care in the community, and recurrence of illness
- terminal stage of illness, dying, and bereavement support.

Key themes for good practice emerged which were common to each stage. These themes are dealt with in Section 4 as

- factors which underpin the effective provision of palliative care.

There were other factors specific to each stage. These are dealt with in Section 4 as

- factors which facilitate good practice in palliative care

3.3 A Palliative Care Matrix was provided at the workshop as a tool to bring together in a working relationship the range of agents conducive to effective palliative care, and the stages at which these various agents may be needed. The matrix is set out in detail in Annex 7 and is discussed in paragraph 4.1.8 below.

3.4 Following the workshop the draft guidelines in the form of consensus statements were circulated to all workshop participants for a further check before being produced as the draft guidelines for discussion at the Consensus Conference in April 1993. Delegates attending the Conference are listed at Annex 4. The guidelines now published are the result of a thorough process of discussion and consultation among those working in palliative care and also those working in related fields.

SECTION 4
CONSENSUS STATEMENTS

4.1 FACTORS WHICH UNDERPIN THE EFFECTIVE PROVISION OF PALLIATIVE CANCER CARE

4.1.1 FOCUS ON THE PATIENT

The Patient's Charter states unequivocally

> "You are entitled to be involved so far as is practical in making decisions about your own care, and whenever possible given choices".

In the effective provision of palliative care this patient-focused approach is far more than a commendation or entitlement. At the heart of palliative care is the belief that the involvement of the patient and family is an essential prerequisite to the planning and provision of care. Such involvement allows for the establishment and maintenance of an agreement between patient, family, and practitioners. In this context the uniqueness of each individual patient can be understood and respected to the point where an individual's choices about care can be identified and, wherever possible, met. Palliative care should follow the patient's chosen path and accompany the patient at his or her pace. These guidelines seek to address people's needs at whatever age. Section 4.3 is concerned specifically with the needs of children.

4.1.2 COMMUNICATION

The patient-focused nature of palliative care leads naturally to recognition of communication as the essential means of establishing and maintaining trust and confidence. Good communication begins with unconditional listening. It requires listening with care, clarifying questions and responding directly to them with openness and honesty. Communication is enhanced by the environment in which it takes place; by the availability of sufficient time; and by the attitude of the practitioner.

Patients should be able to talk about their illness whenever they wish although this need may be intermittent. The continuous availability of open lines of communication allows for the reception of information to develop into the perception of truth. Its function at this point is to encourage the capacities for coping and those inner and mutual strengths which bring therapeutic benefit. Good communication is essential at all of the key points of clinical contact. Failure of communication may prevent the development of relationships which can help sustain patients through their illness.

4.1.3 TEAMWORK

Palliative care is concerned with the whole person - a person's body, mind, emotions, social and family context and spiritual values. The interplay among all the components of the human condition is fully recognised in palliative care. It follows that the provision of palliative care, in order to meet the inter-related needs of the whole person, must itself be inter-related in its practice. Professional people with knowledge and skills ranging from medicine and nursing, the psycho-social and the spiritual, must act as a team with good communication and full co-ordination throughout. Each will know the function of their own skills. Each should understand the limitations of their own skills. Each should recognise the functions and potential of the skills of others.

4.1.4 Teamwork is essential as, over time, each patient encounters many different clinical contacts. Good communication between team members working in a range of different settings is a pre-requisite for continuity of care. Teamwork in palliative care is complex. As in all health care the general practitioner is the patient's doctor. Normally, in the provision of palliative care at home, the general practitioner will involve others in the team as necessary. Different team members will have greater involvement at various times. Specialists with particular skills may join the team briefly, or for specific purposes, and volunteers can provide support and companionship to complement the professional input. It is the patient himself or herself, together with spouse, family, or close friends who remains the central focus throughout. It is by continuing to focus on the patient that any team, however wide-ranging in skills or settings, will be able to ensure the quality of life and continuity of care which are the twin objectives of palliative care.

4.1.5 EDUCATION, TRAINING AND STAFF SUPPORT

Each of the factors which are needed to underpin the effective provision of palliative care are dependent on staff who can constantly refresh their attitudes, sharpen their skills, and up-date or deepen their knowledge. There is now a well developed body of knowledge in the field of palliative cancer care. Specific skills in pain and symptom management, in communication and psycho-social support, and in rehabilitation can be developed to varying levels appropriate to different situations. For example

- for those who encounter the need for palliative cancer care in general clinical practice or in other specialities;
- for those wishing to develop a special interest in the practice of palliative cancer care while remaining in general clinical practice or in other specialities; and
- for those intending to work full-time as specialists in palliative cancer care in hospital, hospice or community settings.

4.1.6 Those responsible for staff working in this field should ensure that sufficient opportunities are created for initial training, for clinical up-dating, and for professional development. Clinical directors and managers should also ensure that systems for management and support of staff are designed, established and maintained appropriately to meet the special needs which can be experienced among staff working in this field.

4.1.7 CARE FOR CARERS

The focus of palliative care on the individual patient must include those caring for the person in whatever setting or relationship. The needs of carers require to be known, understood and met. Any local protocol should identify local resources for carers' support, and ensure that the primary health care team, or social work care managers include this in their care plan.

4.1.8 QUALITY OF LIFE AND CONTINUITY OF CARE

The goal of effective palliative care is the achievement of the best quality of life for patients and their families, through a continuous process of care. This requires both careful planning and continued review of the provision of care. The Palliative Care Matrix (see annex 7) sets out the axes along which the components of quality of life and continuity of care are set in a matrix relationship with 6 key points of clinical contact. The matrix helps to clarify the components of care needed at each stage. Its use will encourage structured discussion and agreement about the factors which make for good practice in palliative cancer care. The matrix is proposed as a tool to assist in the development of local protocols and the review of palliative care provision.

4.2 FACTORS FACILITATING GOOD PRACTICE IN PALLIATIVE CANCER CARE

4.2.1 At diagnosis and during treatment

○ **an understandable explanation**

The patient's right to a truthful diagnosis should be respected. The Patient's Charter states

> "You are entitled, if you want, to accurate, relevant and understandable explanations of:
>
> ○ what is wrong
> ○ what the implications are
> ○ what can be done
> ○ what the treatment is likely to involve
>
> and, if you wish, a second opinion."

○ **the implication of symptoms**

General practitioners should ensure that there is adequate time and opportunity for discussion of the implication of symptoms and exploration of the patient's initial reactions and questions.

○ **patient's current understanding**

General practitioners should ensure that consultants are aware of the information already given, and the probable level of the patient's current understanding of their situation.

○ **rapid diagnosis**

All hospital investigations should be conducted as soon as possible. Appropriate resources for rapid diagnosis must be available and specific time should be set aside for urgent referrals. There should be no avoidable delay in informing the patient and the GP after diagnosis is made. There should be no avoidable delay in initiating treatment where treatment is necessary.

○ **trust and confidence**

Consultants should ensure that the environment of the diagnostic consultation and the way in which the diagnosis is conveyed to the patient are conducive to establishing trust and confidence. The presence of a spouse or friend may be helpful. When appropriate information should be provided for the patient to keep. This may be a leaflet or a tape recording.

○ **grounds for hope**

Communication of a truthful diagnosis should be made in such a way as to promote a positive outlook and to allow for appropriate use of denial by the patient. Those communicating a diagnosis should be sensitive to the patient's psychological needs which may change with time.

○ **consistent response**

There must be effective and rapid communication among all members of the hospital and community teams to ensure a consistent response to the patient's questions. The patient should always have access to members of the health care team.

○ **plan for management**

The complete diagnosis and plan for management should be communicated to the general practitioner as soon as possible. The hospital's interpretation of the patient's understanding of the plan for management should be conveyed at the same time.

○ **right to confidentiality**

The patient's right to confidentiality must be respected. The patient should be the first to know the diagnosis unless there are exceptional circumstances.

○ **sources of support**

The patient should be advised of sources of support including the resources of other professions, and the availability of support organisations.

○ **treatment options**

All available treatment options should be fully set out in discussion with the patient. Informed consent should be sought for any treatment to be used, and the right to refuse treatment should be respected.

○ **symptom management**

It should be made clear that appropriate symptom management will be provided both during treatment of the disease and afterwards.

○ **the patient's carers**

The needs of the patient's carers for support should be assessed and decided jointly between the family, hospital or hospice staff and the primary health care team together with a social work assessor. Appropriate levels of support should be planned at an early stage and provided as soon as the need arises.

4.2.2 ON DISCHARGE FROM HOSPITAL - CARE AT HOME - WHEN ILLNESS RECURS

○ **continuity of care**

Discharge planning undertaken between hospitals and community should begin on admission and the patient and relatives should be involved. Necessary information should be communicated from one setting to the other to facilitate continuity of care.

○ **key contact and key carer**

After discharge the primary health care team should agree with the patient and the carer who should be their contact person responsible for co-ordinating services. Also the key carer in the home/family setting should be identified and links between the contact person and the key carer should be forged.

○ **assessment of needs**

As soon as the patient returns home there should be an assessment of needs with particular reference to current or anticipated pain and symptom management, emotional and psychological support, equipment, and financial and related resources required. The situation should be regularly reviewed. Health service and social work personnel will need to collaborate in the assessment and review of need. The National Health Service and Community Care Act 1990 is relevant at each stage.

○ **rehabilitation**

Rehabilitation concerning the activities of daily living and communication should be given early consideration where appropriate. The aim should be to enable patients to achieve maximum independence according to their abilities, habits, values and interests. The specialist skills and resources of physiotherapists, occupational and speech and language therapists can do much to re-establish and maintain quality of life.

○ **specialist palliative care services**

Identification of the patient's needs and of the appropriate resources to meet these needs may require advice and input from specialist palliative care services. Referral to a palliative care unit or service should be considered wherever possible before critical events occur.

○ **fear of being abandoned**

The fear of being abandoned can erode a patient's sense of well-being. Regular contact with the general practitioner or other key member of the primary health care team is desirable. The companionship offered by support groups should also be considered.

○ **when illness recurs**

When illness recurs the general practitioner should have quick and easy access to the hospital or hospice team for further assessment and help with management as required.

○ **crucial requests**

Throughout this period those in close professional contact with the patient should be sensitive to reading the signals given by the patient and carers. The patient or carer may communicate crucial requests for information, understanding or reassurance by metaphor, or non-verbally.

4.2.3 DURING THE ILLNESS - TERMINAL STAGE - BEREAVEMENT

○ **gentle acknowledgement**

When patients or relatives, perhaps in their growing acceptance of the situation, pose questions indicating their awareness that remaining life-span is short, gentle acknowledgement of the truth should be shared.

○ **unfinished business**

Acknowledgement will allow unfinished business to be attended to. Such business may range from making a will and other financial arrangements to reconciliation of broken relationships. Expert help should be made available if requested.

○ **choices of setting**

The aim is to make it possible for the patient's choice of setting at this time to be respected. Allowances should be made for a change of mind by the patient and the carers.

○ **companionship**

The dying patient may fear being alone. As far as possible such fears should be allayed, reassurance given and suitable arrangements made. The patient's preference for a particular member of the team should, so far as possible, be recognised and respected.

○ **specialist palliative care services**

Throughout this time the effectiveness of pain and symptom management should be kept under constant review along within the level of psycho-social, spiritual, and family support. This will normally be done by the primary health care team and relatives. Later they may need to refer to specialist palliative care staff or services for advice or support.

○ **speedy and flexible responses**

Specific needs for equipment, home help, night-sitter, may develop suddenly. Prior planning should attempt to anticipate this with arrangements made for a speedy and flexible response.

○ **anticipatory grief**

The patient, spouse, close relatives and friends may begin to experience a sense of loss (anticipatory grief) before a person dies. Acknowledgement of this and discussion with someone skilled in counselling can reduce the risk of undue suffering later on.

○ **other cultures - ethnic groups - religious faiths**

A patient whose roots are in another culture, who belongs to a specific ethnic group, or whose religious faith is expressed in specific practices, should be enabled to receive the support and care available from the relevant church, ethnic community, or cultural institution.

○ **at the time of death**

When dying takes place in hospital or in a home or hospice, relatives and close friends should be able to be present and to have privacy. Professional support should always be available nearby.

○ **care after death**

Professional staff should be ready to undertake a range of tasks immediately after death takes place. These will include arranging for viewing the body in suitable surroundings; answering questions about the cause and manner of death; providing necessary certificates speedily; and assisting if necessary with contacting relevant agencies, e.g. funeral directors.

○ **inform the GP**

When death has occurred away from the home setting, a system should exist to inform the GP, district nurses and others involved in the person's care within 24 hours. Conversely when death occurs at home the hospital should be informed.

○ **invitation to return**

When death has occurred in a hospice or hospital relatives may wish to return or keep contact with staff. This wish may not be expressed and so an invitation to return should be offered.

○ **grief reaction**

In the early stages of bereavement the primary health care team and other related professionals should identify those who may experience grief reaction. The help of clinical psychologists, clergy or bereavement counsellors should be offered. It should be recognised that after the initial stages of bereavement many people feel abandoned. The need for continuing support should be identified wherever possible and help offered.

4.3 SPECIAL NEEDS OF CHILDREN

4.3.1 Children have distinctive needs for palliative care both as patients themselves and when a parent, brother or sister or other close relative is the patient. The number of children developing cancer each year in Scotland is small, and cancer services for this group of patients are well developed. These are based at the three United Kingdom Children's Cancer Study Group centres. A co-ordinated team approach is the normal practice so that ongoing care and, where appropriate, palliative care is provided by members of the same team. This is possible because a much higher proportion of children than adults with cancer can be cured. The number in need of palliative care is consequently relatively small. (Children however suffer from a number of often inevitably fatal diseases eg chronic neurodegenerative disorders, where the principles of palliative care are equally relevant.)

4.3.2 Communicating with children and their families places distinctive demands on members of the team who must consider

○ the needs of the parent or carer of the child;

○ the needs of the children of cancer patients;

- the developmental stage and needs of the child; and
- the effect on siblings and the family network.

4.3.3 Needs of the Parent or Carer

Some parents require help with finding ways in which to communicate effectively with their sick child. Support is essential to help to maintain open communication and give them confidence at a time when they may otherwise feel quite helpless.

4.3.4 Needs of the Children of Cancer Patients

The needs of children when a parent or carer has cancer are sometimes neglected in the belief that they are too young to understand or that their natural resilience will carry them through. Support should be available to enhance open communication, appropriate to the child's level of understanding, within the family both during illness and in bereavement. Counselling should be available for children when necessary and the help of a child's school teachers should be obtained.

4.3.5 Developmental Stage and Needs of the Child

The developmental stage of the child patient or child of a cancer patient should be fully taken into account in assessing the needs of the family as a whole and in attempting to meet these needs.

4.3.6 Effects on Siblings and the Family Network

The impact of diagnosis and treatment of a child with cancer on the family members, including the extended family, should be considered and support offered. Treatment centres have self-help support groups for parents and short-term groups for siblings. The needs of bereaved families can often be successfully addressed in a support group.

4.3.7 Resource Material

A lot of written material is available for children and young people which includes information about the disease and also about feelings. The Malcolm

Sargent Cancer Fund for Children and The Butterfly Programme are sources of books and videos suitable for children of various ages.

4.3.8 Adolescents

Currently the needs of this group are not well served. When inpatient treatment is necessary adolescents often are either too old for, and feel out of place in, children's wards or are too young and equally inappropriately placed in an adult ward. The aim should always be to try to meet the needs and wishes of the individual, ideally in an adolescent unit. The emotional trauma of diagnosis and treatment may be particularly acute for an adolescent. Anxieties about body image are common and should be addressed along with the patient's other needs. Appropriate support should be given. The adolescent patient's right to confidentiality and privacy should be respected and decisions about treatment should take into account the wishes of the young patient in the same way as for an adult.

4.3.9 Choice of Setting for the Terminal Stage of Illness

As with the adult patient the wishes of the family and the patient should be respected, recognising that changes of mind may occur.

4.3.10 Teamwork - the extended network

In paediatric oncology as in other cancer services the need for a team approach is paramount. This should extend from within the treatment centre to the team in the community and should include appropriate school staff who may know the patient and have ongoing contact with siblings.

SECTION 5
IMPLEMENTATION - RESOURCES

5.1 RESOURCES

The resources required to provide palliative cancer care include

- specialist staff, units, and services
- organisational systems
- education, training and staff support

5.2 STAFF, UNITS AND SERVICES

Staff with specialist training in palliative cancer care are mainly nurses and doctors. Paramedical staff, social workers, and chaplains have also developed special expertise, and some professional staff are developing skills in certain complementary therapies. Specialist staff may be based in, or available in different settings in a range of different services. These include

- the community, and community hospitals
- surgical, medical, and gynaecological wards in district general hospitals
- palliative care units in or associated with district general hospitals
- regional cancer centres
- hospices, including inpatient and day care services
- nursing and residential homes

Staff working in general clinical practice or in other specialities may also develop a special interest in the practice of palliative cancer care, providing this in their own setting. They often work with the support and under the guidance of a specialist in palliative care.

5.3 ORGANISATIONAL SYSTEMS

Patients who need palliative cancer care may move through many and sometimes all of the settings described above. Systems ensuring communication between all of these settings are essential, to give patients a sense of continuity of care and to ensure fully effective progression of treatment. The information provided to the patient and the carers should be clear and accurate enabling them to retain a sense of autonomy and involvement in decision-making at each stage.

5.4 Palliative care should be provided according to protocols derived from these national guidelines and agreed locally. The operational policies of each unit or service involved should be known to and fully understood by every other.

5.5 EDUCATION, TRAINING AND STAFF SUPPORT

This is dealt with above, at paragraph 4.1.5.

SECTION 6
IMPLEMENTATION - MONITORING, EVALUATION AND AUDIT

6.1 It is the objective of these guidelines to facilitate the provision of palliative care so that it is available throughout Scotland, at the highest standards possible, to all those whose health and well-being can benefit from it.

MONITORING

6.2 The Clinical Resource and Audit Group will have overall responsibility for the monitoring and review of the use made of the guidelines. In doing so CRAG will take advice on the effectiveness of the guidelines from, among others, the Scottish Partnership Agency for Palliative and Cancer Care. The objectives of monitoring the use of the guidelines and of evaluating their effectiveness are

- to ensure that appropriate purchasing strategies for palliative care services are in operation throughout Scotland;
- to facilitate the establishment and maintenance of audit, including quality of care and patient outcomes; and
- to evaluate palliative care provision against assessed needs.

6.3 NEEDS ASSESSMENT

Purchasers must undertake an assessment of the burden of cancer within their population and the consequent need for cancer care. It is widely accepted that about 70% of cancer patients will require palliative care. The statistics required for needs assessments and guidance on their interpretation are available from the Information and Statistics Division of the CSA (see paragraph 2.3 above and Annex 6). SPAPCC is aware that, by Spring 1993, Grampian and Highland Health Boards had undertaken palliative care needs assessments, and Greater Glasgow Health Board had included palliative care in its cancer needs assessment.

6.4 THE PURCHASING STRATEGY

These guidelines, and particularly the consensus statements set out in Section 4, are recommended for use by purchasers to establish the nature, scope and range of palliative care services required for their population. The guidelines indicate the key points of clinical contact and the range of provision which is required at each. They also outline the agents available for effective palliative care provision, the skill-mix of personnel, and the range of services appropriate both for hospital and community. The purchasing strategy should be worked out in joint discussion between purchasers and existing or potential providers.

6.5 LOCAL PROTOCOLS

Palliative care services should be provided according to protocols which are consistent with these guidelines and agreed locally. Within each service the optimal standard of care should be agreed having regard to current knowledge about the most effective and efficient practice and to the available resources. Clinical audit should be included in each contract, to enable the quality of care and clinical outcomes to be demonstrated and continuing improvements in patient care to be secured.

6.6 CLINICAL AND OTHER OUTCOMES

The aims of palliative cancer care include

- relief of undue suffering
- enhancement of quality of life
- provision of choice in the management of the illness and its consequences.

Achievable and measurable outcomes include

- It should be possible to achieve control of pain for 95%-98% of those suffering cancer pain.
- Within 24 hours of transfer from hospital to home the GP should receive information indicating what the patient understands of his condition; diagnosis and prognosis; present medication; and guidance on re-referral.
- It should be possible to measure to what extent expressed desires about the place of death are met, and if not met, to identify why not and to take action to improve the situation.

Other outcomes are equally desirable, but are more difficult to measure. Measures which include qualitative and anecdotal material should be developed. Such outcomes might include among others

- maintaining a person's sense of autonomy and involvement in making choices and decisions about the management of illness;
- health gain measured by a reduction of severe morbidity among the bereaved; and
- the use of coping strengths in individuals and among families in facing distress and grief.

SECTION 7
CONCLUSION

The provision of good quality palliative cancer care can reduce the burden of suffering for many people with cancer and also for those who care for them. Pain and physical symptoms can be controlled, and the capacity of people to cope with illness can be invoked with remarkable effect. These guidelines have been developed and are now recommended as a means of improving the whole experience of cancer among the population of Scotland.

ANNEX 1

GUIDELINES PROJECT STEERING GROUP

Chairman:	Dr John Berkeley	SPAPCC
Members:	Mrs Eileen Barnwell	CRAG
	Miss Jeanette Davidson	SOHHD
	Mr Tom Scott	SPAPCC
	Mrs Margaret Stevenson	SPAPCC

ANNEX 2

WORKSHOP PARTICIPANTS

The following people took part in the Workshop on 26/27 February 1993 at which draft guidelines were prepared.

Chairman:	Dr John Berkeley Deputy Chairman Scottish Partnership Agency for Palliative and Cancer Care
Participants	
Ms Lynn Adams	Clinical Nurse Specialist, Beatson Oncology Centre
Mrs Rae Allen	Community Nurse, Forth Valley
Professor Ann Barrett	Professor in Radiation Oncology, Western Infirmary, Glasgow
Mrs Isobel Bassett	Area Speech & Language Therapist, Dumfries & Galloway
Mr Joe Burns	Malcolm Sargent Cancer Fund Social Worker, Aberdeen
Ms Kate Copp	Macmillan Nurse Tutor, Foresterhill College
Dr M A Cornbleet	Department of Clinical Oncology, Western General, Edinburgh
Ms Cara Downie	Macmillan Liaison Nurse, Perth Royal Infirmary
Mr John Dunne	Consultant Clinical Psychologist, Forth Valley
Mrs Jenny Eldrett	Macmillan Co-ordinator, Highland
Mrs Dawn Foxley	Macmillan Nursing Co-ordinator, Fife
Ms Caroline Hamilton	Social Worker, Strathcarron Hospice

Mr Douglas Harper	Consultant Surgeon, Falkirk Royal Infirmary
Dr Derek King	Consultant Haematologist & Oncologist, Aberdeen Royal Hospitals Trust
Dr Martin Leiper	Consultant in Palliative Medicine, Tayside
Ms Jean McAlpine	Physiotherapist, Strathcarron Hospice
Ms Ruth McMinn	Senior Occupational Therapist, Aberdeen Royal Hospitals Trust
Mrs Freda Main	Chair, Scottish Cancer Support Groups
Ms Cathy Meredith	Lecturer in Radiotherapy Radiography, Queens College, Glasgow
Dr David Millar	General Practitioner, Peterculter, Aberdeen
Mrs Evelyn Miller	Manager, CancerLink
Rev. David Mitchell	Chaplain, Hunter's Hill Marie Curie Centre
Rev. Gillian Morton	Chaplain, Borders General Hospital
Dr Scott Murray	Department of General Practice, University of Edinburgh
Miss Molly Parsons	Matron, Strathcarron Hospice
Mrs Diane Simpson	Social Worker, Grampian Regional Council
Ms Sheila Stark	Dietician, Beatson Oncology Centre
Mrs Margaret Stevenson	Scottish Partnership Agency
Mrs Dora Storey	Matron, Ayrshire Hospice
Mr Tom Scott	Scottish Partnership Agency
Mrs Pamela Warrington	Deputy Chief Pharmacist, SOHHD
Dr John Welsh	Director of Medical Services, Hunter's Hill Marie Curie Centre
Sister Margaret West	Sister, Stobhill General Hospital
Dr Stanley Wright	Consultant Physician, Forth Valley

ANNEX 3

PATIENTS' AND CARERS' VIEWS

A group of patients and carers, all of whom were actively involved in cancer support groups, were asked to discuss the palliative care matrix and to make suggestions for good practice from their point of view. Their views were then fed into the Guidelines Workshop discussions and are summarised below in relation to each of the key points of clinical contact.

KEY POINTS OF CLINICAL CONTACT

Pre - diagnosis

Most patients and relatives were aware that cancer was a possible diagnosis, although this was not generally discussed by the doctor. Waiting for results of tests or the next appointment were seen as more stressful than actually being given a diagnosis of cancer.

Suggestions for good practice were made. These included

- Doctor (usually GP at this point) could discuss fears of possibility of cancer.
- Cut down wait for tests. It may be possible to include quality control measures such as maximum waiting time for chest x-rays, biopsy results, CT scan etc.
- Be given information on when results will be available, and how you will receive them eg clinic appointment, in the mail etc.
- Speed up results of tests eg phone, fax.
- Information on relevant support services, eg CancerLink, Breast Cancer and Mastectomy Association, cancer support groups etc.
- It would be useful to have an identifiable "link" person to put questions to after consultation eg practice nurse.

All this would help prepare patient/relative for the diagnostic consultation.

Diagnostic Consultation

Being unprepared for the diagnosis was seen as a disadvantage, which caused a feeling of being unable to absorb what was being said.

Suggestions for good practice included

- being given written or recorded information to take away.
- being encouraged to have a relative or friend present.
- being encouraged to ask questions.
- a contact person to telephone with any later questions.
- information on support services (as before).

During Treatment

Again, a contact person. Hospital staff were perceived as being very dedicated but very busy. There was often a feeling of questions not being welcomed.

Suggestions for good practice included

- information on treatments and possible side effects before treatment starts.
- information on possible irreversible side effects, such as impotence or infertility, again before treatment starts.
- joint discussions with specialists if there is a choice of treatment options - team approach.
- being given time, information and non-judgemental attitude to support decision making.
- identifying a contact or key person for support and information, especially if an outpatient.

Discharge from Hospital

Suggestions for good practice included

- a contact person to address questions or concerns, or offer counselling. This was not perceived to be the GP, who often had less information than the patient. This was especially important if the treatment had not been in an oncology unit, and if there was no further active treatment. Families were left feeling they had been "written off". "There is nothing we can do".

- good communication between hospital/community service about treatment, palliative care etc.
- information about where to get support - emotional, relationships, financial, practical.

Recurrence of Disease

Suggestions for good practice included

- feeling enabled to make appointment with specialist (rather than GP) or bringing forward appointment if symptoms present.
- contact person, or someone to talk to.
- cut down wait for results of tests and appointments - (one woman reported a wait of 3 weeks for appointment for chest x-ray for possible lung metastases.

Palliative Care

All those who were consulted and who had experienced palliative care, felt that the present Macmillan service answered all their needs, and anticipated needs (Fife Macmillan Service). Those who had no experience, again mentioned the need for a contact person and for information on support services - professional, voluntary, practical and financial.

Bereavement

Good practice should include the following

- GP should be notified within 24hrs if death occurred in hospital.
- GP (or possibly the contact person) should visit relatives, and also discuss support services.

ANNEX 4

GUIDELINES CONFERENCE 29 April 1993

DELEGATES

Ms Lynn Adams (R)	Clinical Nurse Specialist, Beatson Oncology Centre
Ms Elizabeth Allan	Argyll & Clyde Health Board
Mrs Rae Allan (R)	Community Nurse, Forth Valley
Mrs Dorothy A Anderson	Pharmacy Practice Division Common Services Agency
Mrs Helen Anthony	The Prince & Princess of Wales Hospice, Glasgow
Ms Janette Bain	Macmillan Nurse, Alexandra Unit, Dumfries
Dr John C Bass	Medical Director, The Ayrshire Hospice
Mrs Isobel Bassett (C)	Area Speech & Language Therapist, Dumfries & Galloway
Dr Wendy Baxter	Medical Director, Accord Hospice, Paisley
Dr T F Benton	Royal College of Physicians, Edinburgh
Dr John Berkeley	Scottish Partnership Agency for Palliative & Cancer Care
Dr Sidney Bindemann	The Phoenix Cancer Foundation, Glasgow
Mrs Beth Bladworth	Dept of Nursing Studies Glasgow Caledonian University
Mr Joe Burns (C)	Social Worker, Malcolm Sargent Cancer Fund, Aberdeen

(R) = Rapporteur (C) = Working Group Chairman
(PM) = Panel Member for Plenary Discussion

Mrs Chandra Caldwell	Scottish Association of Health Councils
Miss E M Campbell	St John's Hospital at Howden West Lothian
Ms Phyllis Campbell (PM)	Macmillan Cancer Nursing Adviser, Beatson Oncology Centre
Dr David S Carroll	GP Facilitator in Palliative Care, Grampian
Mrs Isabel Caskie	Scottish Health Visitors Association
Miss Aileen Christie	Scottish Motor Neurone Disease Association
Rev Stuart M Coates	Association of Hospice Chaplains
Dr M A Cornbleet (R)	Department of Clinical Oncology, Western General Hospital, Edinburgh
Mrs Shona Crosthwaite	College of Occupational Therapists
Mrs Elspeth Davidson	PLUS Self Help Association
Miss Jeanette Davidson	Nursing Officer, The Scottish Office Home and Health Department
Dr Linda De Caestecker	Greater Glasgow Health Board
Ms Alison Dely	Palliative Care Network Group, Western General Hospital, Edinburgh
Ms Cara Downie (R)	Macmillan Liaison Nurse, Perth Royal Infirmary
Mr John Dunne	Consultant Clinical Psychologist, Forth Valley
Mrs Catherine Duthie	Cancer Relief Macmillan Fund
Mrs Jenny Eldrett (C)	Macmillan Co-ordinator, Highland
Mr W J Farquhar	Clinical Resource & Audit Group, The Scottish Office Home and Health Department
Mrs Carrie Ferrier	Royal College of Nursing Palliative Nursing Forum
Mrs Lyn Forbes	Association of Hospice Administrators
Mr Andrew Foulds	Hospice Nurse Managers Forum
Dr Karen Foster	Grampian Health Board

Mrs Dawn Foxley (R)	Macmillan Nursing Co-ordinator, Fife
Miss M K Gillon	National Board for Nursing Midwifery & Health Visiting for Scotland
Ms Liz Goss	Roxburghe House, Dundee
Mr Sydney Graham	Association of Directors of Social Work
Dr Timothy Habeshaw	Beatson Oncology Centre, Glasgow
Ms Caroline Hamilton (R)	Social Worker, Strathcarron Hospice
Dr A Harnett	Scottish Joint Consultants Committee
Mr Douglas Harper	Consultant Surgeon, Forth Valley
Ms Jo Hockley	CNS (Palliative Care) Western General Hospital
Mrs Brenda Holmes	Social Work Services Inspectorate, The Scottish Office Home and Health Department
Mr Frank Hunter	Health Policy Division, The Scottish Office Home and Health Department
Mrs Muriel Hunter	Scottish Partnership Agency for Palliative and Cancer Care
Mrs Anna Innes	Scottish Partnership Agency for Palliative and Cancer Care
Dr N D Jarvie	National Medical Advisory Committee, The Scottish Office Home and Health Department
Mrs Elaine Kay	National Paramedical AdvisoryCommittee, The Scottish Office Home and Health Department
Ms Nora Lawson	Dept of Nursing Studies University of Glasgow
Dr Martin Leiper (C)	Consultant in Palliative Medicine, Tayside
Mr J Graham Leishman	Pharmacy Project, Glasgow
Miss Moira Leitch	Malcolm Sargent Cancer Fund for Children

Ms Jane McAlpine	Physiotherapist, Strathcarron Hospice
Miss Ishbel MacArthur	Bethesda Hospice, Stornoway
Dr J B MacDonald	Crosshouse Hospital, Kilmarnock
Mrs Mary Macgee	St Vincent's Hospice
Mrs Christine McGilvray (R)	Marie Curie Nursing Service in Scotland
Mrs E M McGovern	Pharmacy Project, Glasgow
Dr Sheila McKay	St Margaret's Hospice, Clydebank
Ms Catherine Mackenzie	College of Speech and Language Therapy
Miss E K McLean (PM)	Chief Area Nursing Officer, Lothian Health Board
Dr A O MacLennan	Roxburghe House, Aberdeen
Ms Patricia McMahon	Borders Health Board
Ms Ruth McMinn	Senior Occupational Therapist, Aberdeen Royal Hospitals Trust
Mrs Fiona McQueen	Lanarkshire Health Board
Dr W Macrae	North British Pain Association
Miss Mary B Madden	Aberdeen Royal Hospitals Trust
Dr Lindsay Martin	Alexandra Unit, Dumfries
Dr Rosalyn Mauchline	The Highland Hospice, Inverness
Ms Cathy Meredith (C)	Lecturer in Radiotherapy Radiography, Queens College, Glasgow
Dr David Millar (C)	General Practitioner, Peterculter, Aberdeen
Mrs Evelyn Miller (C)	Manager, CancerLink
Mrs Frances Milne	Society of Radiographers
Rev. David Mitchell	Chaplain, Hunter's Hill Marie Curie Centre
Rev Alastair Moodie	Tak Tent
Dr Alison Morrison	Ardgowan Hospice, Greenock
Rev. Gillian Morton (R)	Chaplain, Borders General Hospital

Mr Alan Murchison	Health Policy Division, The Scottish Office Home and Health Department
Dr Calum Muir	Information and Statistics Division, CSA
Ms Ruth Murie	Milestone House, Edinburgh
Dr Scott Murray	Department of General Practice, University of Edinburgh
Mrs Vivien Newton	Hunter's Hill Marie Curie Centre, Glasgow
Dr J Oni-Orisan	St Andrew's Hospice, Airdrie
Miss Molly Parsons	Matron, Strathcarron Hospice
Mr Mike Powell	Chief Area Nursing Officers Group
Mr David Reader	Association of Hospice Social Workers
Ms Penny Richardson	Scottish Association of Local Health Councils
Mr Alistair R Robertson	Strathcarron Hospice, Denny
Dr K M Rogers	Royal College of Anaesthetists
Ms Morna Rutherford	West Lothian Unit, St John's Hospital at Howden
Mrs Catherine Sawers	Western Isles Health Board
Dr Sheila Scott	Argyll & Clyde Health Board
Mr Tom Scott (Speaker)	Scottish Partnership Agency for Palliative and Cancer Care and Adviser, Cancer Relief Macmillan Fund
Dr Sheena Scragg	Fife Health Board
Dr George Shirriffs (PM)	Royal College of General Practitioners
Dr S D Slater	Royal College of Physicians & Surgeons of Glasgow
Dr Maida Smellie	Ayrshire & Arran Health Board
Mrs Margaret Sneddon	Department of Postgraduate Medicine, Glasgow
Ms Sheila Stark	Dietician, Beatson Oncology Centre
Mrs Margaret Stevenson	Scottish Partnership Agency for Palliative and Cancer Care

Ms Fiona Stewart	Association of Directors of Social Work
Dr Helen J Stewart	Royal College of Surgeons, Edinburgh
Dr Jan Stjernsward (Speaker)	Chief, Cancer and Palliative Care Unit, WHO, Geneva
Mrs Dora Storey (C)	Matron, Ayrshire Hospice
Miss Vanessa Strong	Palliative Care Network Group, Western General Hospital
Mrs Norma M Sutherland	Association of Palliative Care Nurse Teachers
Mrs M Tannahill	Tayside Health Board
Ms Mary L Thomas	Centre for Medical Education, University of Dundee
Sir Thomas Thomson (Conference Chairman)	Chairman, National Panel on the Care of the Dying and the Bereaved
Dr M Ullah	Senior Medical Officer, The Scottish Office Home and Health Department
Lady Katharine Weir	Association of Hospice Voluntary Service Coordinators
Dr John Welsh (PM)	Director of Medical Services, Hunters Hill Marie Curie Centre/Association for Palliative Medicine
Sister Margaret West (R)	Stobhill General Hospital Glasgow
Ms Fiona Whyte	College of Nursing Gartnavel Hospital
Dr W H Williams	Fairmile Marie Curie Centre, Edinburgh
Miss Moyra Withycombe	National Paramedical Advisory Committee
Dr Stanley Wright (C)	Consultant Physician, Forth Valley
Dr Andrew Young (Panel Chairman)	Deputy Chief Medical Officer, The Scottish Office Home and Health Department

ANNEX 5

Palliative Cancer Care Services - Scotland 1993

HEALTH BOARD	ARGYLL & CLYDE	AYRSHIRE & ARRAN	BORDERS	DUMFRIES & GALLOWAY	FIFE	FORTH VALLEY	GRAMPIAN	GREATER GLASGOW	HIGHLAND	LANARK-SHIRE	LOTHIAN	ORKNEY	SHETLAND	TAYSIDE	WESTERN ISLES	TOTALS
POPULATION (1991)	436200	376800	104100	147800	346500	272800	514400	922000	204200	561300	750500	19580	22500	391900	29420	5100000
IN PATIENT UNITS																
Units	3	1	-	1	1(+1)	1	1	3	1	1	2	1	-	1	1	19(+1)
Total beds	32	16	-	6 (+10)	9	18	21 (+8)	83	10	10	67	3	-	25	4	304(+18)
DAY CARE SERVICES	3	1	-	-	-	1	1	3	1	3	2	-	-	1	-	16
HOME CARE NURSES	9 CRMF	6 CRMF	2# CRMF	2# CRMF	5# CRMF	4 CRMF	5 CRMF	4 4 CRMF	3 CRMF	7 CRMF	6 5 CRMF	1 CRMF	1 CRMF	2 CRMF	2.5	68.5
HOSPITAL NURSE SPECIALISTS																
Breast Care Nurse	-	-	-	-	1	2	1p/t CRMF	2	-	-	3	-	-	-	-	8.5
Hospital Support Nurse	-	-	-	-	-	-	-	-	-	-	-	-	-	2 CRMF	-	2
Clinical Nurse Specialist	1 CRMF	-	-	-	-	1	2 CRMF	-	2 CRMF	-	1 CRMF	-	-	-	-	7
Liaison Nurse	1 CRMF	2 CRMF	-	-	-	-	-	-	1 1 CRMF	-	1 CRMF	1	-	1 CRMF	-	8
Macmillan Nursing Adviser	-	-	-	-	-	-	-	1 CRMF	-	-	-	-	-	-	-	1

ANNEX 5 contd.

HEALTH BOARD	ARGYLL & CLYDE	AYRSHIRE & ARRAN	BORDERS	DUMFRIES & GALLOWAY	FIFE	FORTH VALLEY	GRAMPIAN	GREATER GLASGOW	HIGHLAND	LANARK-SHIRE	LOTHIAN	ORKNEY	SHETLAND	TAYSIDE	WESTERN ISLES	TOTALS
POPULATION (1991)	436200	376800	104100	147800	346500	272800	514400	922000	204200	561300	750500	19580	22500	391900	29420	5100000
MARIE CURIE NURSING SERVICE	98	74	48	89	81	28	143	95	73	95	99	-	-	63	12	998
CONSULTANTS:																
Palliative Medicine	-	1	-	-	1	1	1	4	(1)	-	3	-	-	1	-	12(1)
Other	-	-	-	1*	-	-	-	-	-	1+	-	-	-	-	-	2
NON CONSULTANT MEDICAL POSTS:	2	-	1	1	-	1	-	-	-	-	-	-	-	-	-	5
CANCER SUPPORT GROUPS	4	5	1	2	4	2	6	8	3	6	9	-	-	4	1	55

( ) Yet to be appointed
Also giving hospital support
* Consultant Haematologist
+ Consultant Anaesthetist
CRMF = CRMF pump primed posts

The data given in this provisional chart of services has been gathered by SPAPCC and updated to September 1993. Further data is still being collated and SPAPCC is aware that in particular, numbers of cancer support groups and of hospital nurse specialists may be under-recorded.

ANNEX 6

Cancer Registry Statistics

Number of registrations of malignant neoplasms (ICD 140-208) by age at diagnosis and health board of residence, Scotland 1991.

	Age at diagnosis			
Health Board	**under 15**	**15-64**	**65+**	**All ages**
Argyll & Clyde	17	819	1346	2182
Ayrshire & Arran	8	702	1261	1971
Borders	1	183	466	650
Dumfries & Galloway	3	290	581	874
Fife	10	742	1158	1910
Forth Valley	3	503	889	1395
Grampian	10	813	1316	2139
Greater Glasgow	20	1941	3387	5348
Highland	5	430	695	1130
Lanarkshire	13	916	1376	2305
Lothian	16	1506	2729	4250
Orkney	13	25	45	72
Shetland	0	21	35	56
Tayside	7	755	1479	2241
Western Isles	1	59	119	179
Scotland	**127** **(0.5%)**	**9705** **(36.3%)**	**16882** **(63.2%)**	**26702**

Source - Information and Statistics Division, CSA.

ANNEX 7

THE PALLIATIVE CARE MATRIX

1. THE MATRIX

Attached is a graphic presentation of the palliative care matrix. This provides a template for considering the structure of a palliative care service by plotting

a) the key agents of palliative care related to **Quality of Life** and **Continuity of Care** against

b) each of the **Key Points of Clinical Contact**. For each intersection the essential components of care can be identified.

2. AGENTS OF PALLIATIVE CARE.

These are shown on the horizontal axis and are in 2 groups.

2.1 Quality of Life

Pain Control
Symptom Control
Emotional and Social Support
Spiritual Support
Rehabilitation
Patient Autonomy

2.2 Continuity of Care

Teamwork
Discharge Planning
Key Carer and Key Contact Person
Resources

3. KEY TIMES OF CLINICAL CONTACT

These are shown on the vertical axis of the diagram. They are

Pre-diagnosis and Diagnosis
Treatment
Discharge and Care in the Community
Recurrence of Disease
Terminal Stage
Bereavement

PALLIATIVE CARE MATRIX

	AGENTS OF QUALITY OF LIFE						AGENTS OF CONTINUITY OF CARE			
KEY TIMES OF CLINICAL CONTACT	Pain Control	Symptom Control	Emotional and Social Support	Spiritual Support	Rehabilitation	Patient Automony	Teamwork	Discharge Planning	Identify Key Carer and Key Worker	Range of Resources
Pre-Diagnosis and Diagnosis										
Treatment										
Discharge and Care in the Community										
Recurrence										
Terminal Stage										
Bereavement										

ANNEX 8

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