

Palliative Cancer Care

The Integration of Palliative Care with Cancer Services

A Report of the

**Scottish Partnership Agency for Palliative and Cancer Care
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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

Through this partnership of 89 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.

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Palliative Cancer Care- The Integration of Palliative Care with Cancer Services

1. Introduction

The incidence of cancer in Scotland is rising and despite advances in the treatment of some cancers the reality is that the majority of people with cancer will not be cured. 1 in 3 people in Scotland will develop cancer and it is estimated that 60% - 70% of them will need palliative care. 1 in 4 people in Scotland will die from cancer.

The Council of Management of the Scottish Partnership Agency agreed in December 1995 that it should be a major priority for the Agency to develop proposals for the integration of palliative care with cancer treatment services in Scotland. The identification of cancer services as a priority area for the NHS in Scotland over the next 2/3 years, together with the recommendations of the Calman/Hine Report "A Policy Framework for Commissioning Cancer Services" (1) were prime factors leading to this decision.

The Report of the Scottish Cancer Coordinating and Advisory Committee (SCCAC) on Commissioning Cancer Services in Scotland was published in April 1996 (2) and Health Boards and NHS Trusts have been asked to prepare plans for the development of cancer services in line with the recommendations in the Report (MEL 1996 54) (3) The SCCAC Report welcomed the general principles of the Calman/Hine Report as applying equally to Scotland, thus confirming the Scottish Office's earlier "commitment to the development of palliative care as an integral part of cancer services" (MEL 1994 104) (4). The Scottish Report concentrated on the organisation of secondary and tertiary care. Further work on the role of palliative care and primary care in the development of cancer services is now being undertaken by the SCCAC Sub-Committee.

The SPA invited a representative group of the different disciplines involved in palliative and cancer care to participate in its project (see Appendix I). The group discussed present services at cancer centre, cancer unit and primary care levels and within specialist palliative care services. In all these settings the discussion identified strengths to build on and models of good practice in the delivery of care, together with areas which were in need of improvement and development. This paper is the result of those discussions. It is intended to be of use to those with responsibility for commissioning cancer services and for those providing such services in cancer centres, cancer units or primary care.

The paper focuses on the provision of palliative care for people with cancer because it considers palliative care in the light of the Calman/Hine Report and of the NHS priority for cancer services in Scotland. The SPA recognises however that many people with progressive conditions other than cancer could benefit from palliative care. Few of the present services outlined in the paper are currently restricted to cancer patients and the SPA is committed to the development of palliative care services for all who could benefit from them, not only those with malignant disease.

2. Calman/Hine recommendations on palliative care

The Calman/Hine Report (1) is very clear that palliative care is an essential element of cancer treatment services at primary, secondary and tertiary levels. Throughout the Report there is an emphasis on the need for palliative care to be integrated with cancer treatment and on the need for specialist palliative care expertise and resources to be available.

"Palliative care should not be associated exclusively with terminal care. Many patients need it early in the course of their disease, sometimes from the time of diagnosis. The palliative care team should integrate in a seamless way with all cancer treatment services to provide the best possible quality of life for the patient and their family." "A specialist (palliative care) resource for both primary care and hospital based services" should be provided.

The Report goes on to recommend that "Palliative care and symptom control should be available at all stages of the patient's illness. Hospitals, primary care, social services and the voluntary sector should all be involved." In order to achieve this "Commissioning authorities should develop a local plan for delivering palliative care, bringing together all providers."

(The Section of the Calman/Hine Report on palliative care is copied at Appendix II)

3. Definitions

The generally accepted definition of palliative care is that of the World Health Organisation in 1990 (5)

"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"

More recently further definitions have been developed by the National Council for Hospice and Specialist Palliative Care Services (6) and others in order to clarify the different forms in which palliative care is provided:

3.1 Basic palliative care: Care delivery with a palliative approach is a core skill that every health care professional, in whatever setting, should possess if dealing with patients with incurable progressive disease.

3.2 Specialised palliative interventions: Specialised palliative interventions are non-curative treatments aimed specifically at modifying the illness. They are usually performed by specialists in clinical or medical oncology or surgery.

3.3 Specialist palliative care: Specialist palliative care is delivered by a multi-professional team, led by clinicians with recognised specialist palliative medicine training. The team works collaboratively with those providing a palliative approach and deals with the more complex problems to ensure that patient and family needs are met. The above definitions are adapted from Finlay I G, "Outreach Palliative Care Services: Definitions in Palliative Care" (7)

4. Need for palliative cancer care

In Scotland about 29,000 people per year are diagnosed with cancer. About 15,000 people die from cancer every year and about 150,000 people at any one time are living with cancer. The incidence of cancer is increasing, mainly because of the ageing population and the fact that predominantly cancer is a disease of the elderly. It is estimated that from 1994-2000 cancer incidence in men will rise by 7% and in women by 3%. Most people who die of cancer are over 75 and this percentage will increase, with consequent increased demands on older, frailer carers, and increased numbers of patients who have no family member to care for them.

Not everyone with cancer will need specialist palliative care services but some may need palliative care from diagnosis onwards and all with progressive disease will need palliative care in conjunction with anti-cancer treatment or during the latter stages of their life. All cancer patients have the right to expect the palliative care approach to their care from all the health professionals with whom they come into contact. The content of that care should be varied according to individual need and should alter as the individual's needs change over time. Specialist palliative care should be involved as required.

A survey of cancer patients in England and Wales (8) in the last year of life reported a high incidence of symptoms including pain (84%), nausea and vomiting (51%) breathlessness (47%), constipation (47%) and depression (38%).

Surveys in hospital and in the community have shown that symptom control is sub-optimal. In a study of over 2000 patients who died of cancer in 1990(9) the carers of 47% of those treated for pain by their GPs and 35% of those treated in hospital said that pain had been only partially controlled, if at all.

Good pain relief is possible however if World Health Organisation guidelines are followed. A specialist pain relief team carried out a prospective study of 2000 patients over 10 years (10) which showed that use of the WHO guidelines (11) resulted in good pain relief for 76% patients, satisfactory pain relief for 12% and inadequate pain relief for just 12%.

Thus there is a need for palliative care which should be an integral part of cancer care. Its availability and delivery must be assured in all settings at the different levels outlined above.

5. Principles

The Palliative Cancer Care Guidelines in 1994 (12) identified six "Factors which underpin the effective provision of palliative cancer care":

- Focus on the Patient
- Communication
- Teamwork
- Education, Training and Staff Support
- Care for Carers
- Quality of Life and Continuity of Care

The SPA project in 1996 endorsed these principles and, in the context of considering the Calman/Hine report and its implications, added three more:-

- Equity of access
- Integration with cancer treatment services
- Access early in the disease

Factors which promote trusting relationships between health professionals and patients are fundamental to palliative care. These factors include an openness and truthfulness towards the patient and family; a non-judgmental acceptance of the patient's reaction to the situation and an attempt to allow the patient autonomy and choice throughout their illness. The goal of befriending the patient involves adopting an empathic approach.

6. Elements of care

The SPA project agreed a list of essential elements of palliative care which then formed the framework for discussion of strengths and areas in need of improvement in current practice.

They were:

- symptom control
- psychological support
- social support
- spiritual support
- effective communication
- available physical and practical resources
- ease of access to hospital/hospice facilities
- support for carers
- achieving desired place of care and death
- bereavement support

7. Present services

The needs of the majority of people with cancer can be met by generalists providing they possess a basic level of knowledge of palliative care. (see Appendix IV). A significant minority however need input from specialist palliative care providers.

Specialist palliative care services are currently provided in the following settings:

- Specialist palliative care units
- Hospital
- Community
- Paediatric units

Details of current levels of specialist palliative care in Scotland in each setting are given at Appendix V. The types of service in each setting comprise:

7.1 Specialist palliative care units

These include independent voluntary hospices, Marie Curie Hospice Centres and NHS palliative care units. Specialist palliative care is provided by a multi-professional specialist team led by clinicians with recognised specialist palliative medicine training. Most units provide in-patient care, day hospice, home care and 24 hour advice service together with bereavement support. There are also some day hospices not attached to a hospice in-patient unit. Many units commit considerable resources to education programmes provided for local health care professionals and are also committed to palliative care research.

7.2 Hospital Services

Specialist palliative care (as defined at para. 3 above) is provided in hospitals by hospital palliative care support teams comprising, as a minimum, designated specialist medical and nursing staff with secretarial backup but which, ideally, should also include other professionals such as a pharmacist, physiotherapist, occupational therapist, social worker or psychologist. Very few such multi-professional teams exist in Scotland at present (see Appendix V).

A recent analysis of the effect of a specialist palliative care team in a hospital showed that within one week of the team's involvement the following symptoms had been improved by a statistically significant amount: pain, nausea, anorexia, insomnia, constipation. In addition patients' and families' level of satisfaction with information about their disease improved and with the team's involvement hospital stay was shortened. (13)

The number of specialist nurses in hospitals has increased significantly in recent years. Many of these posts have been pump primed by Cancer Relief Macmillan Fund. Their titles vary and reflect roles which may be wholly concerned with providing and advising on palliative care; may be administering chemotherapy or may be acting as coordinator of palliative care between the hospital and community. They may combine some or all of these roles.

Increasingly hospitals are negotiating with their local specialist palliative care unit for a specialist in palliative medicine to attend for one or more sessions per week. The doctor will work closely with the hospital's specialist nurse if one exists, and will use the sessions to advise on the palliative care of patients with particular problems, to facilitate transfer to the specialist palliative care unit when that is appropriate, to coordinate discharge and to involve specialist palliative care community nursing teams, and to raise the quality of palliative care being provided by hospital staff. In addition to improvement in the care of individual patients these arrangements have substantial educational benefits.

Use of the palliative approach to care by generalists in all professions in the hospital setting lays the foundation for high quality care of all patients and access to specialist palliative care for those who need it.

7.3 Services in the Community

The Primary Health Care Team should play the key role in caring for patients and families/carers in the community, providing medical and nursing services, mobilising social work input and arranging referral to other services including specialist palliative care.

Specialist services in the community are provided by Macmillan Nurses, Marie Curie Palliative Care Nurses and hospice home care nurses. Specialist palliative medicine physicians also frequently make domiciliary visits at the request of the GP. The specialist nurses work closely with the primary health care team in an advisory liaison and supportive role, but do not provide a hands-on nursing service. They provide information, advice to the GP or district nurse on physical symptom control (usually after discussion with the hospice or specialist palliative medicine consultant) and emotional and psychological support to patients and their carers.

The involvement of specialist palliative care teams with the primary health care team may enable more patients to stay at home if that is their wish. Specialist palliative care services are available to those living in nursing homes and residential homes on the same basis as if they were in their own home.

Marie Curie Community Nurses provide regular hands-on nursing care to patients at home, including night nursing, and give respite and support to relatives and carers.

Day hospice care provided by specialist palliative care units and by some NHS Trusts plays a significant part in enabling some patients to live at home, as does temporary in-patient care in a specialist palliative care unit.

The local authority Social Work Department will be involved if, for example, aids or home adaptations are needed, if there are financial difficulties, or if services such as home help or meals on wheels are required. The Social Work Department may also be involved in providing psychosocial support to patients and carers.

Voluntary organisations may be involved to provide services, information or support. Cancer support groups exist throughout the country providing mutual support sometimes on a cancer-site basis and sometimes on a purely geographical basis. Some groups provide voluntary transport services for hospital visiting and appointments, or organise complementary therapies. Spiritual support continuing into bereavement is provided by local clergy and religious advisers from different faiths and cultures, as appropriate to the individual background and beliefs of the patient and carers.

Bereavement support may also come from the primary health care team, voluntary organisations, specialist palliative care, bereavement services and social workers.

7.4 Paediatric Services

The number of children developing cancer each year in Scotland is small. Cancer services for them are based in specialist centres in Aberdeen, Edinburgh and Glasgow. A co-ordinated team approach is the normal practice so that ongoing care, support of the family and, where appropriate, palliative care is provided by members of the same team. As each GP is unlikely to see many children with cancer, the involvement of specialists is vital. National charities such as the Malcolm Sargent Cancer Fund for Children, Cancer Relief Macmillan Fund and CLIC (Cancer and Leukaemia Childhood Trust) help to fund some specialist posts in the paediatric cancer centres (see Appendix V). Marie Curie Community Nursing and statutory services may provide a "hands on" night or day sitting service. The newly established children's hospice in Kinross is open to children with cancer but most of its work is likely to be with children with chronic degenerative diseases and metabolic disorders.

8. Strengths and areas for improvement in present services

The SPA project identified strengths and areas for improvement in the provision of palliative care at cancer centre, cancer unit and primary care levels. The factors identified at centre and unit levels were, not surprisingly, very similar and have been amalgamated in one hospital column for this report.

Strengths

Hospital

Primary Care

Cancer treatment expertise

Rapid access to technology and expertise for symptom control e.g. anaesthesia, radiotherapy

Linked social workers

Good access to hospice services

Centralised paediatric cancer services

Accurate information to primary health care team and families

Educational expertise

Near the patient

Knowledge of patient/family/carer

24 hour access to hospice/hospital expertise

development of GP Facilitator posts

recognition of need for education

cancer support groups in community

Areas for improvement

Hospital

Primary Care

Recognition of potential health gain from palliative care

Consideration of palliative care earlier in disease

Understanding of what the palliative care team can do

Symptom management

Development of guidelines and protocols for symptom management

Audit of all aspects of palliative care

Staffing/resources for psychological, emotional, spiritual support and bereavement care

Continuity of medical care for outpatients Communication with GPs

Communication with patients in relation to emotional and spiritual matters and breaking bad news

Communication with and support for patients' families/carers

Meeting educational needs of lay carers

Attention to patient and family choice in relation to place of care/death

Bereavement support

Education in the palliative care approach for all staff

Organisational

Suitable interview facilities

Continuity of care in the light of the growth of cooperatives and overnight services and possible changes in GP contracts

Symptom management

Use of specialist palliative care services

Teamwork

Psychological/emotional support

Access to psychiatric services/clinical psychology

Coordination of social and economic support

Support for carers

Meeting educational needs of lay carers

Respite/sitting services

Achievement of desired place of care/death

Development of national standards for nursing homes registered for care of the terminally ill

Priority within social work departments for assessment for terminal care

Specialist input to residential and nursing homes

Communication with hospital

Education in palliative care

9. Recommendations for good practice

9.1 In all settings

Palliative care must be recognised as integral to cancer service delivery.

Generalist palliative care to an agreed minimum standard should be available from all health professionals. Standards should be set and audited across all settings to ensure that the palliative care provided by generalists reaches an acceptable level.

All health boards should contract to ensure specialist palliative care input is accessible to those needing it. The input from these specialists should be available for the patient, the family and fellow professionals. Special effort should be made to ensure accessibility of services for members of ethnic minorities and for people living in rural areas remote from specialist centres.

Due to the diversity of organisations involved and the different settings in which palliative care is practised measures should be taken to facilitate collaborative working, prevent duplication and enhance communication. This may be achieved by the appointment of a regional palliative care coordinator.

9.2 Cancer centre and cancer unit

9.2.1 Each cancer centre and cancer unit requires a hospital palliative care team. The team should be available for other hospital patients as well as for those with cancer. It may be peripatetic between hospitals as well as within its base hospital. Its membership should comprise:

Palliative medicine and nursing specialists (specialist palliative care nurses should not be established in any setting without appropriate medical support.)

The team should have secretarial support

The team should be closely linked to professions allied to medicine as needed such as pharmacy, physiotherapy, occupational therapy, social work and chaplaincy.

9.2.2 The team should be strongly linked with the local specialist palliative care unit and with community based palliative care teams.

9.2.3 The team should have its own multidisciplinary record proforma which is compatible with the oncology services. The proforma should detail:

- Patient identity
- Assessment of problems
- Outcome of assessment of problems
- physical
- psychological
- social
- spiritual

- Care plan (agreed with the patient/family to resolve or alleviate the identified problems in order to achieve the patient's goal).
- Discharge planning

9.2.4 Communication from the team to the GP/District Nurse should be rapid (within 1 day) after discharge and should contain an up-to-date report of the cancer condition, future anti cancer treatment plans, what the patient and family have been told and actually understand. A summary of physical, psychosocial and spiritual problems should be included. Follow up arrangements must be clear. Discharge drugs should be noted.

9.2.5 The role of the hospital specialist palliative care team:

- Involvement, on request, in patient care providing advice, liaison and support and ensuring coordination and continuity of care for the patient.
- Control of difficult symptomatology.
- Providing support for hospital staff and promoting open sensitive communication.
- Promoting multidisciplinary education and acting as role models
- Facilitating appropriately prepared discharges, liaison with GP, district nurse, specialist palliative home care teams, delivery of equipment and provision of social work input if needed.
- Setting and auditing standards for palliative care with staff in collaboration with Trust Quality Assurance staff
- Working with relevant health professionals to develop local protocols based on national guidelines.
- Providing a specialist palliative care out-patient clinic
- Promotion of transfer of appropriate patients to specialist palliative care units.
- In cancer centres linking with local Universities to promote inclusion of palliative care in undergraduate curricula

9.3 Community

9.3.1 Education in palliative care to the level agreed by the relevant professional bodies should be provided for the following (a list is given at Appendix IV of topics for a basic palliative care curriculum):

- The primary health care team
- home helps
- community hospital staff
- nursing home staff

9.3.2 Specialist advice should be rapidly available:

to the general practitioner from a specialist palliative medicine physician and to the district nurse from a specialist palliative care nurse to community hospitals and to nursing homes to all health care professionals through a 24 hour telephone advice service generally provided by a specialist palliative care unit

9.3.3 There should be access from the home to specialist palliative care unit facilities e.g. inpatient beds, day care, home care, advice, equipment loan, bereavement service and education.

Specialist palliative care units (SPCU) should have a 24 hour, 7 day a week admission policy predominantly for patients already under their care.

9.3.4 There should be access to 24 hour community nursing (Marie Curie Cancer Care and statutory).

9.3.5 Ready access to equipment (pressure relieving mattresses, beds, bath aids) should be available through an efficient supply service which may be jointly funded by the local authority social work department and the health board. (as recommended by the Scottish Health Management Efficiency Group) (14).

9.3.6 Effective liaison should be established between primary health care teams and local area social work department community care teams to maximise access to social work services.

9.3.7 Specialist palliative care should be available for those in their own homes, residential and nursing homes.

9.3.8 Adequate bereavement services should be established and all bereaved people should be assessed for high risk factors pre-loss and all should be offered a visit at 6 weeks after loss for formal grief assessment.

9.4 Coordination and collaborative working

9.4.1 All health boards should conduct needs assessments for palliative care, in collaboration with providers including local authority social work and voluntary organisations in their area, and develop purchasing strategies (as MEL 1994 104).

9.4.2 Measures should be taken to promote communication and cooperation between services and consideration should be given by purchasers to the appointment of a regional coordinator of palliative care.

9.4.3 Efficient fast and accurate communication is essential and may benefit from use of fax or patient held records.

9.4.4 Specialist palliative care services should form units which would promote the crossing of boundaries between hospital, community and specialist palliative care unit.

9.4.5 Protocols should be developed to promote fast and effective communication between services.

9.4.6 The GP will generally be the leader of the multidisciplinary team in the community but the team may identify a different key worker who will be known to the patient and family. The key worker will coordinate and liaise and may also act as the patient's advocate.

9.4.7 A hospital pharmacist should be involved with the palliative care team in order to ensure continuity of pharmaceutical care across the different settings by liaison with GPs and community pharmacists.

9.4.8 Local authority social work staff should be cancer centre or unit linked hence gaining special expertise and all health centres should have an attached social worker.

9.4.9 All services should work together to realise the patient's preferred place of care.

Note: Appendix III gives an example of a "Cancer Journey" in which best practice and cooperation between services results in an integrated cancer treatment and palliative care service.

9.5 Education

Identify training needs

Utilise expertise in specialist palliative cancer unit to provide undergraduate/postgraduate education in palliative care for all health care professionals

Provide training in basic communication skills for all health care professionals (advanced training should be available if needed)

Link educational resources with special expertise in palliative care with universities

Identify informal carers' educational requirements and make provision to meet these

Provide opportunity for health care professionals to have ready access to continuing education in palliative care

Provide training in the proper use of equipment, e.g. syringe drivers, and a rolling programme of training to keep such expertise up to date.

9.6 Examples of Good Practice

The list is not exhaustive and we are aware that there will be many other examples of good practice.

9.6.1 Education

Final year medical undergraduates 48 hour hospice attachment - highly evaluated by students

A period of attachment to a specialist palliative care unit included in the training for disciplines such as geriatrics, oncology, general medicine

Ensuring communication skills including specific skills relevant to palliative care training are thoroughly taught in undergraduate courses.

Interactive computer programmes on palliative care. e.g. Marie Curie Cancer Care interactive laser video; HELP 1995, Computer challenge for GPs (Macpac), Computer

challenge for hospital doctors, Spotlight series - Macmillan Education Resource Unit, Centre for Medical Education, University of Dundee.

Proposal for employment of peripatetic locum by Health Board to release GPs on rotation for 1 week's specialist palliative care unit attachment

GP Facilitators - an evaluation of a U.K. pilot project shows that they are effective in improving education and training of GPs and primary care teams in all aspects of palliative care.

9.6.2 Standards and protocols.

Palliative Cancer Care Guidelines SPA/CRAG (12)

Relief of Pain and Related Symptoms: the Role of Drug Therapy, SPA (15)

Registered Nursing Homes and People with a Terminal Illness: a Guide to Good Practice, SPA (16)

Core Standards for Specialist Palliative Care, SPA (in press) (17)

Good practice guidance for the care of the dying and bereaved have been prepared by various health boards and authorities.

9.6.3 Communication

For patients/relatives - verbal information given sensitively with, in addition, the offer of a written leaflet about the illness, treatment and specialist palliative care unit as appropriate.

For GP - telephone call to GP on the day of his/her patient's death or within 24 hours. (Practice becoming more widespread)

For hospital doctors/nurses - Access to computer programmes in palliative care through hospital computer network.

Results clinics - If "bad news" has to be broken it is beneficial to have a nurse present with the patient and doctor when the news is given.

1. The nurse and doctor are aware of what has been said
2. The nurse can take the patient to a "quiet area" to allow further questions and support
3. Provision should be made so that the patient can contact the same nurse (or deputy) later
4. When the patient returns to the clinic a system should be in place to ensure that the same nurse (or deputy) is notified and available

5. Consideration should be given as to whether a relative accompanies the patient to the results clinic

9.6.4 Service Delivery:

Palliative care delivery in remote areas: Projects are being developed in different parts of Scotland to provide a small number of palliative care beds in community hospitals. These beds are supported by local GPs and will have links and input from specialist palliative care.

HIV Aids Care: A successful project to improve specialist support to GPs caring for HIV/AIDS patients is relevant also to palliative cancer care:

At patient discharge GP is notified by Fax. Contents include physical aspects, treatment, psychosocial aspects, what the patient knows/has been told, follow-up arrangements (shared care/visits with GP and hospital consultant)

Specialist advice for GP available on a 24 hour basis by telephone.

Regular newsletter to GPs about HIV/AIDS

Quarterly educational forum for GPs

Evaluation of this service showed that GPs felt more involved in the care of their HIV/AIDS patients. Patients themselves were more satisfied and there were fewer outpatient clinic attendances.

Note: For further information about any of the above examples of good practice please contact Margaret Stevenson at the Scottish Partnership Agency

10. Summary of recommendations

Palliative Care is required at primary care, cancer unit and cancer centre levels.

The different definitions of palliative care should be recognised and understood and the input of specialist palliative care acknowledged and integrated within the system.

Only those appropriately trained in palliative care should be designated as specialists in palliative care.

Multidisciplinary hospital palliative care teams should be established in cancer centres and cancer units.

Specialist palliative care units should be integrated with local cancer centres/units and the hospital palliative care team.

The hospital palliative care team should liaise closely with community palliative care services.

Educational programmes should be agreed and implemented for health professionals.

Measures should be taken to promote greater inter agency working (health, social work and the voluntary sector) and the appointment of a palliative care regional coordinator should be considered.

Utilisation of rapid and efficient means of communication is necessary. All team members should be kept informed.

Each health board should carry out a needs assessment for palliative care and devise a definitive strategy. (Some have already done this or work is ongoing.)

Guidelines (based on SIGN criteria) should be produced. Local standards and protocols should be set and audited.

Patients with non-malignant diseases and their carers should also be included in planning palliative care services.

Specialist palliative care practitioners should not be expected to function in isolation. Multi-disciplinary team work is essential.

The services established should base their philosophy of care upon the SPA/CRAG guidelines.(12)

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12. Appendices

Appendix I

Participants in SPA Project

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Mrs Anne Weston, Chief Area Nursing Officer, Borders Health Board

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Mrs Sue Williams, Director of Nursing, Greater Glasgow Community and Mental Health Services NHS Trust

Dr Diana Wilson, Consultant in Palliative Medicine, St Columba's Hospice

Dr Stanley Wright, Consultant Physician, Falkirk Royal Infirmary

Appendix II

Extract from Calman/Hine Report:

A Policy Framework for Commissioning Cancer Services

4.5 Palliative Care

4.5.1. Palliative care should not be associated exclusively with terminal care. Many patients need it early in the course of their disease, sometimes from the time of diagnosis. The palliative care team should integrate in a seamless way with all cancer treatment services to provide the best possible quality of life for the patient and their family. The palliative care services should work in close collaboration with their colleagues at the Cancer Centre and be involved in regional audit and developing integrated operational policies and protocols.

4.5.2. Although much palliative and terminal care is provided in the community by primary care teams, each district must have a specialist resource for both primary care and hospital based services. This facility should work with local hospital oncology services and with primary care teams to allow good communications and rapid access to specialised palliative treatments for symptom control, to provide respite care and to give psychosocial support to the patient and family at all stages, including bereavement. By this means, there should be a smooth progression of care between home, hospital and hospice.

4.5.3. The multi-disciplinary palliative care team should contain trained specialist medical and nursing staff, social workers, physiotherapists, occupational therapists and should relate to other disciplines such as dietetics and chaplaincy.

4.5.4. Patient facilities should be such as to ensure privacy and dignity through the provision of private rooms for confidential discussions, and facilities to allow relatives to remain with very ill patients. Spiritual care of patients must be available when required.

4.5.5. Hospice units have sometimes developed in an ad hoc fashion through voluntary effort and fundraising. As a result, links with health authorities and purchasers are under-developed in some areas. The quality standards and operational policies being developed by leading palliative care units and the National Council for Hospice and Specialist Palliative Care Services should be widely adopted to ensure high standards of care and integration with cancer care services to meet patient need. Where new developments are proposed, providers consulting with purchasers should assess local needs to ensure that services will not be duplicated, that current services are being used to best advantage and that the new service will improve liaison and satisfy unmet needs in patient care. New developments must not remove resources from established palliative care units which are delivering high quality care. Extract from Summary of Recommendations and Action Points xi Palliative care and symptom control should be available at all stages of a patient's illness. Hospitals, primary care, social services and the voluntary sector should all be involved.

Action: Commissioning authorities should develop a local plan for delivering palliative care, bringing together all providers.

Appendix III

A Cancer Journey

The following is an example through the patient's eyes of a "cancer journey" in which best practice and cooperation between services results in an integrated cancer treatment and palliative care service. Generalist palliative care is provided by all the health professionals involved and specialist palliative care is brought in when necessary.

- Worrying symptoms
- Attend GP
- Listened to carefully
- Examined fully
- Physical possibilities discussed in general terms
- Emotions, fears discussed/explored
- Plan discussed and agreed.

Short wait for

- Hospital out-patient appointment
- Consultant - listened - examined - discussed - planned - agreed. General explanation
- Minor operation soon after

News of diagnosis broken sensitively, with empathy, in private surroundings, in presence of nurse/relative

Time given for exploration of feelings

Possible treatment options/side-effects outlined. No promise of cure.

Time offered to consider possibilities

Explanation of team support: primary and secondary/tertiary care where/how it fits together

Decision to have chemotherapy

Made aware of local support groups

GP calls in to offer support from primary health care team

Offers time to listen, answer questions

Speaks to partner and later whole immediate family with my permission

Attendance at Cancer Unit/Centre for chemotherapy as an outpatient

Liaison Sister visits

Travel checked

Plan of action - timing of assessment of response to treatment

- what to do at home if problem

Social work

assess finance

emotions

All going well

Complete remission

Feel exhausted after all the chemotherapy

Period of feeling well/coping well

Anxiety/worry/fear - is it back?

GP explains maybe - arranges early appointment at Oncology Centre

Re-tests show yes - recurrence

Questions

- Was all chemotherapy worth it?

- why me?

- feel cheated

- angry it's come back

- can I take much more?

Some of above discussed sensitively with me by staff in oncology ward

Symptoms a problem

Morphine started after explanation - won't be an addict

Specialist palliative care team involved - assessment and ongoing support

Pain worsens

See Radiotherapist - explanation/choice

Plan agreed

Radiotherapy given

Symptoms better, feeling better

Later further symptoms

Regular meeting with specialist in palliative care and as the numbers of people increase one of the team is designated as the key person: I now know who to contact.

Seeing lots of different professionals all asking which drugs - shared care card very helpful (lists all drugs and details what I understand of my illness).

Details of illness discussed with me and then family together - openly, slowly, honestly, with empathy and concern.

Recognition that I am weakening quickly. Support is there GP, district nurse, specialist in palliative care.

I can tell those looking after me are communicating well.

Reassured by coordination of input. Professionalism, honesty, access to specialist palliative care unit if needed, specialist palliative care nurse, district nurse, GP visiting regularly.

Marie Curie night nurse three times per week to give my family a night's sleep.

I do want to make a choice about where I die.

Good-byes said, arrangements made, and I'm where I want to be.

Support available for the bereaved.

Appendix IV

Palliative care knowledge for generalists: suggested curriculum

The following are the topics which should be included in training for generalists in palliative care. The depth of study of each topic will depend on the background of the trainee group or individual.

Principles and Philosophy of palliative care

Epidemiology of chronic progressive incurable disease

Symptomatology:

- Physical
- Psychological
- Social
- Spiritual

Communication skills

Bereavement

Cultural aspects

Ethical issues

Legal issues

Availability of services including voluntary organisations

Appendix V

Specialist Palliative Care Services in Scotland 1996

(13 voluntary hospices and 4 NHS specialist units - excluding small "satellite" units with GP beds and some specialist input)

Hospice beds: 308

Day hospice services: 17

Palliative Medicine Consultants: 17

Hospital Services

Hospital Palliative Care Teams: 3

Macmillan Clinical Nurse Specialists/Hospital Support Nurses: 27

Hospitals with contracted sessions by hospice palliative medicine consultants: 7
(others have informal arrangements to receive advice and support)

Community Services

Macmillan/Hospice Home Care & Marie Curie Palliative Care Nurses: 87

Marie Curie Community Nurses provide an annual total of 114,800 hours of hands-on nursing across Scotland according to individual patient/relative need.

Paediatric Services

Malcolm Sargent Social Workers: 6

Malcolm Sargent Paediatric Oncology Nurse Specialist: 1

Macmillan Paediatric Nurse: 1

CLIC Oncology Liaison Nurse: 1

Paediatric Haematology Oncology Nurse Specialist (Terminal Care and Community Liaison): 1