PALLIATIVE CARE
This working paper has been prepared by Professor I G Finlay, Professor of Palliative Medicine and Medical Director of Holme Tower Marie Curie Centre, Cardiff. The report has been written as a result of visits to different services in Wales and interviews with professionals in primary and secondary care sectors and in hospice type services. The report also draws on published evidence from the literature on palliative care. The recommendations in this report have been agreed by the Cancer Services Expert Group.

Further information, regarding recommendation priorities and mechanisms for monitoring their implementation, is available from the Project Office.

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1. **EXECUTIVE SUMMARY**

1. There are three separate but interrelating aspects to palliative care:
   - Care delivery with a palliative approach should be a core skill of every health-care professional dealing with patients with life-threatening disease whether in primary health care, hospital practice or other community places of care.
   - Specialised palliative interventions are non-curative treatments aiming to improve the quality of a patient’s life. They are usually carried out and monitored by specialists in the relevant disciplines, for example, palliative radiotherapy, chemotherapy or surgery. Other specialised care includes psychosocial and physical support to cope with the disease or treatments.
   - Specialist palliative care is care delivered by a multiprofessional specialist team, led by clinicians with recognised specialist palliative care training. They work collaboratively with those giving care with a palliative approach to ensure that patient and family needs are met.

2. The provision of palliative care involves a generic service applicable to patients irrespective of the site of their cancer, but determined by the rate of disease progression and the impact that cancer has on the patient’s quality of life in many domains including physical, emotional, social and spiritual.

3. Palliative care services also have a responsibility beyond cancer to other patients with advancing life-threatening disease: care extends to the patient’s family and beyond the patient’s death into bereavement care. Therefore multiprofessional specialist palliative care service delivery must be widely available to enable all those dealing with patients to access specialist advice and help and to ensure the patient’s quality of life is optimised even in advanced disease.

4. The multiprofessional team must:
   - work across geographical and administrative boundaries.
   - have clearly defined roles for the different professionals within the team and the way they relate to other teams.
   - have two-way communications with primary, secondary, hospice and nursing home care
   - audit quality standards, ensure duplication of service provision is avoided through education, ensure clinical effectiveness by implementation of research findings into practice.

5. The characteristic components of specialist palliative care have been addressed in paragraph 4.5 (EAGC Report) and in the National Hospice Council statement of definitions document.

6. Formal partnerships should be forged between different small providers to form a functional unit for the provision of specialist palliative care services.

7. An estimated 20-22 consultants in Palliative Medicine will be required to meet the need in Wales.

8. An individual professional, even after specialised training, cannot function as a specialist unless working as part of a specialist team and undertaking continuing professional education and audit of practice. Those who have undertaken specific training in this area act as an important resource to their clinical team providing care with a palliative approach, and can be a valuable link for education and care provision.

**Communication**

9. Within the specialist team a single core form of documentation should be used. This multiprofessional patient record should be in a rapidly readable format, maintained up-to-date and be accessible to all members of the team caring for the patient.

10. The record should contain current problems and focus around care planning and evaluation, with the information told to patient and family clearly documented. The patient, as the focus of care, should be involved in drawing up and implementation of their care plan.

11. Computerised systems and drug formularies must be compatible through all parts of the clinical service.

12. Patient-held records are helpful.
Continuity of Care

13. A key-worker in the support team may be separate from the lead clinician.

14. Where General Practitioners use deputising services the increased workload on community pulliative care teams should be recognised in contracts.

Avoiding Duplication

15. Defined links and co-operative working between oncology and palliative care services must exist. The evaluation of need should support service developments; this should be undertaken with the local providers at specialist and non-specialist level and must recognise the role of specialist palliative care in care of non-cancer patients.

16. In each region or district a specific agency should take responsibility to co-ordinate service development and planning and evaluate standards of care.
2. PROVISION OF PALLIATIVE CARE TO CANCER PATIENTS

Background

2.01 Although much care of patients with cancer is of high standard, review of the literature reveals some deficiencies. The need to improve cancer care was recognised by the Expert Advisory Group Report (EAGC 1995) and is outlined in the Barcelona Declaration on Palliative Care (Appendix 1).

2.02 In the community and in hospitals substandard care of some patients with advanced cancer and the devastating impact of the diagnosis on patient and family have contributed to recommendations for the reorganisation of cancer services. Inaccessible, inadequate or delayed professional care and support, lack of practical help, financial advice and failing health of the closer carer compromise home care; hospital inadequacies include lack of information, poor symptom management and poorly planned discharged. Amongst those with advanced disease satisfaction with care tends to be higher among hospice patients.

2.03 Poor communication between professionals at all levels and with patients may be helped by education of professionals and by patient held records.

2.04 Specialist hospice services have developed ad hoc and are difficult to evaluate because of the complexity of care needed; the effectiveness of hospital follow up and of community care have also not been adequately evaluated and patterns of service provision vary.

2.05 The report has prompted new research into patterns of service delivery and discussion between patient groups and providers. The National Council for Hospice and Specialist Palliative Care Services has produced a document “Specialist Palliative Care: A Statement of Definitions” which defines the elements of specialist provision. Monitoring of this service provision by using a minimum data set as developed for specialist palliative care services will allow comparisons of workload and activity. Useful documents in setting standards for care are available.

2.06 The core knowledge and skills required by all doctors, whether general practitioners or hospital doctors, have been defined in the curriculum for teaching palliative care to recommended levels of competency. Similarly for nurses, curricula for training and standards of care have been defined.

2.07 The purchaser must ensure that the organisation of services allows patient and family to access appropriate and timely care of their choice, which are not subject to professional bias or prejudice in availability.

Achieving Improvements in the Separate Components of Palliative Care Services

Multiprofessional Team

2.08 The characteristic components of specialist palliative care have been addressed in paragraph 4.5 (EAGC Report) and in the National Hospice Council statement of definitions document.

2.09 A specialist team requires specialised competencies in all members of that multiprofessional team.

2.10 In some areas, formal partnerships should be forged between different small providers to form a functional unit for the provision of specialist palliative care services.

2.11 An individual professional, even after specialised training, cannot function as a specialist unless working as part of a specialist team and undertaking continuing professional education and audit of practice. Those who have undertaken specific training in this area act as an important resource to their clinical team providing care with a palliative approach, and can be valuable link personnel for education and care provision.

Roles of the Team

2.12 Primary care teams and hospital teams dealing with cancer patients should be able to provide care with a palliative approach (non-specialist palliative care) as part of routine clinical practice. Where a team is for any reason unable to provide this, it must ensure that the individual patient can access appropriate care.

2.13 Whatever the level of training of clinicians working in the non-specialist team, patients must remain able to choose to seek specialist care help on an individual basis.
Modern cancer care may require a transfer between different services, different administrative units, such as NHS directorates and trusts or the non-statutory providers, as well as between primary and secondary care. Co-operation at managerial level is essential to ensure that services for an individual patient are not duplicated and that there is consistency in care.

**Communication**

Documentation is an important means of communication. Within the specialist team a single core form of documentation should be used. This multiprofessional patient record should be in a rapidly readable format, maintained up-to-date and be accessible to all members of the team caring for the patient.

The record should contain current problems and focus around care planning and evaluation, with the information told to patient and family clearly documented. The patient, as the focus of care, should be involved in drawing up and implementation of their care plan.

Patient records, including computerised systems, must be compatible with documentation at the cancer centre and cancer unit to allow rapid transfer of clinical information through defined communication links. Where possible computerised links should extend to the primary care team. Adequate safeguards for technical failure and to protect confidentiality are essential.

Time must be allowed for adequate and accurate record keeping and for the rapid transfer of information to other clinical services.

Patient-held records encourage and aid communication between professionals and with the patient and family. These should contain a minimum data set agreed between cancer centre, units and primary care, to include information on drugs, treatment proposed and treatment given.

A core drug formulary for the local specialist palliative care teams, compatible with the cancer centre and units, can avoid medication being altered by administrative boundaries of different hospitals or Trusts when patients transfer.

Quality of standards should include standards for sharing information, both physical and psychosocial, that can alter patient management. Audit of patterns of communication should occur between specialist hospital and primary care teams and between the different professionals within each team.

**Continuity of Care**

For general practitioners to fulfil their role at the focus of care for cancer patients (para 4.1.2 Calman/Hine) they will need to take a lead role to ensure effective communication and cascading of information between those different professionals and agencies such as social services, involved in the patient’s care.

For some patients where care is complex it can be helpful for a team to define at any one time who is the key-worker in the support team and who is the lead consultant for decision making. These roles require communication with all others involved.

Patients with advancing cancer at home should be able to access support at all times from clinicians aware of their clinical condition. Where General Practitioners deputising services cover out of hours, the workload often falls to community hospice services to provide 24 hour support to patients known to them, and carers, in their own homes. This workload should be recognised in contracts.

**Information Transfer**

A minimum standard of information transfer on patients should specify the minimum information, including the diagnosis, current problems, proposed management plan, information given to the patient, involvement of family in care, other agencies involved and current treatment including medication.

The time frame for information transfer and the two way nature of communication between services, including communication from primary care to the secondary sector should also be specified. Communication must be two-way, accurate and timely, so the patient is not subject to delays in care through lack of clinical information. Effective clinical care depends on accurate up-to-date information on a patient, therefore all involved in a patient’s care have an equal and ongoing responsibility to communicate with and provide relevant information to others.
2.27 A local directory of services should list the specialist services and be compatible with locally developed protocols for the management of different site-specific cancers; this should include information on fast track routes for referral and recommended criteria.

Audit, Research and Education
2.28 All those providing care for cancer patients have responsibility to audit their own provision of care. This responsibility applies to primary care teams, hospital teams and to specialist palliative care teams. The level of their service provision will determine their pattern of audit.

Avoiding Duplication
2.29 Purchasers of care will need to specify quality standards and, through bench-marking, comparative levels will eventually be established as criteria are defined.

Avoiding Duplication
2.30 Purchasers have the responsibility to monitor delivery of care when patients are transferred from one provider to another as well as monitoring individual providers.

2.31 Defined links and co-operative working between oncology and palliative care services must exist. The evaluation of need should support service developments; this should be undertaken with the local providers at specialist and non-specialist level and must recognise the role of specialist palliative care in care of non-cancer patients.

2.32 In each region or district a specific agency may be needed to take responsibility for ensuring co-ordinated service development and planning, to evaluate standards of care and to monitor development.

2.33 Each health authority will need to have a consultative process in place, with co-operation between adjacent health authorities, to examine the need and feasibility of new developments and to assess the role of current providers of specialist palliative care.

Summary
2.34 There is a need for all those purchasing care for cancer patients to ensure that there are three levels of provision available to all patients who may need them. These are:

- General services whose professionals possess minimum competencies, including communication skills, in providing care with a palliative approach.
- Accessibility to specialised palliative treatments, with comprehensive psychosocial and care support, given by specialist teams in fields other than palliative care, such as radiotherapy, chemotherapy and surgical interventions and access to specialised radiological diagnosis and techniques.
- Specialist palliative care provided by those working in multiprofessional teams in the palliative care field, who have undergone recognised training programmes, where these exist, and whose competencies have been assessed by an external validation body such as an educational institution. These specialist multiprofessional teams should function as defined in section 4.5 of the Calman/Hine report and accord with the recommendations above.

3. WELSH ISSUES IN THE PROVISION OF PALLIATIVE CARE SERVICES

Background
3.01 There is a relative paucity of palliative medicine in Wales, although the numbers of nurses working full time in the field are probably the same as in other parts of the UK. Data on nursing numbers is not readily available on a UK wide basis, unlike the numbers in medicine which are available from the Association for Palliative Medicine.

3.02 In North Thames, with a population of about 4 million, there are 30 consultants in palliative medicine. This compares with seven current consultants in palliative medicine in Wales, three additional posts planned and one more proposed.

Service Distribution
3.03 The distribution of hospice services is changing. There is one consultant recently appointed in Bangor, one in Wrexham, two consultants with plans for a third based in Swansea, one consultant in Bridgend, one consultant in Merthyr, 2.6 consultants to cover Mid and Southern Bro Taf, one consultant in South Gwent with a second post advertised.
3.04 However, this remains inadequate as projections suggest there should be at least 1 consultant in palliative medicine for a population of 200,000. This then ensures that there is specialist senior medical input to co-ordinate the multiprofessional team development and to act as a specialist medical resource to consultants and general practitioners in the area. Rural areas place different demands from urban, particularly as the infrastructure of roads in Wales is poor compared to many parts of Britain.

3.05 It is difficult to quantify the pattern of nursing services, but specialist multiprofessional teams are being established where there is a consultant, specialist trained nurses, physiotherapy, occupational therapy and social work.

3.06 The demands of the cancer centre need special consideration. Increased teaching time, research time and the complexity of some of the clinical cases will mean that the need for input there is slightly different and higher than for posts that are linked to cancer units; therefore it would be important to add an additional 1 WTE post to service the demands of cancer centre services.

3.07 There is little good needs-based evidence for the development of a children’s hospice separate from the children’s services at Llandough. However the popular appeal of the project amongst the fund-raising public will probably mean that it can become self-financing and will provide respite for children with long term chronic disease, rather than those with advanced cancer.

**Relationship with Primary Care**

3.08 The role of the specialist team needs to be clearly differentiated for the generalist team, both in hospital and in the community.

3.09 The role of the general practitioner in delivery of services to patients in their own homes should not be underestimated.

3.10 The increasing use of deputising services is shifting the pattern of care delivery and the role of the palliative care team out-of-hours. The patients are increasingly contacting the services out-of-hours directly, rather than contact the GP first. This is because the deputising doctor does not know them, often has little or no knowledge of palliative care and has a workload demand such that it is not possible for even the most motivated deputising doctor to spend time in the house of a terminally ill patient. There are financial implications in this changing pattern of workload. The GP is saved expenditure by the patients not using deputising, but no contract and therefore no payment exists for the home care palliative care team to cover their increased workload.

3.11 The other implication is in drug prescribing. Where patients deteriorate suddenly at night or over weekends, it may become necessary for the nurse visiting to set up a syringe driver as a patient deteriorates. At present the arrangements for the prescribing of drugs is not satisfactory in some parts of Wales and cumbersome in others, due to the lack of appropriate medical staff to assess the patient and then prescribe appropriately.

3.12 Communication needs to be a two-way process over the patient’s progress. Although all the palliative care services visited for this report do appear to be striving to communicate at all times with the GPs, there are several instances we became aware of when the communication back from the GP failed. This included failure to notify a service when a patient they had been involved with had died at home; this had caused a great deal of unnecessary distress to the relatives when later contacted by the service. Other instances related to failure to inform of alterations in the clinical or social condition of the patient (e.g. the illness or death of a near relative); the increasing introduction of shared-care patient held records should help to prevent this continuing.

**Relationship to Other Specialist Services**

3.13 In some areas the communication between the different specialist services is excellent, particularly in South Glamorgan. However throughout Wales there were examples of reluctance or refusal of some surgeons and physicians to involve palliative care services when timely in the patient’s condition. This relates to an ignorance of the role of palliative care, to a difficulty in accepting the non-curable nature of the patient’s condition and a failure to recognise the importance of psychosocial support and planning in the care of patients.

3.14 Outside the Cardiff area, oncology related poorly at a professional level with palliative medicine and with other specialities involved in the care of these patients.

3.15 The chronic pain services are developing throughout Wales. The link between the Wrexham services is to be commended and is the result of much hard work by all concerned.
Team Working

3.16 Team working must be considered at inter-team and intra-team levels.

3.17 The importance of multiprofessional working to ensure the patient has access to a range of skilled professionals to provide support and help to improve patient’s quality of life. The range of people potentially involved requires good team-working to ensure that the patient is not overwhelmed by too many new personal contacts and that continuity of care is not lost. The concept of a key-worker of the patient is implemented in many areas by the palliative care team and is usually a role undertaken by a nurse. This requires the nurse to liaise closely with the team and to seek appropriate help and assistance.

3.18 The term specialist has not been clearly defined for professional other than medicine. In palliative medicine all higher professional training can only occur in these posts that have been inspected by the Specialist Advisory Committee of the Royal College of Physicians and that carry manpower approval; these posts are monitored by the Postgraduate Dean. After January 1997 it will be illegal to appoint at consultant grade a doctor who is not already on the specialist register or holding a certificate of completion of specialist training. In nursing, social work, physiotherapy and occupational therapy there is no structure to the establishment of training posts nor any clear definition of when a person can be considered a specialist. This has historic origins as the speciality developed, but means that at present a person may be labelled as a specialist simply by having been successful at interview for a post; there are several examples in Wales where the appointee to a specialist post had little or no experience in palliative care and then worked relatively unsupervised; with no-one with specialist knowledge to turn to.

Future Developments

3.19 The planned units in North Wales should proceed as fast as possible to enable the populations of Bangor, Llandudno and those around the new Ysbyty Glan Clwyd development to have the service that is available in Wrexham and in South East Wales.

3.20 In rural areas of central Wales and in West Wales, both North and South, the provision of two or four Macmillan beds in community hospitals should not be considered as meeting the needs as these beds are currently not serviced or staffed by a multiprofessional team able to provide specialist palliative care advice or on site care. There is therefore a need to create a community consultant in the central rural parts of Wales to act as a resource to the local primary care teams and to the community hospitals. The development of a network of general practitioners at clinical assistant level who have special education and are responsible for education of their peers and audit may be a way of cascading knowledge and skills rapidly through the patient services in these areas.

3.21 Consideration should be given to a faculty of palliative care that would develop on an all-Wales basis:
- A basic level education course for non-specialists, which could be followed by the more specialised diploma course available through UWCM.
- Standards to define and accredit specialist staff and monitor their ongoing educational development.
- Unified data collection procedures to make comparative data available on workload, referral types and which could form a research base.
- Role definitions and defined standards of working practice for the different professional staff and different grades in teams caring for patients.
- Concepts of partnership between the different voluntary sector and NHS sectors to provide a seamless multiprofessional service to patients across trust and other administrative boundaries.

Minimum Recommendations

3.22 Increase the number of palliative medicine consultants in Wales to be nearer the norm for other parts of the UK.

3.23 Ensure that all those working with cancer patients have a minimum standard of communication skills training.

3.24 Develop standardised data forms through patient-held records, written multiprofessional records and on computerised systems; these should also be compatible with the cancer registry data collection system.

3.25 Define the roles and work patterns of:
• specialists
• those working in palliative care, but not at specialist grade
• generalists.

3.26 Undertake job sizing for specialist posts in Wales in nursing and other disciplines.

**Proposed Template for Service Delivery in Palliative Care**

3.27 Although the aim of cancer services is initially to provide cure, a great number of patients require palliation for their symptoms during the process of their treatment, especially when the treatment is at best aiming to be life prolonging, but may only be achieving a degree of disease control, until progression of the process towards death.

3.28 The need of the population as a whole can therefore be summarised by the following diagram, whereby some patients need palliative care from the time of diagnosis and many will progress, with increasing palliative needs towards death. Palliative care does not end with the death of a patient; the bereavement needs of the family and in particular of the children must be addressed and support given. There is increasing evidence that adequate provision of support at the outset can decrease morbidity in the bereaved and the pattern of grief can be prevented from becoming complicated by good pre-bereavement and peri-bereavement care.

![Patient needs with time diagram]

3.29 The personnel providing palliative care should be focused around the patient and the family.

3.30 The family are frequently more dependent emotionally on the palliative care team than on the primary care team for many reasons. This should not be viewed as threatening to the primary care team as the roles should be complimentary in meeting needs of families, but does require excellent communication between all those giving care to ensure consistency of practice. There is concern that some services fail to communicate fully with colleagues, resulting in patients being denied access to palliative treatments, such as nerve blocks, radiotherapy or chemotherapy. This poor communication also results in late referrals to services, which then fulfil only a terminal care role for the dying who may have had inadequate palliation during prior treatments.

3.31 The link role of palliative care between hospital and community functions optimally where there are close working relationships between all disciplines such as surgery, oncology and palliative care.


Features of a Palliative Care Service

3.32 Hub and Spoke Configuration - This allows education and training of staff at all grades. The hub will contain the key resources such as inpatient beds, adequate consultant staff and tutor staff. Outreach from the “hub” allows concurrent clinics to be held with other specialists such as oncology.

3.33 Dedicated specialist beds - are essential for good palliative care to those with difficult or intractable symptoms as well as for those families with many psychosocial difficulties. These beds must be staffed by nurses with some expertise in palliative care backed by knowledgeable medical input.

3.34 Specialist pain services, both anaesthetic and neurosurgical, should have a special interest in care of patients with malignant pains.

3.35 The team should act as a back-up resource to general practitioner services and to hospital services; in most of Wales palliative care will be provided by collaboration between referrer and team.

3.36 Day care facilities provide different levels of care, from social support to day treatments. Those considered under the banner of specialist palliative care should provide full multiprofessional care, not only nursing services.

3.37 Clinical nurse specialists have an important role working in site specialised treatment teams for cancer patients and in cancer information services. They need to have established links and guidelines on cross referral to palliative care to prevent patients slipping through the net of provision.

3.38 The multiprofessional palliative care team must have:

- evidence of co-operative working
- clear lines of clinical answerability within the team
- appropriately qualified key members
- ability to take referrals for any appropriate condition, including cancer
- cross boundary work patterns
- service audit
- a facilitative and educational role for other clinical teams

Job Sizing Estimates for Palliative Care

3.39 After some consultation the following is a recommendation of an approximate job sizing for Wales giving a minimum number quota.

3.40 For a population base of approximately 200,000 there will be comparable numbers of cancer and non malignant diseases amongst patients who require palliative care. The difference between rural and urban areas needs to be accounted for although in many urban areas, deprivation will be an additional compounding factor affecting workload. However, at present there is no guidance whatsoever and therefore this is intended as a template.

Population base 200,000

3.41 Consultant in Palliative Medicine: one whole time equivalent minimum.

3.42 Specialist nurses: three whole time equivalent for the community.

3.43 For a cancer unit hospital: 3-5 sessions of Consultant in Palliative Medicine time and a minimum of one specialist nurse in palliative medicine.

3.44 Community will require approximately 0.5 whole time equivalent of dedicated social work input.

3.45 Physiotherapy and occupational therapy should be available on approximately one session per week minimum to be attached to the palliative care team.

3.46 The palliative care team could cross hospital community boundaries to good effect.

Consultant Staff

3.47 The training to specialist level in palliative medicine is now laid out by the Royal College of Physicians, and palliative medicine is recognised as a distinct speciality. After January 1997 a Certificate of Completion of Specialist Training (CCST) will be required by all doctors applying for consultant grade posts.
Specialist Nurses

3.48 Specialist nurses to date have not been defined but discussion with several senior nurses in the area suggest that the following may be a working definition:

3.49 Specialist nurse should have a minimum of three years clinical experience in a recognised training establishment for palliative care services and should have been trained to a minimum standard of the WNB/ENB 285 Course or Diploma in Palliative Nursing level.

3.50 The ENB 931 course is insufficient training to practice as a specialist nurse. The training course is excellent to improve general generic skills in palliative nursing. The specialist nurse should be undertaking a clinical role, a teaching role and also some audit/evaluation/research in palliative nursing. It would be appropriate for other nurses working full time in palliative nursing either in the community or in the hospital setting to be answerable to the specialist nurse and to work under the specialist nurse’s supervision. The specialist nurse will carry responsibility for maintaining the clinical effectiveness and clinical knowledge of the other nurses within the team and to work with the Consultant in Palliative Medicine to ensure that the team functions well. Currently there seems to be a need for about 1 full time palliative care nurse at non-specialist grade, i.e. F or G grade, for 20,000 population in the community.

Rural Areas

3.51 In rural areas specific specialist palliative care units of beds and day care may be an inappropriate use of resources. The use of clinical assistants and nurses who have undergone basic training above the standard requirement for their routine work will be an additional resource who should have a “link” attachment to the locality specialist palliative care team to ensure that the standard of care of patients in community hospitals and in district general hospitals is to an appropriate standard. The specialist palliative care team will be responsible for ensuring the evaluation tools are in place and the education programme is in place for their locality.

3.52 These calculations suggest that 15 consultants in palliative medicine will be required for Wales - it is worth noting that for a population area of 3.5 million in the south east of England there are currently 30 consultants in palliative medicine. The number of training posts required within Wales is currently four - probably this should increase to five. These consultants will need to have clinical assistants/staff grade support for out of hours cover, etc.

3.53 In England the workload of a consultant is a maximum of 440 referrals per annum and a ratio of one consultant to 2.4 specialist nurses has been suggested. A consultant could be expected to be looking after 6 to 20 beds, depending on other commitments to the community day care, etc. The cancer centre with its increased workload of complex cases will require more specialist staff per patient ratio than elsewhere.

3.54 All palliative care services need to ensure they are in partnership arrangements to ensure out of hours cover. Where GP deputising services are used, the number of nurses in the team and the amount of medical input will need to be increased to ensure continuity of care.

3.55 In addition to this baseline staffing level an academic unit of palliative care will require staff over and above this to oversee the development on an all Wales basis. It would be appropriate that the academic unit is attached to the principle cancer centre for Wales.

4. RECOMMENDATIONS

1. The specialist multiprofessional palliative care team should work across geographical and administrative boundaries(a,b).

2. There should be clearly defined roles for the different professionals within the team and the way they relate to other teams(a,b,c).

3. There must be two-way communications with primary, secondary, hospice and nursing home care(a,c).

4. All professionals who hold NHS contracts at any level, including honorary, and are involved in the care of the patient in the community, but who are not members of the specialist palliative care team, must have clear clinical accountability within the framework of the primary health care team (PHCT). If specialists in palliative care, they must have clear accountability within the framework of a multiprofessional specialist palliative care team; in many areas this will require partnerships being forged between different small specialist palliative care teams.
5. All those providing care in association with any NHS service must work within a professional framework of clear accountability. Individuals, for example those working for a non-statutory agency, must have accredited training, properly constituted appointment procedures, continuing education and supervision. These procedures must be monitored by purchasers.

6. PHCTs have continuing patient responsibility. Wherever the demands of palliative care exceed the resources available from the PHCT, then it is the duty of the general practitioner to refer the patient to an appropriate specialist service for the provision of care, this may be community-based. Such referral could include specific provision of care out-of-hours (c).

7. Formal partnerships should be forged between different small providers to form a functional multiprofessional unit for the provision of specialist palliative care services (c).

8. Patients at home can require rapid and frequent changes in medication to maintain optimal symptom control. The supply of drugs to achieve this and avoid wastage may require a revision of pharmacy services and regulations (d).

9. Patient-held records should be used as a means of communication (a).

10. Within the specialist team a single core form of documentation should be used. This multiprofessional patient record should be in a rapidly readable format, be up-to-date and be accessible to all members of the team caring for the patient (d).

11. The record should contain current problems and focus around care planning and evaluation, with the information told to patient and family clearly documented. The patient, as the focus of care, should be involved in drawing up and the implementation of their care plan (a,c).

12. Computerised systems and drug formularies must be compatible through all parts of the clinical service.

13. A key-worker in the support team may be separate from the lead clinician (a).

14. Where general practitioners use deputising services the increased out of hours workload on community palliative care teams should be recognised in contracts.

15. Defined links and co-operative working between oncology and palliative care services must exist. The evaluation of need should support service developments; this should be undertaken with the local providers at specialist and non-specialist level and must recognise the role of specialist palliative care in care of non-cancer patients.

16. In each district a specific agency should take responsibility to co-ordinate service development and planning and evaluate standards of care (a).

17. The multidisciplinary team should audit quality standards and ensure duplication of service provision is avoided. Through education, clinical effectiveness will result from the implementation of research into clinical practice (b).

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**Evidence base:**

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<td>a.</td>
<td>Published Papers</td>
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<td>b.</td>
<td>Welsh Health Planning Forum 1990</td>
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<td>c.</td>
<td>National Cancer Alliance 1996</td>
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<td>d.</td>
<td>National Hospice Council 1995</td>
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**REFERENCES**


34. Buckley M. *Patient Held Record.* Velindre NHS Trust 1995

104 Palliative Care Task Group Report

41. Stamatakis JD (personal communication in press)
42. Clark D (personal communication, in press)
46. Information for Purchasers: Background for available Specialist Palliative Care Services. National Council for Hospice and Specialist Palliative Care Services, June 1995
47. *Standards for Cancer Nursing Education* (to be published 1996) The Royal College of Nursing, London
48. Association for Palliative Medicine of Great Britain and Ireland, Southampton. *Palliative Medicine Curriculum 1992*
49. A *Core Curriculum for a Post-Basic Course in Palliative Nursing.* The International Society for Nurses in Cancer Care, approved by the Cancer and Palliative Care Unit, the World Health Organisation 1991.
APPENDIX 1 - THE BARCELONA DECLARATION ON PALLIATIVE CARE

The Problem

Worldwide, 52m people die each year. Approximately 1 out of 10 deaths is due to cancer and millions more suffer from other life-threatening conditions including AIDS and diseases of old age. Of patients with advanced cancer, 70% have pain. In the developing countries of the world, people with cancer are only identified, if at all, after their disease has become incurable. Unrelieved suffering on this scale is unacceptable and unnecessary.

What we know

Palliative care is the active care of people whose illness can no longer be cured. In recent years, major advances have been made in pain and symptom management in people with progressive incurable diseases. Great studies have taken place in understanding the psychosocial, social and spiritual aspects of dying and death. Health professionals, family members, volunteers and others are working together to create dynamic partnerships for the relief of suffering at the end
of life. Palliative care, centred on patients and families, incorporates medicine, nursing, social work, pastoral care, physiotherapy, occupational therapy and related disciplines.

**What must be done**

Palliative care must be included as part of governmental health policy, as recommended by the World Health Organisation.

Every individual has the right to pain relief. Palliative care must be provided according to the principle of equity irrespective of age, race, gender ethnicity, social status, national origin and ability to pay for services.

Cost-effective methods exist to relieve pain and other symptoms. Thus cost should not be an impediment.

The experience gained from palliative care of cancer should be extended to the care of people with other chronic incurable diseases in a non-invasive manner.

Governments should use knowledge about palliative care in a rational way to:

- establish clear and informed policies
- implement specific services
- educate health professional and the public
- ensure that necessary drugs are adequately available
- simplify prescribing procedures

Systematic assessment of needs and outcomes in palliative care should occur with the establishment of any service at the local, regional and/or national level.

Families in the broadest sense are essential contributors to the delivery of effective palliative care. They should be recognised and empowered by government policy.

*Barcelona, December 9, 1995*

*Ministry of Health, Government of Catalonia*
*World Health Organisation Cancer and Palliative Care Programme*
*IVth Congress of the European Association for Palliative Care*
*1st Congress of the Spanish Society of Palliative Care*