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A Strategic Direction for Palliative Care Services in Wales

August 2002
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INTRODUCTION

Wales has many examples of good practice in palliative care and there are increasingly strong networks of palliative care providers and commissioners which are helping to spread good practice. However, services vary from area to area. This Strategy brings together existing guidance, promotes good practice and makes recommendations on development of services. The aim is to provide a strategic framework which will provide a blueprint for consistently high quality palliative care services that are available uniformly across Wales.

This Strategy has been produced in close cooperation with the Wales Association of Palliative Care. It seeks to provide a distinctly Welsh strategy to meet the needs of the people of Wales but it draws upon the work done by the Department of Health in England and the Association’s parent body, the National Council for Hospice and Specialist Palliative Care.

BACKGROUND

In Wales one in three of the population will get cancer and one in four will die from it. In 1999 8456 registered deaths in Wales carried a diagnosis of cancer. Of these, 80% will have experienced moderate or severe pain; other frequent distressing symptoms including nausea and vomiting, breathlessness, severe weakness, depression, bowel problems and mouth discomfort.

Many of these symptoms can be controlled through adequate care with a palliative approach. However, when a patient’s distress shows no sign of improvement after 48 hours, referral to Specialist Palliative Care is recommended and is a standard specified in the All Wales Minimum Standards from the Cancer Services Coordinating Group.

The recognition of the value of specialist palliative care in the management of non-malignant incurable conditions is increasing. Chronic cardiac and neurological conditions can cause complex symptomatology. Furthermore, the progression of disease often means that specialist symptom control may be required over many months or years. Palliative care in non-malignant life-limiting conditions is particularly important for children.

THE DEFINITION OF PALLIATIVE CARE

The World Health Organisation defines palliative care as “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 quality of life for patients and their families.”
Palliative and supportive care differ in philosophy from curative strategies in focusing primarily on managing the consequences of a disease rather than its cause or specific cure. (This does not mean that palliative care may not also be necessary for patients receiving treatment aimed at cure.) The approaches are therefore necessarily holistic, pragmatic and multidisciplinary. There is practically no distinction between palliation and support.

Traditionally it has been thought that palliative care and hospice services only apply to those who are dying, but it has become increasingly evident that palliative care is often needed from the time of diagnosis, whether or not the disease will be responsive to curative treatment. It is evident that the cost-efficacy of palliative care is far greater than curative treatments in eg cancer, in terms of quality of life for the individual and for their family. This has changed the emphasis of services, towards services working in parallel with other specialties, earlier in the disease.

Palliative care services have an increasing role in care of those with other incurable disease apart from cancer. Services should also be responsible for ensuring bereavement care is provided to those at risk of complicated grief. It is important to realise that palliative care may be required by any patient with a progressive life-limiting disease. Thus data from cancer workload significantly underestimates the need for palliative care services in adults and especially in children.

THE POLICY FRAMEWORK

The 1995 report of the Expert Advisory Group on Cancers (the Calman Hine Report) emphasised:

- the need for multi-professional specialist palliative care teams containing trained specialist medical and nursing staff, social workers, physiotherapists, occupational therapists and should relate to other disciplines such as dietetics and chaplaincy.
- These teams 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.
- 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 through bereavement.
- There should be a smooth progression of care between home, hospital and hospice.
- 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 and may be required by patients with any progressive life-limiting disease, such as those with AIDS, motor neurone disease, and end stage cardio respiratory failure. Lymphoedema is a specific condition which needs
consideration in its own right as it occurs commonly and has significant associated morbidity.

- Importantly, the report also recognised the specialist nature of palliative care and that care with a palliative care approach is a core duty of every health care professional. Staff in social care also have responsibility for understanding and contributing to optimum outcomes for those undergoing palliative care and in support of their carers.

The Cancer Services in Wales report (commonly known as the Cameron Report) outlined the implementation of the Calman Hine report in Wales, with staffing levels and strategies required for all aspects of cancer services.

The Welsh Office document Palliative Care in Wales: Towards Evidence Based Purchasing established a framework for the development of local policies and recommended closer working links between agencies. It advised on protocols for referral and had four key themes:

- access to palliative care services of a high standard
- adequate appropriate and widely available information
- funding and support for research in all professional areas
- increased training of existing staff

Palliative Care 2000 was produced by the National Council for Hospice and Specialist Palliative Care Services in England, Wales and Northern Ireland, and has been modified by the All Wales Executive Committee of the National Council for Hospice and Specialist Palliative Care Service to fit the Welsh context. It outlines three levels of team: specialist, intermediate and generalist.

In October 2000 the Welsh Medical Committee commissioned a report on palliative care services in Wales. The aim was to review the current provision of services, define the standards of care that should be available, highlight deficiencies and recommend service developments required to ensure that an adequate service is provided equitably in Wales.

In April 2001 the Directors of Public Health Medicine with responsibility for Child Health in all five Welsh Health Authorities agreed the document ‘Paediatric Palliative Care in Wales’. The document contrasts palliative care services available for children in Wales with the recommendations from the Royal College of Paediatrics and Child Health published in 1997 (the findings of this paper also inform the current strategy).

RESEARCH EVIDENCE OF EFFICACY OF SPECIALIST PALLIATIVE CARE

A systematic review of the effectiveness and cost effectiveness of palliative care teams commissioned by the Wales Office for Research and Development found that there is evidence to show positive benefit of palliative care services on patient and carer outcomes, with possible advantages of specialist palliative care services over
intermediate level services demonstrable. This is across a range of services, although the data is most strong for home care services. Also in reviewing the economics of palliative care, there was no evidence that home care was less expensive overall. This report (which will be published next year as a Cochrane review), recommends that as well as effective services delivered in the patient’s home, hospice and specialist palliative care services should be supported by the NHS as an effective method of caring for patients in advanced illness. It also highlights that research should be supported to evaluate different models of palliative care teams and the relative merits of hospital, home and inpatient hospice support. Analysis of the type of care delivered by different teams suggest that full specialist and intermediate level teams both have benefit on outcomes, compared to generic care.

THE PRINCIPLES OF PALLIATIVE CARE

- There are certain key principles which should govern the approach to commissioning, delivery and evaluation of palliative care services.
- Every person with life-limiting conditions, irrespective of age, should be able to receive palliative care, appropriate for their assessed need.
- Every health care professional should incorporate basic palliative care in their approach to clinical practice, knowing when to call in specialist palliative care colleagues to improve the quality of life for patients.
- Health care commissioning bodies should ensure that there is a clear strategy for the delivery of palliative care services to their defined population, that the resources (both facilities and trained staff) are available to meet the plan and that providers of care meet agreed standards of delivery both in volume and quality terms.
- Health care commissioners should ensure that NHS and voluntary sector providers work together in developing palliative care strategy and delivery of services.
- Every commissioner and provider of palliative care should ensure that patients and families are consulted on the quality and nature of the services.
- The three cancer service networks in Wales must ensure that specialist palliative care services are incorporated into all aspects of service provision, and are equitably available to the population served by the network.
- The cancer services networks should promote and facilitate research and education in palliative care as well as in oncology.

KEY ISSUES

We set out below the key issues in palliative care and list below the general aims which govern our approach to them. Later in the document, we list recommendations which provide the detailed actions required to achieve these aims.
Pain in Palliative Care

Pain has a complex pathophysiology and those with advancing life-threatening disease appear to have different receptor responses than others with pain. This may be due to genetic differences, different pain mechanisms, particularly in neuropathic pain, to tolerance and cross tolerance of opioids, and differences in opioids metabolism in disease. Pain is common in cancer: many patients’ presenting complaint is pain. On admission to a hospice, over 75% of patients reported being dissatisfied with their pain control and 89% had experienced severe breakthrough pain on top of their baseline pain; they had 1-5 different pains per patient. In advanced disease pain is often a complex phenomenon. It can have multiple causes, occur at several anatomical sites simultaneously and the distress caused by pain is worsened by the emotional, social and spiritual distress of the patient.

Aim

We need a coherent approach to pain management and we need to ensure that good practice is spread across Wales so that everyone has access to good quality care. In doing so, we need to stress to practitioners that the successful and sympathetic treatment of pain is a key element of palliative care. Many factors influence the perception and expression of pain. Some factors are amenable to pharmacological modification, while for others medication alone may be merely meddlesome. Other physical symptoms can exacerbate pain, so the clinical assessment of causes and the clinical management of any underlying conditions are of paramount importance. The holistic approach to the treatment of pain extends to the family and to staff, whose frustrations at the complications around benefits and procedures to facilitate discharge will be shared by the patient. Those who are isolated, have family and interpersonal problems, financial issues, or cannot go home for other reasons may remain as what they perceive as unwelcome ‘guests’ on a busy ward. Social Services play an important role in securing effective discharge arrangements and substantial effort has been put in recently to avoiding unnecessary stays in hospital. Welfare rights teams can also assist in providing advice on benefits. The role of the chaplain can be key to helping patients and their carers who may face existential restructuring of their belief system through the crisis that they face. There is also evidence that expression of pain is strongly influenced by the ethnicity of patient and that such responses are not confined to those with cancer, but are also evident in patients with cardiac failure.

Involvement in Decisions

Despite much publicity about patients’ desire to be involved in decisions about their care, a recent UK survey by BACUP revealed that 54% respondents were not involved in decision-making about their treatment. When considering where people wish to be cared for and where they prefer to die, home as the preferred place of care is prominent. This preference is almost universal among families of dying children [Ref: Goldman A, Beardsmore S, Hunt J. Palliative care for children with
cancer – home, hospital, or hospice? Arch Dis Child 1990; 65 (6):641-3]. However, for some cultural groups and where resources (physical, financial or emotional) are insufficient, the patient and/or family may prefer the burden of care to be borne in a hospital or hospice unit and some may feel safer in an inpatient unit.

Aim

All services, voluntary and statutory must develop systems which give proper and balanced weight to the preferences of patients and their carers. This includes honouring as far as possible wishes on where people wish to die. This is not simply a matter of honouring the wish unless complications set in. A more imaginative approach is needed. For instance, some acute admissions shortly before death could be avoided by rapidly available specialist palliative care support and advice out of hours. In some places rapid response teams involving both health and social services have been developed.

Out of Hours Services

The failure of out-of-hours care can cause patients much distress. Some components to this are:

- Patients attended by professionals not familiar with the patient their condition and their particular needs;
- Lack of speedy response to request for a home visit and interrogation by the answering service before a home visit is agreed;
- Drugs not immediately available;
- Lack of district nursing support out-of-hours;
- Inability to access equipment, such as a commode or wheelchair, particularly over holiday weeks;
- Putting together emergency packages of social care – most social care emergency services only provide an on-call “crisis” response.

Holme Tower Marie Curie Centre provides telephone advice to professionals throughout Wales, with over 80 telephone calls per week, mostly at nights and weekends. For many parts of Wales this is the only out-of-hours cover available. Other units, for example Nightingale House in Wrexham, provide this service to their locality.

Aim

The ‘Palliative Care and Out of Hours Services Working Group’ identified three main routes by which access to palliative care drugs can be made outside normal working hours:

1. Supply by the General Practitioner from his/her “on-call bag” (access to oxygen will need to be made via an alternative route)
2. Proactive supply during normal working hours in line with the ‘All Wales Collaborative Care Pathway for the last days of life’.
3. Supply by a local pharmacy operating an on-call or similar out of hours service. Information on local services available out of hours to be accessed via NHS Direct (available on a 24-hour basis). Implementation of one or more of these systems will be required in each Local Health Group/Board area and will need to be adapted to meet local need and circumstances.

Specific actions to achieve these aims have already been identified. Each Health Authority/Local Health Board must identify a named person who is responsible for:

- ensuring that systems are in place to enable out of hours access to palliative care drugs by General Practitioners in their locality by September 2002.
- arranging and maintaining the systems that are established and for ensuring that local General Practitioners are familiar with the arrangements in place.
- ensuring that NHS Direct continually holds accurate information about local out of hours services that will provide access to palliative care drugs (including oxygen)
- maintain a dialogue with the Collaborative Care Pathway Project manager and update her as necessary, for example regarding local pharmacy schemes in the area.

**Barriers to co-ordinated care**

Palliative care is not as well co-ordinated in Wales and the barriers to co-ordinated care include:

*Inter-professional boundaries:* where ‘ownership’ of care of a patient prevents appropriate access or referral, co-ordinated care between specialist palliative care and other services can be jeopardised. This can be exacerbated by poor understanding of the nature and role of specialist palliative care.

*Voluntary / statutory sector boundaries* occur as service provision in the voluntary sector is not accountable to the NHS (except in cases where the NHS is funding care) and can work to different standards of care, staffing ratios etc. Patients accepted or refused by voluntary sector providers, whose risk management strategies are sometimes determined against stringent criteria, can result in NHS staff at times feeling let down by the withdrawal of voluntary sector services when referrals are refused.

*Failure to involve occupational therapy, physiotherapy and social work in care planning and delivery* at all stages can result in uncoordinated care, leaving needs unmet. The unified assessment process launched on 1st April 2002 is a step towards tackling such difficulties.

*Commissioning boundaries* are setting different service criteria in different areas, although this is now less than under GP fund-holding.

*Poor communication* and information transfer are responsible for many complaints in the NHS, being the source of dissatisfaction in the care received by both patients and
their families. Where communication is poor, patients do not feel involved in their care and feel unable to make decisions appropriate to their own needs. Communication is a two way process, requiring specific skills which training can enhance.

**Barriers between secondary and primary care:** these certainly exist but can be broken down by close liaison between staff, e.g. by specialist nursing staff working across hospital and community boundaries, and by specialised general practitioners working across boundaries as part of the specialist team.

**Aim**

The introduction into the NHS of Clinical Governance will require different specialist providers in one area to come together to address these issues. For example an agreed single shared clinical record, such as the one developed through ISCO (information systems for clinical organisations) could underpin rapid, accurate and consistent transfer of information across different provider boundaries in all parts of patient care services. This will also extend to the voluntary and private sector as commissioners require evidence of similarly high standards from all providers.

**Level of knowledge amongst General Practitioners in Wales**

A study of 587 general practitioners in Wales was conducted in 1998. It included GPs practicing in the Welsh Valleys, defined as the area included in the previous Team Care Valleys project. Overall knowledge of appropriate care varied. For example prescribing appropriate opioids was good amongst over 70% of respondents, but 5% would prescribe a mild opioid for severe cancer pain, rather than a strong opioid. Over a quarter had received no training in any aspect of palliative care as a medical student or as a junior hospital doctor.

**Aim**

When training was compared by UK medical schools, it was evident that until about 10 years ago training at UWCM lagged behind other medical schools, but has subsequently been shown to have developed more quickly at UWCM than elsewhere. This process should continue and be built upon.
The Work Force

Throughout Wales there are:

- 42.3 inpatient palliative care beds per million population, compared with 50.8 in England on average and 67.4 in Scotland. This suggests a deficit in Wales of up to 56 beds, as the demography is similar to Scotland.
- six inpatient units that have a critical mass of 8 or more beds to be able to provide cost-effective specialist palliative care.
- eight beds in a single children’s hospice in South Wales. Hope House Children’s Hospice also provides a service to Wales.
- nine teams that are true specialist services. Of those, four have a consultant vacancy or absence through sickness, so they are functioning as intermediate level services at the time of writing the report.
- there are additional posts in adult specialist palliative medicine required to cope with current unmet need; these are detailed later in this document.
- several nurses working in professional isolation, without any specialist support available nearby.

The need for on-call specialist palliative care for children has not been assessed.

Of the cancer deaths in Wales, the majority of adult patients die in hospitals with home death rates slightly higher amongst men than amongst women. The inadequacy of 24-hour home support may influence this.

Aim

The shortfall in personnel is the major deficit affecting services. Although this is quantifiable for medicine, variations between areas in working practices in palliative nursing means that the requirements at specialist and at intermediate level are more difficult to assess. For other professions, e.g. physiotherapy, occupational therapy and social work, work must also be undertaken to define the size of the deficit and the recommended staffing levels. There is evidence that only a very small number of the patients with need currently access palliative care advice. The shortage of palliative medicine consultants and supporting medical staff could, in part, be remedied by developing specialist general practitioners, linked into and working to a managed network of care in the district. To be compatible with other networks and the emerging regional structure of the National Assembly, there should be three regional networks covering Wales based on North, Mid and West, South and South East Wales. Through the new workforce planning process the Welsh Assembly Government will address the human resource issues identified above and will begin work with partners on setting up the managed networks of care.

Palliative Care for Children

A [three year] senior lecturer post in paediatric medicine has been created with the support of LATCH. This is one of the only two consultant posts in the UK, the other being at Great Ormond Street in London. The post requires long term funding.
specialist registrar training post is being developed in paediatric palliative medicine in
Wales. Early discussions suggest that the Children’s Hospital at Alder Hey is
planning a paediatric palliative medicine service, which could be an asset to North
Wales.

Aim
A study should be made into all work force issues, including funding, and should
include the situation at Alder Hey and its impact on North Wales services. Hospices
are particularly important in paediatric palliative care and their role is discussed
below.

Education and training

Palliative medicine was recognised as a specialty in 1987, but training and entry
requirements were only clearly defined in 1994. Higher specialist training in palliative
medicine is regulated through the Joint Committee on Higher Medical Training.

Definitions of training to a higher specialist level in nursing and other disciplines are
not yet defined in a regulatory framework. Although the UKCC has defined "specialist
nursing", the core education and training requirements for palliative care nursing at
all levels are not agreed nationally or contained in a definitions framework.

There are currently two postgraduate validated courses in Wales for health care
professionals: the Diploma in Palliative Medicine from University of Wales College of
Medicine (which includes a paediatric option), undertaken by most of the GP
facilitators in Powys, and the subsequent parallel Diploma in Palliative Nursing run
from Holme Tower Marie Curie Centre, Cardiff. Many pursue these educational
pathways from within generic practice.

The UWCM Certificate, Diploma and an MSc in Palliative Care/Medicine provides an
educational resource to Wales, with a paediatric option for those working principally
with terminally ill children.

At medical undergraduate level in Cardiff, approximately 120 half days per annum
are taken up by formal or informal medical student tutorials, lectures and clinical
competency seminars. In addition, each specialist team in Wales provides about
30-40 teaching half days per annum in palliative medicine to medical
undergraduates.

A certificate course, based on portfolio learning, is being developed by UWCM and is
currently undergoing validation. This aims to target 80% of GP practices over 10
years in Wales. Currently much education is ad hoc and many courses are neither
validated for content or delivery, nor have they been evaluated for efficacy in
changing practice. There are two Macmillan Nurse Lecturers in Wales, working to
develop an educational strategy for nursing post holders carrying a Macmillan title.
There are also approved validated diploma and degree course modules in North
Wales as part of the University of Wales Bangor. A palliative care module and a loss
and bereavement module are available at Diploma level. The therapies (occupational
therapy, physiotherapy, social work, pharmacy, dietetics, chaplaincy) can all contribute to team education. They are also essential for the formulation of robust care pathways and guidelines in care.

**Aim**

A “Task and Finish” should be set up to examine these developments to ensure they are compatible and that they provide a coherent framework for training in Wales.

**Voluntary Sector**

The voluntary sector has a tradition of providing palliative care services. Independent hospices exemplify this and in Wales these units play an important role in delivering services that are highly valued by the public and by professionals. Care is provided in a number of ways. Some hospices have in-patient beds while others provide hospice services in the patient’s home. Some concentrate on respite care while others focus on long-term provision. They can provide other valuable services such as counseling and family support, which are offered too by other voluntary organisations outside the hospice movement.

**Aim**

The hospice movement should play an integral part in provision. It can add quality and flexibility to complement the range of NHS palliative care. the private and voluntary sectors should work together constructively to achieve this aim. It can be seen from existing good practice how well this can be done. Such cooperation should be the pattern across Wales.

In working towards this end, the development of hospices should be initiated as a response to an assessment of need and be integral to local planning structures. This lies at the heart of the tension which can occur between the statutory services and hospices. The Welsh Assembly Government will not lend support to any movement or public appeal for a new hospice unless there is proven need and support for such developments from the NHS community and its partners in the area.

Existing hospices should be closely integrated into local provision. This means that Health Authorities and Local Health Boards should work positively with the sector to ensure contractual and funding issues are placed on a sound footing to enable hospices to plan confidently for the future. Hospices and their supporting services must be able to operate in a stable and sustainable financial environment.

**Carers**

Carers are known to have specific needs as outlined in the document "Caring for Carers"; these will need to be addressed in the implementation of this strategy. At present, attention to carers’ needs and opinions can be inconsistent and occasionally absence although there are many examples of good practice too.
Aim

We mention above the need to take the wishes of patients and carers into account when considering care plans, treatments and choice of place to die. However, it is vital to address the needs of carers themselves in terms of support, counselling and where necessary healthcare. All services should have protocols in place to ensure this happens.

STANDARDS FOR SPECIALIST PALLIATIVE CARE

These general aims need to be underpinned by a number of key detailed actions. As discussed above, much work has been carried out by the Department of Health in England and the National Council for Hospice and Specialist Palliative Care Services to develop standards of specialist palliative care for cancer. These draft standards point the way ahead for services and they are detailed as an attachment to this strategy as a guide for the strengthening and development of palliative care services in Wales. In addition, we consider that there is a need for action on the detailed recommendations set out in the following section.

RECOMMENDATIONS

The following recommendations set out the key areas needing to be addressed to enable the achievement of effective services and high quality care in Wales. They are derived from the WMC survey of providers and users of palliative care and hospice services across Wales, and from the available research evidence base of the efficacy of such services.

The overarching recommendation is that a standard range of core service components should be available to any given population. The Welsh Assembly Government recognises that to achieve many of these recommendations additional resources will be needed and that this must be addressed at both the local and national levels in a systematic and planned way.

Recommendations for generic services

Primary care should have in place:

- 7 day/24-hour availability of district nursing
- Information on how to access 7 day/24-hour specialist palliative care advice
- GP hand-over sheets to ensure that information is handed on to the primary care co-operative detailing the out-of hours care plan
- Out of hours emergency packs for GP co-operatives, to include drugs and equipment likely to be needed for a palliative care patient in an unforeseen emergency e.g. a syringe driver, hyoscine, cyclizine, levomethamphetamine, dexamethasone, and details of how to access diamorphine for emergency use

- Increased availability of domiciliary nursing and home carers to supplement district nursing by providing prolonged respite in the home

- Computerised prescribing to decrease errors

- Education programme for primary care teams, linked to their current clinical needs, to ensure minimum competencies in providing care with a palliative approach, and sustained through deep and reflective learning

- Identified GPs with specialised competencies, in each Local Health Group, to work as advisory/facilitator links with other GPs and intermediate level services, and be linked to their local specialist provider

- Patient held prescription and administration record cards so that all carers visiting the child’s home to prescribe or administer medications can record that they have done so in a single location.

**Secondary and tertiary care should have in place:**

- A single computerised system, well supported, used across Wales for palliative care provision and linked to oncology and other disease-specific providers’ services. This will provide data collection and allow audit. Further work is needed to develop common information flows and management systems with local authorities and non NHS care providers. This work needs to be linked to the other initiatives underway aimed at rationalising IT systems across the NHS.

- Beds in hospitals designated as joint care beds between services, with adequate levels of staff, trained for palliative care provision.

- Pathways of care, building on the work done for the pathways of care in the last 48 hours of life.

- Education programmes, which are flexible to meet the needs of the clinician, so that the advisory services important role of ‘on the spot’ education is recognised in contracts.

- the voluntary sector should be viewed as full partners with the statutory sector in producing a comprehensive package of service provision. This should include the establishment of sound, stable funds and service agreements with independent hospices.

- the Welsh Assembly Government should support the expansion of residential respite facilities, including if necessary new hospices but only if they are carefully planned in co-operation with the whole local health community. Clear agreed protocols must be in place to ensure that responsibilities for the continuing care of
patients is managed seamlessly between clinicians and social care providers. These protocols will need to agree and describe relative responsibilities and discretion in the provision of respite care which support and promote patient and carer choice and empowerment.

Recommendations for specialist palliative care

Staff
• There should be sufficient numbers of appropriately trained and educated specialists in palliative care to ensure that access to specialist services is available in all care settings.

Facilities
• There should be adequate facilities to enable all areas of Wales to access integrated home care support, day care and in-patient facilities.

Education
• All health care Professionals across Wales be given the knowledge skills and competencies to ensure that each patient receives palliative care to address the individual’s clinical needs.

Management changes
• Equity of access to palliative care for those people with progressing life-limiting diseases.
• Access to specialist services for those with non-cancer diagnoses should be provided according to need on a basis that is comparable for those with cancer.
• Support and advice from specialist services should be available across 24 hours.

CONCLUSION

This strategy presents a significant challenge to all those organisations, health professionals, volunteers, carers and others involved in the provision of palliative care. There is much to do if we are to achieve the aims of this Strategy. The funding of improvements to and the development of palliative care services is a major issue, particularly in view of the competing demands for resources and the heightening expectations relating to all health and social care. However we must ensure that achievable improvements are made as soon as possible and much can be done within existing resources.

We expect to see services begin to implement this Strategy now and to maintain progress throughout the expected 10 year life span of this document. Taken
together, the standards and recommendations provide the necessary framework to allow this to happen.

We intend to set up a representative group to oversee implementation of the Strategy across Wales and to devise appropriate accountability measures and methods of monitoring progress.
ATTACHMENT

Network Standards for Specialist Palliative Care

Standard 1.1 Strategy Development and Commissioning

There should be an agreed, published, up to date strategy in place for specialist palliative care that is designed to achieve the policy objectives

- The strategy is based on health needs assessments that have already been carried out of the population served
- The local Health Improvement Programmes and Disease Orientated Networks’ (DON) strategies and 3-year plans incorporate the recommendations of this strategy
- Specialist palliative care is provided by named teams in the hospital, hospice and community sectors
- Specialist palliative care support and advice is defined for out of hours services
- The role of individual service providers is agreed with the network
- Development of services takes place only with the agreement of the Network
- Implementation of the strategy is regularly monitored and evaluated
- Health care needs are regularly reviewed
- The needs and rights of children will be considered in developing strategy

Standard 1.2 Processes and Procedures

There should be network-wide procedures in place to ensure that all potential referrers to specialist palliative care services know when and how to refer

- There is easily accessible guidance for Cancer Unit/Centre clinical staff, General Practitioners and other community and hospital staff on when and how to refer to specialist palliative care
- Teams are available, according to need, for advice, support and care of patients at any stage of their illness from diagnosis onwards
- There are common, unambiguous criteria across the Network for provision of care and procedures which provide for rapid assessment of individual patients
- Standard response times to referrals for specific service components are defined, documented and continuously monitored for each provider
- There are network-wide protocols for patient assessment, referral and discharge, access to palliative interventions and liaison with all providers who are involved in the care of the patient and/or carer
- Protocols for carer assessment and referral to support services are developed and incorporated into care pathways
- There are procedures for staff, patients and their carers for accessing out of hours specialist advice and support
- There are agreements and procedures in place with Social Services about the provision of social support including the conditions under which it is supplied
- There are care pathways in place which incorporate the above standards
- Processes and procedures involving children will conform to the standards of the National Service Framework for Children
Standard 1.3 Clinical Guidelines and Arrangements

There should be network-wide clinical guidelines in place

- Relevant national evidence-based clinical guidelines are identified and adopted for network-wide use
- Network clinical guidelines are developed for areas not covered by national guidelines – this includes guidelines for non-specialists in palliative care e.g. dissemination of knowledge about common symptoms and their treatment
- A core drug formulary is agreed and developed in consultation with pharmacists for use by specialist palliative care teams and compatible with the cancer units and centres, based on the work already done in developing the All Wales Guidelines, as published in Dr Ian Back’s book, and on relevant sections of the national paediatric formulary ‘Medicines for Children’
- Procedures ensure the ready availability at all times of medicines not used routinely in the community

Standard 1.4 Staff Resources

There should be sufficient numbers of specialist palliative care staff functioning in multi-professional teams to ensure that specialist palliative care needs of patients and carers are met

- The Cameron Report, 1996, set out recommendations on staffing levels for palliative care
- Similarly, the RCPCH report 1997, *Paediatric Palliative Care In Wales*, set out staffing levels for paediatric palliative care
- The Welsh Assembly Government recognises that meeting these standards will set a major challenge and will need considerable investment in training and in workforce planning. It will work with its partners, and in particular with the Implementation Team, to develop a plan to achieve these levels of staffing over the 10 year lifespan of the Strategy

Standard 1.5 Education and Research

There should be an All Wales co-ordinated education programme in place for specialist and general palliative care

- There is a programme for education in assessment of palliative care needs (from diagnosis onwards) across the dimensions of physical, psychological, social and spiritual needs
- There is a programme of education in communication skills for all health and social care professionals
- There are arrangements for encouraging collaborative clinical research across the Network
- Appraisal must consider palliative care education needs; this information must inform continuous professional education and development.

Standard 1.6 Information and Communication
There should be common arrangements across the Network for ensuring that all clinical staff communicate with patients with sensitivity, that patients receive all the information they want concerning their condition, treatment and care

There should be Network-wide arrangements to ensure continuous access by health and social care professionals to up to date records and other information about patients and their carers

• Local directories of services define and describe what each provider offers and how services may be accessed
• A wide range of clear, culturally sensitive information is available
• Designated local patient and carer self help and support groups are linked to the network provision
• Audit occurs against Wales-wide agreed criteria
• Common secure IT systems across the Network are capable of collecting, analysing and merging patient and carer data including clinical data
• All professional staff involved in the care of the patient have continuous access to up to date clinical records

Standard 1.7 Carer Support

There should be agreed, consistent and documented arrangements across the Network for the assessment of carer needs and for provision of services which meet those needs

• The carer knows how and where to access support according to clinical need.
• There are Network-wide criteria for access to respite care
• Specialist palliative care teams provide, according to need, general psychological care and counselling, referring to specialist psychological or psychiatric intervention when required
• Specialist palliative care teams address the needs of children as relatives
• Protocols assess for those who are at risk of complicated grief
• There is a range of bereavement support services in place to meet the spectrum of need, including for children
• There are Network-wide arrangements for the provision and funding of practical support: sitting services, equipment, financial help
• Recent guidance on Carers Assessment should support these processes (Policy Guidance - Carers and Disabled Children Act 2000 and Practitioners Guide to Carers Assessment – National Assembly for Wales 2001

Standard 1.8 Patient/Carer Views

There should be Network wide arrangements for regularly and systematically obtaining patient and carer views about their experience of using the specialist palliative care services which should be benchmarked on an all Wales basis

• The service works with the local Community Health Council to ensure patients' views are heard

Provider Standards for Specialist Palliative Care

Standard 2.1 General Management
Each provider should define its role through a mission statement, strategic plan/aims or objectives, business plan, unit or team objectives and plays a full part with the other partners in the Network

- Services are provided and delivered within their role agreed with the Network
- Multi-professional specialist palliative care teams are recruited, developed, educated and trained for each core service that the provider has agreed to deliver
- Core service developments are not undertaken without the agreement of the Network
- The care environment is conducive to good quality palliative care, respecting the privacy and dignity of patients and carers
- Services are provided to encourage access by people of different cultural and ethnic backgrounds

**Standard 2.2 Processes and Procedures**

Each provider should deliver services in accordance with the standards of the network care pathways and associated protocols and procedures

- Patients and carers are assessed for their needs within agreed time parameters
- The assessment is regularly reviewed
- A care plan is agreed with each patient/carer
- All teams have clear ways to be contacted
- Each team contributes to the Network arrangements for out of hours advice and support
- Arrangements for the care of patients after death meet the wishes of the patient and family considering religious, cultural and legal requirements

**Standard 2.3 Clinical Guidelines**

Clinical staff should employ clinical guidelines agreed for use across the Network. There should be a programme for development and review of guidelines and pathways

- Clinical staff are active in the development of Network guidelines

**Standard 2.4 Staff Resources**

Each Provider should have in place a multi-professional team for each service component it offers.

- Multi-professional specialist palliative care teams are recruited, developed, educated and trained for each core service component that the provider has agreed to deliver
- There are arrangements for annual staff appraisal and continuing professional development for all staff
- All team members are educated in communication skills including the breaking of bad news
- All clinical staff are trained in the assessment of carer needs and how to provide general psychological support
- There are formal arrangements for staff support

**Standard 2.5 Education, Audit and Research**
- There should be a contribution to the Network programme of education in palliative care
- Each provider should contribute to the network training programme in assessment of palliative care needs and in communication skills including the breaking of bad news
- Specialist staff should be engaged in collaborative clinical research and audit

**Standard 2.6 Information and Communication**

*The following operational requirements should be complied with:*

- Each provider produces information about its own services and how they can be accessed by health and social care staff and by patients and carers
- Treatment and care choices are clearly explained to patients and carers with sufficient information, time and assistance to make informed decisions including informed consent where appropriate
- All specialist team members keep patient records up to date to ensure transfer of information or access to information by others within agreed time parameters
- Written and other communications between teams is concise, fit for purpose and in a language which is readily comprehensible between professions
- There is a regular multi professional team meeting (at least weekly) for patient management
- Regular, formal, multi-professional team meetings are held with other inter agency involvement, for audit, service operation and communication review
- There is access to a computer system which is capable of supporting clinical audit and outcomes analysis
- Collection of the minimum data sets agreed within Wales is undertaken

**Standard 2.7 Carer Support**

*Each provider should assess and address the needs of carers and others that matter to the patient*

- The specialist team identifies a member of the team who will provide carer support including bereavement support
- All carers are offered an assessment of their needs
- Information on carer support services and how they may be accessed is easily available in a variety of formats and places
- The services offered as elements of the core service components e.g. respite care, social support, bereavement support, are defined and agreed with the Network

**Standard 2.8 Patient and Carer Views**

*The survey results of patient and carer views should be discussed and responded to at multi-professional team meetings and taken into account in the operation and planning of services*

- The views of all patients and carers are sought and appropriate action taken

**Standard 2.9 Children**
The needs of children with life limiting conditions should be equitably met across Wales

- A confidential register of children with life-limiting conditions (malignant and non-malignant) is maintained
- All children needing palliative care have access to appropriately trained professionals
- Residential respite provision is available