A Strategic Direction for Palliative Care Services in Wales

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1. 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 co-operation with the Welsh Association for Hospice and Specialist 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.

In producing this strategy we would like to thank the Welsh Association for Hospice and Specialist Palliative Care, especially Professor Ilora Finlay (Baroness of Llandaff) and Dr Andrew Fowell for their help in compiling the document. We extend our thanks to Dr Richard Hain for his input into the strategy. We would also like to recognise and thank all those who took the time to comment in detail during the consultation process.

Implementation of the Strategy will take place during a period of great change for the NHS in Wales. Following the dissolution of the 5 Health Authorities, the responsibility for commissioning and funding palliative care services will be integral to the Cancer Services Networks. This will help ensure continuity of clinical care for patients, underpinned by education, training and research.

Local Health Boards will provide a local focus with which to deal with local health problems. They will be required to work together with local councils, involving other key stakeholders, to produce and implement local health, social care and well-being strategies that will ensure an integrated approach to the planning and delivery of services. From April 2003 Local Health Boards will have responsibility for securing primary care, community care, intermediate care and secondary care services, based upon local needs assessment.

2. 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, loss of mobility, oedema including lymphoedema, depression, bowel problems, malnutrition and mouth discomfort.

Most 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 Co-ordinating 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. Whilst palliative care in non-malignant life-limiting conditions is significant to adults, it is particularly important for children.

3. THE DEFINITION OF PALLIATIVE CARE

The NCHSPCS has offered the following definition of palliative care, based on The World Health Organization's definition. Palliative care is “the active holistic care of patients with advanced, progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments”.

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 e.g. 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 specialities, earlier in the disease.

Palliative care services have an increasing role in the care of those with other incurable disease apart from cancer, which would include chronic deteriorating conditions and non-malignant conditions. 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.

Hospice is defined as a service dedicated to the provision of palliative care, which may be managed by the voluntary sector, the NHS or partnership arrangements.

4. 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).
Current specialist palliative care services will be working to minimum standards outlined by the Cancer Services Co-ordinating Group (CSCG). CSCG have also produced a strategic development plan 2003/04 – 2007/08, which outlines current and future developments facing cancer services in Wales, including specialist palliative care.

Guidance on Cancer Services Improving Supportive and Palliative Care for Adults with Cancer is being developed by the National Institute of Clinical Excellence. This must complement this strategy by identifying service models most likely to lead to high quality care and services for all people with cancer and their carers. It describes organisations and professional interventions for the differing service components that make up supportive and palliative care, underpinned by effective co-ordination.

5. 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 services from non-specialist or uni-professional teams. 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 specialist teams have benefit on outcomes, compared to generic care.

6. 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 clinical, cultural, social and psychological needs.
- 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, education and training in palliative care as well as in oncology.

7. KEY ISSUES

Set out below are the key issues in palliative care and 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, and which will form the basis for its implementation.

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.

Pain and symptom control often requires multidisciplinary specialist input. Radiotherapy, anaesthetic nerve block techniques, palliative surgery, palliative chemotherapy, dentistry and other specialties have much to offer in improving quality of life for individual patients.

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 using methods appropriate to the patient’s needs 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. Benefit claims and complex procedures around discharge can be particularly frustrating for patients, families and staff when time is short. 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 some evidence that expression of pain is strongly influenced by social and individual factors 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% of 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, Beardsmore & Hunt]. 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.

The NHS Plan, *Improving Health in Wales* involves fashioning an NHS characterised by patient focus and public involvement. This means a health service built around the patient’s perceptions of need, which respects their privacy and dignity and which provides sufficient evidence to help patients to make informed decisions about their own care. The Plan also includes a commitment that a network of “expert patients” will be established in Wales by 2003. Establishing an Expert Patients Programme is about developing user-led self-management courses to allow people with chronic illness to have opportunities to develop knowledge, confidence and skill to manage their condition better. Self-management tasks the individual to manage their physical and psychological well being. It is about patients and health professionals problem solving and decision making in partnership to deal with the consequences of the illness.

**Aim**

All services, voluntary and statutory must develop systems, which give proper and balanced weight to the views and 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 unable to access their own GPs and nurses during out of hours;
- 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 weekends and out of hours.
- 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 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 as necessary, for example regarding local pharmacy schemes in the area.

**Barriers to co-ordinated care**

Palliative care is not well co-ordinated in Wales. The barriers to co-ordinated care, identified as part of the Welsh Medical Committee review 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 [Ref: Barclay, Wyatt, Shore et.al.]. It included GPs practising 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 [Ref: St Christopher’s Hospice Information Service]
- 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 full inter-professional teams with specialist training comprising medicine, nursing and other disciplines working from the same clinical base [Ref: Calman Hine 1995]. 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, in particular the cancer and cardiac 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 number of pieces of work are underway that are considering paediatric palliative care e.g. the review of children’s tertiary services in Wales, the Children’s NSF and research being undertaken by the RCPCH. They will all be used to help inform and shape future palliative care services for children.
Wales is at the forefront of this young and evolving specialty. Palliative care is delivered to children by many different agencies, both in the statutory and voluntary sectors. These include children's hospices, Diana Nursing Teams, paediatric teams based in hospital (especially, but not only, oncology) and in the community. A relatively recent innovation is the establishment of a consultant-led tertiary specialist service based at Llandough Hospital in Cardiff.

It is axiomatic that ‘children are not small adults’. This is particularly important when considering palliative care, which addresses a child’s illness in a holistic manner. Paediatric palliative care (PPC) must grow out of services for children. At the same time, it is essential that those working with children have access to the expertise that has already developed in adults. PPC must be firmly rooted in children’s services, but establish strong links with the adult specialty.

Palliative care for children is one of the service groupings in the forthcoming SHSCW review of tertiary services for children in Wales. Insofar as this defines a palliative care strategy in relation to children in Wales, the relevant section in the SHSCW document is considered to be a part of the All Wales Strategy for Palliative Care and the reader is referred to it.

The National Service Framework for children in Wales will also address issues of strategy relevant to palliative care in children and should be considered part of this document. The reader is also referred to the publication ‘Guidelines for the Development of Paediatric Palliative Care Services (Baum D, Curtis H, Elston S, et al. A guide to the development of children's palliative care services (1 ed.). Bristol and London: ACT/RCPCH) which defines current national strategy at UK level. This document is currently being updated and will be reissued in late 2003.

In summary, paediatric palliative care inevitably exists in the overlap between strategies for paediatrics and palliative care. Plans for developing palliative care for children are already being defined, as part of Wales and UK national strategies for the development of paediatric services. These strategies are to be found in:

- the ongoing review by SHSCW of specialist services for children
- National Service Framework for Children in Wales
- research being undertaken by the Royal College of Paediatrics and Child Health and ACT for the whole of the United Kingdom.

The current document acknowledges the importance of these strategies and considers them to be part of the palliative care strategy for Wales.

**Aim**

Paediatric palliative care requires a specific needs assessment and strategy.

**Education and training**

Palliative medicine was recognised as a speciality 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 validated courses in Wales for health care professionals: the Diploma in Palliative Medicine from University of Wales College of Medicine, undertaken by most of the GP facilitators in Powys. A parallel Diploma in Palliative Nursing has also been available. The School of Health Science, University of Wales Swansea offers a BSc (Hons) Nursing (Palliative Care). The School of Care Sciences, University of Glamorgan offers a distance learning diploma in Palliative Care. University of Glamorgan is also planning two further degree programmes, one in cancer care the other in pain management for 2003. 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 multi-professional certificate course, based on portfolio learning, has been developed by UWCM. 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, and 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 group” should be set up to examine these educational developments to ensure they are compatible and that they provide a coherent framework for education and training in Wales.

**Voluntary Sector**

The voluntary sector has a tradition of providing palliative care services. Many services in Wales have developed through voluntary sector funding in partnership with the NHS. Some 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. The voluntary sector also provides other valuable services such as counselling and family support, which are offered by a range of voluntary organisations.

**Aim**

The voluntary sector should play an integral part in the provision of palliative care services. It can add quality and flexibility to complement the range of NHS palliative care. The statutory 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 co-operation 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 Local Health Boards and Networks 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 play an important role in palliative care, and should be seen as part of the core team. 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 absent although there are many examples of good practice too.

**Aim**

When considering care plans, treatments and choice of place to die, the wishes of patients and carers must be taken into account. It is also vital that the needs of carers themselves are addressed in terms of support, counselling, emergency respite care and general healthcare. All services should have protocols in place to ensure this happens.

**8. 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. A new set of standards based on the NICE guidance for
generic and specialist palliative care provision are currently being drawn up and will be published in due course.

**Aim**

Adopt and implement the NICE guidance for generic and specialist palliative care provision.

**9. 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.

Service guidance is currently being produced by the National Institute for Clinical Excellence, which includes specialist palliative care provision applicable to England and Wales. Standards produced by CSCG in 2000 are currently being revised, taking into account all available guidance.

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, levomepromazine, dexamethasone, and details of how to access diamorphine for emergency use.
- Increased availability of domiciliary nursing and social care 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 Board, 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 patients 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, in particular the implementation of the Cancer Information Framework (CIF).
- 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) and the Unified Assessment process involving all relevant services such as occupational therapy, physiotherapy and social work in care planning and delivery.
- 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.
- Strong partnership working with the voluntary sector. 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 and other relevant support services.
- 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, meeting local needs.
- 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;
  - Effective communication across professional boundaries, agencies and with patients and carers, and in assessing and addressing patients needs.
10. 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 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, and networks.

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 will provide the necessary framework to allow this to happen.

We intend to set up a representative group to implement the Strategy across Wales and to devise appropriate accountability measures and methods of monitoring progress.
11. REFERENCES


National Council for Hospice and Specialist Palliative Care, *Palliative Care 2000: Commissioning through Partnership*, National Council for Hospice and Specialist Palliative Care, March 1999

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