

Implementation of Palliative Care Report
Palliative care services funding 2008 to 2009

Palliative care services funding 2008 to 2009

Response to the Minister

Summary of recommendations

- The aim of the implementation of the report on Palliative Care services in Wales is to ensure that every patient receives the best possible care whichever bed they are in.
- Generic health care services deal with the patients who are dying; the role of specialist palliative care services is to act as a resource to support these clinicians to ensure the standard of care is raised across Wales. Specialist services do not have the capacity to take over care from generalist services and should only do so when patients and their families have complex care needs.
- The funding model suggested aims to ensure fairness of service provision across Wales, recognising rurality, poverty and areas of ageing populations as well as the higher mortality rates in Wales than in England. It also takes account of the particular needs of terminally ill children and recognises the Integrated Boards that are replacing individual NHS Trusts in Wales.
- Services should move to being consultant-led specialist multi-professional services, evidence-based in provision – both in terms of service configuration and in terms of the clinical care delivered;
- There appears to be a shortfall in Allied Health Professionals (AHPs) (particularly physiotherapy and Occupational Therapy); there could begin to be addressed this year.
- The move to 24/7 provision should begin immediately, with initially establishing seven day working of specialist providers across Wales.
- All money allocated should be against clear service specifications that outline the requirements of the provider, and build collaborative working across all sectors in any one area.
- Care must be evidence-based, both in the model of service provision and in the interventions in clinical care planning.
- The Implementation Board should continue and should oversee the changes required of services, reporting to the Minister; an external view on the direction of travel could be sought from the Scottish Partnership for Palliative Care.
- All Wales core standards of care are developed for services; services that receive any NHS funding should be required to be registered with either Health Inspectorate Wales or with the Care and Social Services Inspectorate Wales.
- No new services should expect to receive NHS funding unless their development has been discussed and agreed with the Implementation Board ensuring it fits with the overall strategic direction of service development in Wales.
- Current levels of Local Health Board funding to services should not be decreased without consultation with the Implementation Board; it is not replaced by any allocation of central Welsh Assembly Government funds.
- Expansion of CaNISC is recommended to ensure a core computerised clinical record for rapid transfer of key information, and to monitor and audit services. Registration on CaNISC could be accompanied by a small wallet-sized card to

patients across Wales indicating they are a registered palliative care patient and who to contact out of hours to avoid unnecessary delays.

- Use of the end of life Care pathway and access to out of hours medication needs urgent attention.

Background

Following the report of the palliative care planning group for Wales (chaired by Viv Sugar), the Minister established a working group to implement the report. Baroness Finlay was asked to lead on this work and an Implementation Board was established (Appendix 1).

The overall aim of implementation of The Palliative Care Planning Group Report is to ensure that every patient receives the best possible palliative and end-of-life care whichever bed they are in, whether home, hospital or hospice and respecting, as far as possible, their preferred place of care. The template for hospice / specialist palliative care provision is designed to provide consistency across Wales.

Throughout all branches of healthcare professionals encounter dying patients; good end-of-life care can be considered to be a core duty of everyone working in the NHS at every level, particularly those providing direct patient care. The role of specialist palliative care and hospice services is to support the generic services. The majority of those who often provide such care (e.g. primary care staff and secondary care staff in fields such as A&E, care of the elderly etc), whilst those who rarely encounter dying patients (e.g. prison services staff) may need to seek expert support and advice earlier.

Every health care professional should have good communication skills, particularly in breaking bad news and discussing end of life issues, be able to assess patients' needs and preferences, plan care and initiate symptom control. The education and training of the NHS Wales' workforce is a core duty of specialist palliative care services. It is a responsibility of specialist palliative care services to drive up standards of end-of-life care through education, both formal and informal, of other services and through support to other clinicians that is focused around meeting patient need.

The immediate task for the Implementation Board is to advise the Minister on the distribution this financial year of the £2million 'hospice' money from the Welsh Assembly Government. The Assembly Government's legal definition of a hospice in Wales¹ uses the term '*vested in*' which has been defined as meaning '*owned by*', implying that those independent charities in Wales whose purpose is to fund hospice services, but not directly manage them on a day to day basis (Ty Olwen and Gwynedd Hospice-at-Home), could be considered eligible to access this funding. Independent

¹ The definition of voluntary hospice has been stated as a hospital in England or Wales

- (a) which is not carried on for profit and is not vested in an NHS trust, Local Health Board, Primary Care Trust or NHS Foundation trust or is not vested in Welsh Ministers or the Minister of Health; and
- (b) the whole of main purpose is to provide palliative care for persons who are resident there and are suffering from progressive disease in its final stages.

Hospices Cymru describes a hospice as being '*professionally led*'², which resonates well with the Sugar Report recommendation of a consultant-led service.³

However, given the amount of work to be done overall to improve end-of-life care across all sectors in Wales, it is proposed that the Implementation Board continues for 3 years in the first instance. In particular, the relationships between specialist paediatric and teenage palliative care disciplines, the voluntary sector children's hospices and transition to adult care need attention. The work plan for the Board is laid out in Appendix 4.

Other background healthcare developments

Other relevant work in progress includes a review of district nursing services across Wales, a review of continuing care funding across Wales and the reconfiguration of health services, which will result in seven Unified Boards for healthcare delivery across Wales in place of the present Trusts.

As part of the preparation of this report I have met, spoken with or visited senior staff in almost all the specialist palliative care providers in Wales, as well as key staff in the Welsh Assembly Government. In addition the Integrated Hospice Forum Cymru and the all Wales palliative medicine consultants group have been consulted on the principles underpinning the Board's recommendations. There is general agreement that the direction of travel set in this year's allocation will be built on and followed up in the next three years. There was a recognition by all providers (bar one) that there is a need to improve service delivery and that changes will be of benefit to patients; most providers are keen to embrace change and recognise the need for clear 'direction setting' through implementation of the 'Sugar Report'. (The one voluntary sector provider that proved resistant felt that there was a 'moral obligation' to continue funding as in previous years).

During NHS reorganisation, the current ring-fenced allocation of palliative care money is a lever for change as the new NHS structures come into place. To date, the voluntary sector has not been regulated through registration; the service level agreement proposed will lay out clearly the expectations from both parties, to be monitored against All Wales health care standards and through quality data.

The Sugar Report's recommendations

The principal recommendations from the report (Appendix 2) were considered by the Board and core principles were agreed. All developments must meet these criteria of:

- fairness of care provision,
- consultant-led specialist services,
- services available out of hours for patients, with a seven-day working,
- evidence-based care to meet patient and family need.

² An autonomous charitable organisation that operates in a defined location is part of a national organisation and which delivers a professionally-led palliative care service as its core function.

³ Medicine is the only palliative care profession whose registration requires successful completion of accredited training against a standard national set of assessed competencies.

It was also felt important to bring about change without seriously destabilising patient services.

Principles underpinning care delivery planning

The principles underpinning funding calculations are laid out in the attached document on the options and funding to individual palliative care units. The calculations have been done in detail for the current year, and will be subject to revision annually. They aim to set a direction of travel.

It is important that no new services start up and subsequently expect to receive NHS funding. If such a service is to have any future claim on NHS money prospective approval of service expansion must be signed off at Ministerial level, on the advice of the network and the Implementation Board.

The Sugar Report did not recommend that services for lymphoedema (usually a complication of cancer or surgical treatment) form part of palliative care provision; they should be considered under cancer care services.

To avoid removing patient services completely during a period of change, it is recommended that this year's funding is allocated within clear parameters that allow services to choose whether they wish to change to meet the requirements or prefer to forego any further NHS funding from 2009 onwards.

Monitoring

This report deals with the immediate action particularly in year one, but the direction of travel that it establishes needs to be checked, monitored and supported on an ongoing basis. Therefore part of the recommendations for implementation of the Sugar Report is that:

- there should be an Advisory Board able to provide assurance to the Minister and to the Assembly that the action on palliative care is being taken and the momentum maintained,
- Healthcare Inspectorate Wales (HIW) and the Care and Social Services Inspectorate Wales (CSSIW) must develop and inspect against joint core standards on end-of-life care, applicable across all age ranges.

This is particularly important given that this will be happening over a period of other significant structural change in NHS Wales; it is essential that the improved palliative is embedded in the work of the new organisations, both on a daily basis and at a strategic level.

Specific issues in Wales

The extensive rural nature of Wales, the existence of poverty in the densely populated valleys of South Wales, the variation in age population in different areas and the difficulties with primary care in some parts of Wales mean that straightforward figures to compensate for these issues are not robust. The amount of work involved in looking after a young adult dying is very much greater than in looking after the most elderly people who are dying. Of course there are exceptions and difficult cases across all ages, but in general compensations for age become extremely complex

when taken down to LHB level. It is therefore proposed that such compensation formulae should not be used. Similarly, the length of time taken to travel around rural areas in Wales, some of which have pockets of severe poverty, balances the difficulties of caring for patients in areas of known urban deprivation.

In future it will be worth looking at the role of Council Tax banding as a marker of poverty; providing a high level of sophistication. However, current deprivation formulae probably give a false reflection of palliative care workload⁴, and therefore currently no such revising of the template for Wales is recommended.

The patient's needs

Some clear issues have emerged from complaints and from surveys of patients' needs and wishes. The service must therefore be patient-focused on direct patient need, irrespective of the patient's diagnosis, age or domicile.

The service must:

- communicate clearly and sensitively with the patient and family
- be flexible to meet the individual patient's needs, and the needs of their family and carers
- have specialist skills to apply evidence-based medicine
- be linked into collaborative working with other local providers
- be available seven days a week
- fast track patients through areas such as acute admissions, accident and emergency etc
- be accountable for how public money is spent, so that health money (NHS) is spent on evidence-based health care
- clearly record and respond to the patient's wishes.

During the summer months since the establishment of the Implementation Board there have been clear messages from families of patients describing the devastating effect of feeling unsupported out of hours and not knowing who to call.

This is a problem to be addressed urgently and therefore a patient held card and the establishment of a single 0800 number for patients will be explored with urgency. The card would steer health care professionals to try to ensure that patients are not sent into hospital unnecessarily and, when they are admitted acutely, the appropriate team are rapidly involved in their care.

Different patterns of care delivery

Overall in Wales, there are fewer charitable sector funded hospice beds per million population than in England. In addition, the development of paediatric palliative care services in Wales was initially very rapid, but has slowed in recent times.

Several providers provide hospice-at-home services. These appear to be effective in ensuring that patients are not unnecessarily admitted to hospital or to distant hospice

⁴ Disease progression to death, its concomitant problems and specialist palliative care needs appear to be independent of social class: Beale N. Personal communication. Sept 2008.

beds. However, at present they are not all led by multi-professional specialist teams; this needs to be rectified urgently.

Several community hospitals in Wales have designated palliative care beds. However, all such beds must be adequately supported by specialist advice to ensure care can meet the needs of patients in more remote communities.

Funding models

To establish equity, there needs to be a formula of funding for services. The formula needs to be equitable in terms of palliative care needs, recognise various differences, and take into account the different levels of funding that providers have obtained historically, both in the LHB and from Welsh Assembly Government central funds.

Peter Tebbit, on behalf of the National Council for Palliative Care, has developed models of palliative care need assessment. These consider the number of deaths in an area, particularly cancer deaths, as benchmarked against the numbers across the country as a whole. Although this may hold good for Wales, it does not compensate for rurality versus urban deprivation, nor that when young people are terminally ill on average they have more complex problems produced by their disease than those who are elderly. This is particularly important when young parents are dying, leaving children. Another problem to be addressed is that Wales overall has a population with an annual mortality rate about 15% higher than England, is on average more socio-economically deprived and has fewer in higher social class bandings.

Two other estimates of need are worth considering. The SchARR report, from the School of Health and Related Research Sheffield University, tried to calculate the number of staff required for a particular locality to provide comprehensive specialist palliative care services across that locality. Their models provide some guidance on the predicted specialist staff numbers and have been tested against localities with established services in England. The SchARR group drew on the 1996 Cameron report in Wales. However, SchARR's use of the Welsh suggestions in Cameron for hospitals do not sit easily with SchARR's English community models and take no account of very small specialist units such as exist in Wales; economic data has shown the most cost effective units have at least 10 beds, but few in Wales reach that size.

Beale has undertaken some interesting work on deprivation and found that the Council Tax band may be a better guide to deprivation than indices currently in use, such as the Jarman or Townsend index. In addition, the Royal College of Physicians has suggested that there is a need for 305 palliative medicine consultants in England (population 50,763,000). This is currently being reviewed, and it is expected to be revised upwards to take into account the increased demand on services, in part as a result of changes in primary care, the other recognised needs of non-cancer patients and increased referrals. All these estimates are however 'rough guesses' and the number of consultants cannot be viewed in isolation; the number of support medical staff is also important in a specialist service. Similarly, the specialist nurses need to be part of a broader team; a change to seven-day and out of hours working will require more specialist nurses in the rota than had been estimated for in funding

models to date. There are areas of good practice in Wales that can guide future calculations.

A funding model for 2008 for voluntary sector providers

The funding model assumes that all charity-supported services are fully compliant with the Charity Commission guidance over financial reserves and therefore does not take account of reserves.

Funding cannot be based on current hospice expenditure as some services are not optimally configured to meet local needs, some have high management expenses and there is no consistency or clarity about health service delivery costs versus costs of social care and fundraising infrastructures. Therefore no funding formula should be examined on the basis of a percentage of the voluntary sector provider expenditure, but should ensure stability of the core specialist patient service, working closely with other providers of care.

Marie Curie services are a supplement to generalist home care services, in large part similar to that provided by hospice at home services. Since the Marie Curie nursing service provides a closely monitored accountable standard of care, in following years the funding model of Marie Curie nursing service can be used as a benchmark against which components of the hospice at home service should be assessed. It would be reasonable to expect matched funding from other services providing this type of input.

The model recognises the core duty of all health care professionals, both in the community and in hospitals, to provide good end of life care to patients. It recognises that specialist palliative care and hospice services cannot, and should not, take over the routine care of patients at the end of life but are to act as a specialist resource to all generalist services in their area. The model is based on calculations for the expected needs of a community, the need for advice to hospital services, and the specialist cover to oversee and lead dedicated hospice/palliative care inpatient beds. It also recognises that some areas of Wales have established beds, but others do not and that an alternative model of care delivery can be provided by high quality hospice at home services rather than create more inpatient units in Wales. For children's services it recognises that those using children's hospice differ in diagnosis and type of problems from those using adult hospice services and have different requirements.

The principles behind this model aim to come up with a formula which allows an All Wales perspective of how the resources for specialist palliative care services should be distributed to meet need. When looking at workload, there are inherent tensions across Wales; these are principally:

- Rural versus urban settings – and associated transport difficulties
- Deprived versus non-deprived areas
- Older communities versus younger working populations
- Variations in standardised mortality rates and variations in disease presentations
- Variations in the provision of district nursing out of hours and the pattern of out of hours GP cover.

- Proximity to a major specialist disease centre (cancer centre, neurology, renal, cardiac etc)

However, correction for one factor is often cancelled out by another, so for the purposes of setting the initial direction of travel it was felt that, without better evidence, no corrective factor should be applied across Wales to modify the perceived need for any one local service.

In the hospital sector the workload data of referrals to current specialist palliative care hospital support teams indicates that the number of general hospital beds approximates to the team's workload. Cardio-respiratory, renal, neurology and other patients with end-stage disease could often benefit from palliative care input. The specialist team can also undertake an important educational role within a hospital to improve the quality of care delivered by generic services; this is particularly important across weekend-days. Such a team also has an important outreach role in educating general practitioners, district nurses and allied health professionals in their area.

The figures used to calculate the consultant and supporting medical input have been verified against the experience of those specialist services already in Wales.

For inpatient hospice beds, the number in Wales (174; currently equates to one per 17,000 population) is lower than Tebbit's estimate of 246 beds needed (one per 12,000) population. For the purposes of calculation, a mean of the two has been taken, giving a need of one per 15,000 population, to allow for hospice-at-home services providing an alternative service configuration that compensates for the perceived shortfall in beds and to avoid pressures to build beds in areas of under-provision. Where hospice-at-home services exist, these are considered as notional beds in lieu of in-patient beds. The Tebbit estimate is probably higher than will be cost effective in Wales given the geography and other services such as community hospitals. For those patients in a hospice bed, the NHS is being spared either the cost of a hospital bed or the continuing care costs of a nursing home. Therefore a notional bed cost has been calculated. Where hospice-at-home services exist, they have been attributed with one third of this, as patients' 'hotel costs' etc are not incurred and a single (often overnight) shift of hospice at home is required, whereas in patient units require staff across 3 shifts per 24 hours.

These figures for actual or notional bed costs do not include the specialist staff to oversee care in these beds, but are a way to take account of general care staff; thus the money allocated to the provider is made up of the estimated bed cost as above *plus* the additional specialist costs of consultant and CNS input. These figures are suggested as the basis of determining an appropriate division and allocation of the available funding and should not be taken as indicating the actual cost of providing in-patient hospice beds.

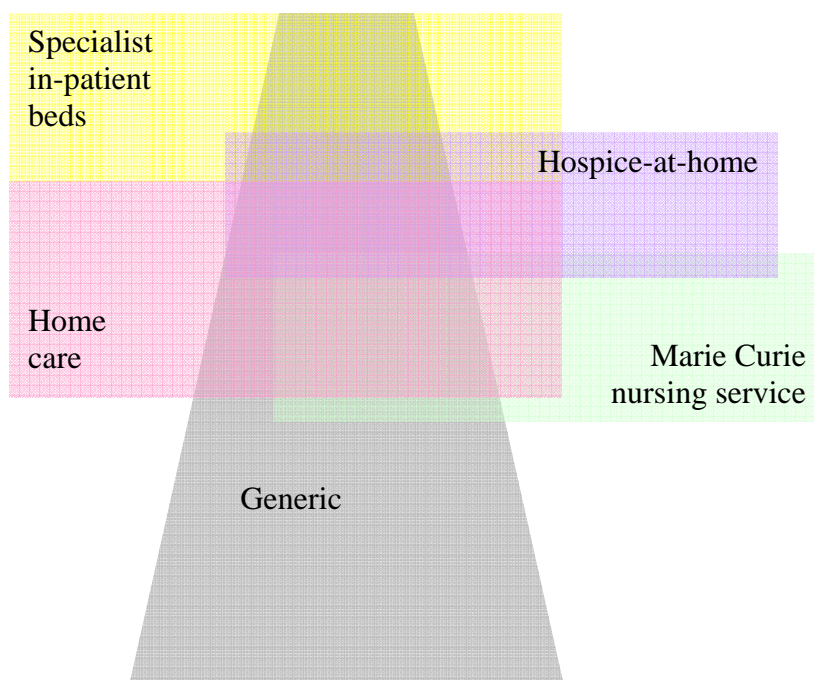


Fig 1 Schematic diagram of relationship of different home care services

A consultant-led service and workforce planning

There is evidence from the literature, incorporated in the NICE guidance on palliative care, that multi-professional teams provide a more effective and efficient service than uni-professional teams. In the long term, there are probably almost enough specialist registrars in palliative medicine to meet the need for consultants and associate specialists into the future. However, at present, there is a deficit in Ceredigion, and there seems little prospect of rectifying this without targeting training at an identifiable, motivated clinician in that area. The severe gaps in Gwent and in Ceredigion need to be rectified urgently.

Until recently there were no national criteria for specialist nurses. However, the core skills and competences as have been outlined by Skills for Health and are being defined by the Nursing and Midwifery Council; several high quality courses assess against these.

For the purposes of determining funding this year, the calculations have been undertaken on the following basis:

- One consultant per 850 district general hospital beds.
- One consultant per 20 hospice beds, to also cover those attending for outpatients and for day care treatments, but does not include community care.
- One consultant per 300,000 in the community (this figure will need to be corrected in future years to allow for variations in the mortality in the area).
- One consultant to cover support to 40 cancer centre beds.
- Each consultant needs support from a matching doctor, either a trainee or staff grade or clinical assistant.

- One associate specialist can be considered as equivalent to 0.7 WTE consultant or one WTE supporting doctor.
- One specialist nurse per 300 district general hospital beds.
- One specialist nurse to oversee 7.5 hospice beds, whether inpatient or hospice at home.
- One specialist nurse per 50,000 in the community (this figure will need to be corrected in future years to allow for variations in mortality in the area).
- One specialist nurse per 30 cancer centre beds, to also cover those attending for outpatients and for day care treatments.
- It is expected that the specialist nurse will oversee care given by a variety of nurses and care assistants are determined by the size and configuration of the provider's service.
- Allied health care professionals, social workers and other members of the multi-professional team are allocated pro rata, estimating that half the number (compared with consultants) are required in the hospice and the district general hospital, but more are required in the community. This requires further work in future years.
- Hospice beds requirements are based on one bed per 15000 population. Where hospices provide more beds than their catchment population needs, they should not be funded for the extra beds.
- For in-patient hospice beds a notional sum is allocated of £25000 per bed per annum excluding specialist team cover, which should be reimbursed using the formulae above.
- Hospice at home services are pro rata on the above at £25000 per 3 notional beds for care in patients' homes.

These figures assume supporting an equal number of medical staff at training and other grades, and that lower band nurses will be in training to become specialist nurses.

Sources to underpin these calculations have been The Cameron Report (Wales 1996), National Council for Palliative Care guidance 2007, the Tebbit needs assessment reports (2005), the ScHARR report from Sheffield University (2002) and modelling based on workload of current consultants in Wales.

When determining the amount to be allocated to the hospice sector, it has been important to know the amount of funding obtained in LHB contracts. The in-patient units and hospice-at-home services relieve pressure on NHS resources, as well as allowing patients to die in a hospice or their own home, if this is what they wish. Currently patients cared for by in-patient hospice services have not been considered eligible for continuing care funding. This anomaly seriously penalises the in-patient units. It would seem equitable to recognise that patients cared for by voluntary sector hospice providers (in-patient or hospice-at-home), would otherwise be in an NHS funded unit. Many of these patients would fit the criteria and be considered for continuing care funding.

There are general care costs for patients in addition to the specialist palliative care staff costs. In light of the hospices wish to retain independence by not being NHS

managed and the concept of matched funding (50:50 = NHS:hospice), it has been calculated that the generic bed costs would warrant a sum of £600/ week as the cost reimbursement. Taken as an annual cost, assuming 80% bed occupancy, an indicative figure of £25,000 per hospice bed per annum has been used for calculations.

For hospice-at-home services, a notional bed number can be attached to account for those patients managed at them who otherwise would require admission. This takes into account the need for these notional beds to be overseen by the specialist team and that a higher level of generic service care is provided than can be provided by district nursing and primary care. It recognises the nursing input required while recognising that costs such as food and heating are not incurred. Therefore for costing purposes the cost of a notional hospice at home bed had been calculated as being one third (£8,333) of the cost of an in-patient hospice bed. This can also be used pro rata, where there are specialist day-care services, which have more than a social role, as they provide specialist day respite.

Table 1 Summary of calculations
to determine specialist palliative care staff needs in Wales for adult services

<i>Palliative care specialist</i>	<i>Domain covered (one in whole or in combinations of fractions of each listed)</i>
1 WTE Consultant (supported by minimum one other doctor)	300,000 population 20 hospice beds 40 cancer centre beds 850 DGH beds
1 WTE CNS (may be leading a team of other nurses at more junior grades)	50,000 population 7.5 hospice beds 30 cancer centre beds 300 DGH beds
AHPs and others	To be further calculated
Beds / notional beds (excludes cost of supervising specialist staff)	One / 15,000 population £25,000 p.a. in patient bed £8,333 p.a. hospice-at-home bed

The overall figures for Wales in the proposed model, when compared with the figures from the Tebbit calculations and those from the ScHARR report, suggested a reasonably close agreement between the figures. The number of consultants calculated in the proposed model for Wales is slightly higher than had been calculated by Tebbit, but seem significantly lower than those suggested in the ScHARR report. The All Wales Palliative Medicine Consultants Group have been consulted on the proposed model of calculation and consider it to be fair and equitable, but a minimum in reflecting workload; thus it forms a working base.

As the new Unified Boards come into being, the Welsh allocation share to each will be revised and the figures for future years should be tested against this allocation.

Children and teenagers

Children’s hospices provide care to a different population compared to adult hospices.

Many of the children have long standing disease which eventually becomes life threatening and from which they die; four broad groups of children have been delineated as needing palliative care.

A small number of children (Group 1) develop disease de novo which fails to respond to treatment and becomes terminal. Of this group, leukaemia and sarcoma are managed almost exclusively in the paediatric oncology setting with relatively short but intense palliative care phases. Others (Group 2) have progressive conditions which have failed to respond to intensive treatments, such as those with congenital heart and cystic fibrosis, for whom transplant may represent a last hope; sadly many die while waiting for transplant due to a shortage of organs. Other children with progressive disease (Group 3) such as muscular dystrophy deteriorate with age, whereas others (in Group 4), such as those with cerebral palsy, are handicapped from the outset and the developmental delay gap widens with time, making the care needs greater with time.

Children’s palliative care is provided principally from the major paediatric centres and by the hospices in Wales which provide a mixture of respite and palliative care; care of dying children is a rare experience for the GP and primary care team.

Children’s hospices in Wales are most frequently offering services to the last two groups of children. Much of the admission to hospice is respite care and has a very important social function for the families, but for each child a proportion of their care can be classified as expert palliative care review and input and can therefore be considered eligible for specialist funding. This can be schematically represented by Fig 2.

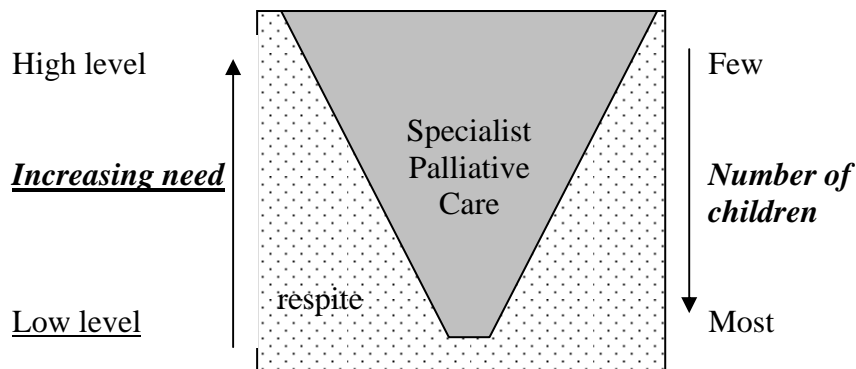


Fig 2 Schematic representation of specialist palliative care need in children receiving hospice respite care

Children's hospices cannot therefore be regarded as only providing social care. During respite admission the palliative care needs of the child must be addressed and children's hospice staff need to maintain competencies in all aspects of palliative care delivery. They also need access to specialist medical advice and need to have specialist nurses overseeing the care delivered by other staff.

The levels of health care staff required for children's services is higher than for adults and some ancillary staff are required – such as play and teaching staff – as part of children's health care. In addition, the required number of specialist paediatric nurses per bed is higher and so figures for the Children's Hospices have been revised to allow one clinical nurse specialist overseeing care of 5 beds, with the notional bed cost set at £50000 per bed per annum. These levels of funding are accompanied by required closer integration with statutory paediatric services to maintain clinical competencies amongst staff.

It is recommended that this should be recognised by apportioning a notional 'specialist palliative care beds' allocation to calculate the specialist palliative care component of their service, based on the population they serve, assuming that the service is available 24/7 and that it is staffed to specialist level. For nursing, the number of specialist nurses per bed will be higher than for adult care. A similar formula (modified from the adult one) can be adopted for the service providing advice into the specialist children's hospital, and for the developing dedicated unit for teenagers.

The Sugar Report did not suggest that bereavement services are included in palliative care funding. However, the needs of bereaved children have been recognised as being particularly important to their future health and wellbeing. There appears to be no lead in education or health or social care to ensure that anyone faced with a bereaved child can be steered towards a framework for providing support. It is therefore suggested that a simple scoping is undertaken to assess the provision in Wales, the training needs of all those who work professionally with children and whether a simple toolkit can be developed to equip such people (teachers, social support staff, nurses and others in primary and secondary care, and in ambulance and trauma services)

Standards

The standards have been written for adult palliative care services in Wales and published by the Cancer Services Coordinating Group (CSCG). They are due to be fully implemented by March 2009. They are written as standards to apply to non-cancer patients as well as cancer patients; the standards as they apply to adult cancer patients are monitored and reported on through CSCG, based on self assessment.

The monitoring tool to go with the standards can easily be altered to ensure that the criteria against which the service is judged are captured in the monitoring process. This process is currently being reviewed through CSCG and will be produced with a new and more sophisticated monitoring tool.

HIW and CSSIW need to have an active role with all the hospice services and should be made responsible for the inspection and registration of all such services

irrespective of whether they have in-patient beds, day-care and outpatient or community services, or a combination of all or any of these. Training of the inspectors will require a small budget allocation to make sure that Health Inspectorate Wales can register all the services; there is also need to revise the standards to ensure that the correct benchmark is used during inspections. No provider should receive NHS funding if it is not registered; such registration should for part of the terms and conditions of funding.

Data collection and audit

CaNISC should be used as the definitive database to collect data on all palliative care/hospice providers, possibly including children's services. The palliative care module needs to be built on and expanded to capture data from all the providers. The data working party is currently looking at ways to routinely capture clinical process' data that reflects the quality of patient care, and not only data that reflects throughputs. Much work to establish a database has already been undertaken and the minimum dataset to verify the work of individual providers has been agreed for some time, but as yet these have not been reviewed by the Cancer Information Framework Project (CIF), for which Informing Healthcare is responsible. This needs to happen immediately so that the CIF project can consider the dataset and can ultimately recommend to Welsh Information Governance and Standards Board (WIGSB) that it can then be published. The CIF project can then develop the CaNISC software to collect the prescribed data.

As part of the baseline implementation work, I have met with Simon Dean and Gordon McKenzie in the Welsh Assembly Government, and consulted the Cancer Information Unit (CIU) who lead on CaNISC and the clinicians involved in producing the core requirements. The Palliative Care module is a priority for ensuring rapid coordination of patient data and for monitoring services in Wales.

It is recommended that the CIF Project is asked to give priority to considering the draft dataset, taking it through the governance process and develop the working model for the clinical services. This should be funded over and above current projects of the Cancer Information Unit, to avoid the momentum being lost on the development of the site specific cancer modules in CaNISC. There are start-up costs for the Cancer Information Service in supporting the service development, training, information support, helpdesk support and costs involved with connection to the system i.e. server costs, licences (e.g. Microsoft, Citrix).

The collection of accurate data should be a key performance indicator of providers in receipt of central funding. These services however require training. Each needs to have a dedicated data input clerk, who is trained in the use of CaNISC and confident in inputting data. In addition, there is a need for a support person centrally at Velindre Cancer Centre to answer IT queries in palliative care. This person needs to be completely aware of all aspects of the database in order to be able to manage the queries. The current helpdesk is already working at full capacity and does not have the capacity to take on additional queries from hospices across Wales; it is an efficient and helpful helpdesk and it would seem more sensible to add one other person to this centralised service than to try to replicate support across Wales in different areas.

Other costs for the individual palliative care teams are staff resources in the teams to enter data and access to the intranet i.e. computers, etc. These costs are variable and depend on the resources already in place, e.g. independent hospices will need access to the internet and tokens to access the NHS intranet; they may also need support from IT consultants if they do not have the IT knowledge in house. NHS teams already have access to the NHS intranet but their connectivity varies. Such investment will be small for each unit and will vary – it should be considered as soon as the core module is developed.

It is recommended that part of the money that has not been committed to the hospices is used to build up the infrastructure, for the development of the module for the palliative care data collection and for training in what is required.

Children's services in the UK have a database (CHASE) into which patient data is collected; this system has been recommended by the Association for Children's Palliative Care (ACT). Part of the work by CIU would be to look at links of this data collection system with CaNISC.

Consideration should be given to the integration of the CaNISC with other networked patient record systems. Although the final decision has not been made in Wales over whether the computerised patient record will be a patient-held smart card or similar, or an integrated computerised network system, there is a place for a simple generic credit card-sized Welsh NHS card to be given to all patients registered with a palliative care service. This simple card would mean that, whenever a patient presented to the out-of-hours on call service, or to a hospital through admissions or accident and emergency, the card would state that the patient is a registered palliative care patient. Their details would then be obtainable from CaNISC, and the out-of-hours palliative care team could be contacted immediately for the needs of the patient to be best met. This card will also state the 0800 number for patients to call, to link the patients with their on call specialist palliative care team, and ensure that where primary or secondary care are called on to intervene, they are aware of the specific needs of that patient as recorded on CaNISC.

Establishing 24/7 working

The move towards 24/7 working will require a higher number of specialist nurses than previously. The main change will be in the work pattern of the specialist nurses. Key decisions have to be made as to whether it is economically appropriate to have the specialist nurses available overnight, or whether they should routinely be available every day of the week, with a telephone advisory service and mobile rapid response service covering a broader geographical area.

With immediate effect, the change to 7-day working must be implemented, with details of the hours reviewed through workload monitoring to determine cost effective development to a 24 hour service. Staggered start times of working would provide better cover across the early evening. Models of integrated working across hospital and community sectors and of out-of-hours rotas exist across Wales; cost effective implementation could be made a condition of NHS funding.

The consultant on call rotas for South East, North and West Wales, already cover large regional areas and provide an advisory service. This could be supplemented by specialist nurses working between hospital and community out of hours, possibly being able to cover a population area of up to 500,000 population, so that each of the three main regions in Wales (North, West and South East) would have one consultant on call out-of-hours and three to four specialist nurses. The rural area of Powys needs to be considered separately and will probably need one specialist nurse in North Powys and one specialist nurse in South Powys available out-of-hours to provide support to the district nursing service. This needs workload monitoring to determine the optimal configuration.

Hospice-at-home services are provided in large part by health care assistants trained to NVQ level 3 in palliative/end of life care; a large percentage are not registered nurses and therefore are dependent on specialist and general (district nurses) for support and supervision. These services can develop relatively easily to link with multi-professional teams. The hospice-at-home service can be viewed as equivalent to low intensity inpatient beds; the service should be covered out-of-hours by the on-call specialist nurses, backed up by the on-call consultant.

The Marie Curie nursing service provides a model of home nursing to supplement district nursing, working to national standards. The Local Health Boards (excluding Pembroke and Monmouth) have contracted with Marie Curie for the service which is funded by matched funding from Marie Curie Cancer Care. When Marie Curie nursing is involved, over 90% of these patients achieve a death at home. The size of each contract from an LHB does not reflect the population base of that LHB, nor does it reflect need; some services exhaust their set budget early in the year (Cardiff and Vale LHBs) and others over perform and rectify this shortfall in contractual funding at the end of the year (last year Carmarthen, Neath Port Talbot, Anglesey, Denbigh, Newport etc).

Last year 1100 patients were supported at home by the Marie Curie nursing service at an average cost per patient of £785.16 to the LHB for 496 hours (7.7 shifts). In 2008 the budget was only £67000, compared to an estimated budget this year of £1.3 million from LHB's. Marie Curie have evidence that when they are involved the delays in waiting for continuing care assessment are circumvented and the ultimate continuing care funding requirements are lowered. The standards set by Marie Curie should be taken as minimum standards against which hospice-at-home services can be benchmarked.

Strengthening generic care delivery

The majority of palliative care is delivered by health care professionals who work with patients in a broad range of settings and specialties. Most of the patients' palliative care needs can be met most of the time by such clinicians; indeed it is core duty of every clinician to do this.

However, some clinicians will be more familiar than others with dealing with end of life issues in patients (e.g. geriatricians, GPs and district nurses). Some who are less familiar with end of life issues on a routine basis (e.g. dermatologists) may need supportive advice earlier in a patient's journey. In some parts of the NHS a small

change in attitude will result in a much improved patient experience; specialist teams working flexibly can provide the catalyst for such change to establish patient focused working and ensure patients' needs are met.

General training

A programme of district nursing training has been rolled out in the Cardiff and Vale area to all district nurses. This provides core training in palliative care. It is currently being run and evaluated. This programme, modified in the light of the evaluation, should be rolled out across Wales; some of the finances should be used to fund this proactively over the next three years.

A short-course, using blended learning of face to face and e-learning, for general practitioners is being developed at Cardiff University and will be available to GPs. The course has been designed so that general practitioners can simply attend, but those who wish to gain a certificate of accredited training will need to complete coursework which is assessed. Such an award would provide a transferable credit that could then be used towards further study in palliative care.

The third area of education and training needed for healthcare professionals is communication skills. Communication skills are inherent in the short-course designed for general practitioners. A similar course could be attached to the district nurse training module.

Take-up of such courses should be encouraged from those working in NHS Trusts, who are dealing with palliative care patients for much of their working time. By strengthening the specialist based at consultant and specialist nurse level, a network of appropriate educators is being developed.

Several hospices around Wales run courses in palliative care, but few of these have been formally evaluated and accredited. Those hospices running these courses should be encouraged, possibly through the hospice group, to develop educational partnerships with universities, Royal Colleges and NHS providers and obtain accreditation and single transferable credit ratings from established educational units. This would then allow a network of accredited education to occur around Wales without undermining the current providers, but would strengthen the type of course that they are offering.

Palliative care professionals should all have advanced communication skills and training and a large proportion of those, comfortable with teaching, should be trained as trainers.

There is a need to ensure that all clinical generalists have the necessary skills, knowledge and attitudes to ensure optimum standards of care for their end of life patients. End of life care (EOLC) is often a continuum of chronic conditions management and must form part of clinical care pathways – the clinical generalist being the person who cares for the patient from diagnosis through to death and bereavement of the family and carers. Clinical generalists work as members of multidisciplinary teams and it is appropriate that much of the education and training is done on a multidisciplinary basis. There is already provision for generalist education

through a variety of methods in Wales and determining the present provision of EOLC education would be useful in determining future areas of educational needs. This would enable a database of EOLC education provision in Wales to be created – communicated through a web based network and forming links with all providers. Identified areas of EOLC educational need should lead provision of comprehensive generalist education – these include symptom control, communication skills and models to ensure continuity of care, particularly out-of-hours care.

Keeping palliative care on the new Trusts' agenda

It is essential that the direction of travel to improve palliative care becomes the key performance indicator that the most senior level in the new NHS Trusts. These are large organisations, and it would be easy for palliative care to slip behind the pressing priorities, particularly in times of financial stringency. As most of the changes required to improve palliative care services are attitudinal amongst the generic services, the board feels that it is essential that:

- End of life care must be an agenda item on the papers for the meetings or Chief Executive's of all the NHS Trusts in Wales.

This will ensure that improving end of life care becomes a key performance indicator.

Service level agreements and collaborative working

Service level agreements need to state clearly

- what the service is to provide,
- the services is to collaborate with local NHS and other providers,
- the expected timeframe for implementing required changes / service reviews,
- the reporting and audit requirements,
- aspects of the service which are health-related and are eligible for funding.

It is a key principle that:

- Funding allocated from Wales Assembly Government does not replace any current LHB contract money.
- WAG money is not for general support services, such as delivery of district nursing, but education and training of generalist services is a core duty of all specialist services

Services such as the Marie Curie nursing service provide support to district nursing and to hospice-at-home provision. Marie Curie nursing service is part of LHB contracts and as such should be maintained from the LHB budget, at least at the current level, as a minimum. If the number of patients cared for at home and dying at home is to rise, these contracts will need revision upwards.

Where a service level agreement is broken the Welsh Assembly Government should have the right to request a return of funding allocated as part of that agreement.

Monitoring

Monitoring the Implementation of the Sugar Report is key to driving up standards of palliative care across Wales and establishing change. The Board should be responsible for the monitoring of the processes and report directly to the Minister. The Board should receive reports on progress of the individual service level agreements, link with HIW/ CSSIW and be able to conduct audit of services, including how well they are collaborating with other providers. The Board should also liaise with the individual network palliative care groups to encourage strategic implementation of the plan and with CSCG over routine monitoring of cancer standards.

Support to the Board will require 2 days per week of a senior NHS Manager. Velindre NHS Trust has offered this as a secondment of Lisa Miller, Cancer Services Manager, to support the work.

Priorities for 2009-2010

Develop multi-professional services in Ceredigion and Powys, and hospital support team in Bronglais.

Undertake a needs assessment of potentially unfunded vulnerable posts that were pump primed by MacMillan.

Explore the funding models and standards of hospice at home services and benchmark these against the Marie Curie nursing service.

Commence audit of clinical services using baseline data collected on CaNISC.

Audit use and efficacy of patient held palliative care registration card.

Evaluate 7-day working by specialist nurses and evaluate cross boundary (hospital – community – hospice) working.

Ensure specialist nurses are all appropriately trained or in the process of updated training.

Evaluate the role of respite services, including day care.

Work with children's and teenage services in both the NHS and the voluntary sectors to determine agreed standards of care and collaboration between services, including clarifying the health based components of care.

Establish common care pathways across disease pathways, responsive to individual patient's needs.

The lack of clinical psychology across Wales needs to be evaluated and addressed as there is a serious shortfall.

Workgroups

Group

Data and IT

Workforce planning

Generalist training needs

24/7 working

Children and Transitional issues

Service level agreements

Lead for the group

Rhian Owen

Andy Fowell

Helen Herbert

Mel Lewis

Jane Fenton May

Viv Cooper and Marion Arthur Evans

Appendices

Appendix 1

Terms of Reference – for the implementation group for the Viv Sugar Report

To establish a Board responsible for the implementation of the recommendations coming out of the Palliative Care Planning Group of the Welsh Consumer Council (chaired by Viv Sugar).

The Board will, through working groups:

- Receive reports from all sectors about how they can meet the recommendations and requirements as laid out in the report
- Lead on increased coordination between all sectors, particularly statutory NHS and the voluntary sector, in providing care of the dying
- Advise on establishing equity of high quality care delivery to meet the needs of patients and their families / carers
- lead on ways to improve care delivery
- Advise on research priorities
- Advise on education and training priorities and programmes,
- Consult on verifiable standards of care that are imbedded in everyday practice
- Establish effective planning and delivery mechanisms for palliative care services that are holistic and patient centred to deliver the core elements of a palliative care service as defined by the report. .
- Recommend mechanisms to ensure that each service implements the relevant evidence based tools for improving services, such as the All Wales Pathway for End of Life Care.
- Establish ways to support generalist services, enhanced by specialist palliative care service providers

To advise the Minister for Health and Social Services on allocation of future funding and the funding available in 2008-09 for hospice and palliative care services by mid September.

To advise the Minister on changing priorities during the implementation process, including those which may mean re-prioritising the short, medium and long term recommendations.

Chair of the Board: Baroness Finlay

Board members: Dafydd Wigley
Paul Williams ABM NHS Trust
Vivienne Cooper
Marion Arthur Evans
Helen Herbert

Support to the Board from Jan Firby and Cathy White, Wales Assembly Government.

Advice on standards in palliative care from Dr Andy Fowell.

Appendix 2

Recommendations of All Wales Palliative Care Planning Group

Chair: Vivienne Sugar, Welsh Consumer Council

The following recommendations are within a suggested timeframe of either short term (12 months) or medium term (1-3 years) dependent on the complexity of each recommendation. The prioritisation of these recommendations is to be determined by future work arising from this report, and the following timescales are a guideline only.

The work to be taken forward should be done so by a working group that includes both service provider (statutory and independent sector) and patient representation, including providers and users of children and young peoples services as well as adult services.

Short term (12 months)

- Establish an All Wales network to co-ordinate existing expertise, including representation from cancer, renal and cardiac networks, and organisations concerned with life limiting conditions for;
 - Children and Young People's palliative care
 - Adult palliative care
- Identify priority areas for action as arising from the findings of this report, for example consultant numbers for adult and paediatric care.
- Provide initial investment to achieve a minimum core service level across Wales and across all sectors for both adult and paediatric palliative care services.
- Use the core palliative care service level as a basis for distributing additional funding to the voluntary sector.
- Strengthen and improve the existing Continuing Healthcare process and ensure the current review of this guidance considers mechanisms for rapid access to funding and more flexible processes for application and renewal of equipment.
- Agree an All Wales standard guidance for all palliative care services, building on the current Welsh Cancer Standards that sets out the core service specification with requirements that the core service be established in a set timeframe.
- In order to develop or nominate one single template, undertake an all Wales review of the templates used for;
 - i) individual care pathways
 - ii) patient pathway through services

Medium term (1-3 years)

- Establish a 24 hour secondary and tertiary support service for professionals across the whole of Wales (for both adult and paediatric services) using staff from the specialist palliative care team who have access to an on call consultant.
- Produce a separate circular for adult palliative care commissioning guidance, including:
 - mechanisms for approval of and continuing support for new services
 - agreed service specifications
 - arrangements for provision of care by the private sector
 - arrangements for pooled budget arrangements
 - arrangements for reimbursement for NHS and Local Authority provision
 - arrangements for reimbursement for voluntary sector provision
- Develop an All Wales Training and Education Programme with agreed Standards for all palliative care Providers in the following settings:
 - Primary Care
 - Secondary care and community hospitals
 - Nursing and Residential Care Homes
- Nominate a single regulating authority for inspection of all core services and develop inspection regimes for all clinical governance systems with peer review against agreed standards.
- Collate all Wales data on patient numbers and conditions to be used to inform commissioning and form a register of need.
- Develop information for patients, families and carers at a network level, including a directory of services.
- Develop the current IT systems for adult palliative care and establish an IT system for children's palliative care.
- Conduct further work to identify the specific needs of adolescents and young adults and nominate a member of the palliative care network to liaise with all networks on transition issues.

Appendix 3

Notes of the Implementation Board Meeting
For the Palliative Care Planning Group Wales
1st August 2008
Professor Finlay's Office at Velindre Hospital

Present

Professor Ilora Finlay (Chairman)
Mr David Wigley MP
Dr Helen Herbert
Ms Marion Andrews- Evans
Mr Paul Williams
Mrs Vivian Cooper

In attendance

Dr Andy Fowell

No apologies received.

Minutes as follows

The Board agreed:

1. It was important that all members were there to contribute expertise across several domains and were not there to represent any particular group or interest.
2. Dr Fowell should be in attendance because of all the work he has done on setting the standards for palliative care across Wales and on ways of maintaining the standards.
3. The decisions recommended to the Minister in September over the allocation of £2 million to hospices and a further £1 million must;
 - a) Set the "direction of travel" of the strategic implementation of the Sugar Report.
 - b) Work towards equity of service to patient, irrespective of who the provider is (NHS or Voluntary Sector).
 - c) Underpin evidence based care.
 - d) Foster close collaboration between all providers (whether NHS or Voluntary sector) in an area to ensure patient care and support to carers is needs focused.

The group agreed that the priorities for year one are to work towards:

1. Palliative medicine consultant leads to specialist palliative care services across Wales.
2. All specialist nurses having a palliative care qualification, in line with emerging nursing and midwifery council recommendations.
3. All palliative care providers having advanced communication skills training.
4. Clinical specialist palliative care services available to support generalist teams in the community, hospitals and nursing homes on a

- 24/7 basis, with direct clinical support available every day of the week so that any patient with complex problems can be seen, assessed and management started within 24hrs of urgent referral.
5. Data collection on palliative care will allow all services to be audited for clinical standards. Such data should be data which is routinely collected in the course of clinical care and should build on the work already done on expanding CaNISC.
 6. Voluntary sector providers may need support in linking to CaNISC and in training staff in its use.
 7. Training to generalist teams should be rolled out as fast as possible, using programmes that have been formally accredited such as the district nurse programmes in Cardiff & The Vale that is currently being piloted, the RCGP education programme for GP's and the Cardiff University short and longer courses. Such training should include use of the Welsh end of life care planning (pathway) system.
 8. NHS funding to the voluntary sector should focus on funding towards the core clinical team to meet the specialist palliative care 24/7 requirements, without impeding the voluntary sector ability to provide additional flexible care to meet local needs.
 9. Those areas which have NHS provisions but no voluntary sector must not be financially penalised.
 10. The proposed task and finish groups were agreed. The terms of reference for the groups would be drawn up based on the priorities of the Sugar Report.
 11. The LHB's and the Regional Networks will be informed of the work to ensure they do not duplicate work unnecessarily. They will be invited to send in any strategic plans they have in their areas at present.
 12. Access to out of hours drugs needs to adopt models already piloted and working well in some areas.
 13. The Chief Executives of the new NHS organisations should be requested to have "Palliative Care Developments" as a permanent agenda item on their meeting schedule.
 14. The Board should receive reports annually from all providers and those reports should include accounting for the finance and the audits against standards. The Board should be prepared to report annually to the Minister.

The next meeting is on: Friday 19th September 2008 11.00am

Appendix 4

Implementation Board plan of work

Work-streams will engage providers in the change process, with work being undertaken in task and finish groups covering:

- Data collection and IT provision – including CaNISC and embedding monitoring processes
- Workforce and standards – workforce development and planning; setting clinical standards
- The educational needs of the generalist services
- Children and teenage/transitional palliative care – interface of children's hospices with paediatric and adult services
- 24 / 7 working by specialist services; interface of specialist services with other services – including out of hours
- Service level agreements

Each group will have a core theme of Patient Needs running through the work. Monitoring of services through their reports will be via the 3 regional networks, reporting to the Board. The Implementation Board will advise the Minister on progress and on funding allocations in subsequent years.

Discussions with LHB's and their successor bodies will establish core service level agreements across Wales. Providers will be expected to work as a federation of providers within an LHB cluster and / or at network level.

A Wales-wide needs assessment can be undertaken in conjunction with Peter Tebbit – who has been approached by individual LHB's to date. A Wales-wide view would ensure clarity and fairness, update previous work and provide a template for ongoing support. This should only require 15 days work from Peter Tebbit, costing to build on the LHB contracts already established for his work.

The management of the process will need two days a week work from a dedicated senior officer as well as contracted sessions from the Implementation Board chair.

Costs:

These are laid out in the 'Options in Funding' paper.

For work commencing this year, projected costs have been estimated. However there will be costs associated with implementing the Sugar report recommendations that will be over and above costs estimated for this year.

Also, it has not been possible to estimate the costs for the ongoing work, outlines in the priorities for 2009-2010 as yet.

Options in funding to individual hospice units for 2008 to 2009 (transition money)

History

In 2004, £10 million was allocated to hospices in Wales. Distribution of this money was spread over three years. In 2007, £2 million was announced as a one-off grant to hospices in Wales. Bids were invited and the money allocated according to the bids received; thus those services already in existence and in a good position to put in a bid stood a greater chance of receiving funding than the smaller services. Those areas in Wales without services received none of this money. It was clear at the time that this money was for one year only and services were warned that they should not incur recurrent funding as there was no guarantee that this money would be repeated.

For the year 2008 to 2009, the Minister announced that there would be ongoing money towards hospice services, providing the £2 million to the voluntary sector and an additional £1 million of One Wales palliative care funding; this £1 million is to be uplifted in future years to £3 million and then £5 million.

This document focuses on the £2 million to be distributed to voluntary hospices, with the realisation that inflationary costs will mean that in future years One Wales funding will need to be used for some services. The allocation of the £2 million in this year is transition money as services move towards an all-Wales template to correct the inequities in provision of specialist palliative care services across Wales. The amount of money allocated this year should not be viewed as an indication of funding in future years, but it does set the direction of travel for services; those able to demonstrate a close fit with NICE guidance, which will often be achieved through working in partnership with others, can feel more secure in the level of funding table they will receive in the future.

Eligibility

The following criteria must be fulfilled for an organisation to be eligible for funding through the One Wales palliative care fund hospice allocation (£2 million):

- A voluntary sector 'hospice' is defined as a registered charitable organisation that operates in a defined location, is part of a national organisation and which delivers a professionally-led palliative care service as its core function.
- The hospice must be compliant with, or working towards, the criteria set out in the NICE guidance on palliative care services.
- The multi-professional clinical team should be consultant-led as set out in the report of the Palliative Care Planning Group for Wales (chaired by Viv Sugar).
- The specific terms of the service level agreement that accompanies the allocation must be fulfilled. Non-compliance with the criteria laid out in the service level agreement will result in the funding being recalled.
- Fundraising, charity management costs and social care costs are not eligible for funding.

Funding is allocated as a top-up to the Local Health Board funding and does not replace it. It is a contribution to the clinical service costs. It is not allocated as percentage of a hospice's running costs.

Options in allocating the £2 million

Option 1 Allocate transition money around clusters of local authorities, coterminous with the new integrated NHS organisations in Wales.

On a population basis, the clusters would receive a portion of money as follows:

Integrated Board area / Local authority cluster	% of population	of SMR	Allocation from £2m support for voluntary sector hospices	Allocation from £3m One Wales Palliative Care funding 2008	Allocation from £5m One Wales Palliative Care funding 2009
North	22.77	101.4	455384	683076	1138461
Powys	4.43	93	88594	132890	221484
Hywel Dda	12.59	98	251821	377731	629551
ABM	16.76	110.67	335179	502769	837948
Cf & Vale	14.93	104.5	298668	448002	746669
Cwm Taf	9.71	124	194168	291251	485419
Gwent	18.81	111.8	376187	564281	940468
WALES	100	106			

Advantages:

At first sight it appears equitable

Coterminous with the new Integrated Boards of the NHS in Wales

Disadvantages:

It takes no account of:

- LHB funding currently to the voluntary sector,
- the funding of services provided wholly by the NHS,
- the historic inequities in service development.

Option 2. Allocate new money around each regional cancer networks

Regions	% population	Allocation from £2m support for voluntary sector hospices	Allocation from £3m One Wales Palliative Care funding 2008	Allocation from £5m One Wales Palliative Care funding 2009
North	24.77	495400	742500	1237900
West	31.35	627000	940500	1567500
South East	45.69	913800	1370700	2284500

Advantages and disadvantages as above.

Plus disadvantage that the networks are not funding bodies and are not set up to monitor contracts or service level agreements.

Option 3 (Preferred option). Allocate new money to individual units based on topping up the current LHB contract(s) to the hospice and cognisant of the configuration of other local providers to avoid duplication of services

This is based on the formula calculated for each individual hospice as:

Income from LHB + part of £2m hospice money GOES TOWARDS the costs of the *required* specialist team (consultant + specialist nurses + specialist allied health care professionals) with an additional allowance towards inpatient beds/notional 'hospice-at-home beds' general care costs over and above the care that should be provided by primary care services.

Independent hospices have been keen to maintain their independence often arguing for 50% funding of their clinical service. Another precedent is Marie Curie nursing services; Marie Curie Cancer Care provides matched funding for the nursing hours contracted from Marie Curie for care in a patient's own home. Therefore an estimate of the general care costs for a patient in an inpatient hospice bed of £1200 per week has been taken as an indicator. If 50% of this is NHS funded, an additional basic amount of £25,000 per inpatient hospice bed per annum has been factored in for general care costs, assuming bed occupancy rates of around 80%. For hospice at home care there are no building maintenance or 'hotel' costs and part of the general care costs are covered by the district nursing service; therefore, for hospice at home services the top-up generalist care notional bed costs of £8,333 per 'notional bed' per annum has been allowed.

Calculations this year do not include any consideration of day-care. They do, however, consider the need to increase the availability of specialist palliative care services to patients with non-cancer diagnoses.

Advantages:

- This provides transitional funding to help services reconfigure and change working patterns to meet the NICE standards.
- The funding rectifies inequities that occurred through the bidding process
- It avoids the risk of duplication of LHB allocated funding.
- Those services that have already changed to provide a comprehensive specialist service are not penalised.
- Different patterns of service delivery can be matched to local needs.
- It decreases the risk of destabilising established services.

Disadvantages:

Lack of accurate data on details of individual LHB contracts and details of other local specialist services means that this funding is transitional; it is not guaranteed recurring funding for an individual unit.

Principles

It is essential that, overall, the end-of-life care of patients and their families is improved, whatever setting the patient is in.

In 2008 the amount of money allocated generally should specify very clearly what the money is and is not for. Such specifications will include:

- Having the nurses trained to specialist level
- Having a consultant clinical lead
- Nurses working a 7 day / week rota with the same level of service each day
- All specialist staff gaining experience in working in the environments of their collaborating organisation, including nurses rotating to spend time in the hospital / hospice / community, in preparation for 24/7 working next year as the specific needs of across the 24/7 time frame are established
- Strengthening the multi-professional team by establishing linked physiotherapy / occupational therapy posts with lead units, through NHS Integrated Boards
- Specialist staff providing support, education and training to other services
- Establishing computerised links for the clinical record to CaNISC.

For some services a fundamental review of their service is required; it is suggested that money allocated is to take them through this transition to plan their future direction. Such funding is strictly for this financial year (6 months remaining).

Hospices in receipt of transitional top-up funding will be required to report on their progress and will be monitored by the Implementation Board, both directly and through reports from the regional palliative care networks. Any voluntary sector provider failing to comply with the direction agreed in the service level agreement associated with their top-up transitional funding will be required to return the funding to the Assembly Government.

One Wales £1 million palliative care funding

There is a need to analyse the total spending in Wales on all specialist palliative care and hospice services and examine whether changes would improve governance, support generalist services, meet clinical need better and provide benchmarking against agreed standards.

The use of funds should be to:

- strengthen the infrastructure of patient services,
- increase the skills and competencies of the generalist services, in hospitals and in the community,
- begin to address the lack of out of hours support to patients and their families
- begin to instigate rapid response systems to enable patients to remain at home if that is their preferred place of care.

Other work to be done this year includes:

- negotiating with Healthcare Inspectorate Wales and the Care and Social Services Inspectorate Wales to ensure that all units are registered
- review the monitoring arrangements for the palliative care standards developed through cancer services coordinating group

- reviewing transport and emergency call responses for palliative care patients with the ambulance service and with NHS direct
- establish a patient-held card and an 0800- number for patients out of hours
- explore models of out of hours pharmacy provision
- explore the development of a rapid response support and equipment supply service to enable patients to remain at home, possibly operated through the ambulance service or the out of hours specialist nurse rota.

Calculations this year do not include any consideration of day-care. They do, however, consider the need to increase the availability of specialist palliative care services to patients with non-cancer diagnoses.

It is recommended that further money this year should be allocated as below, with projections for ongoing funding:

Item	2008-09	2009-10 Indicative costs	2010-11 Indicative costs	Provider
Implementation Board task and finish workgroups (6)	£15,000			WAG
Tebbit review across Wales	£5,000			Velindre
Primary and secondary care course development	£73,000	£50,000	£52,000	Cardiff University
Scoping of child bereavement	£7,000			
Project Manager 2 day/wk	£12,500	£25,000	£25,000	Velindre
Prof Finlay at £330 per day for 61 days	£20,130			Velindre
Board expenses	£2,000	£2,100	£2,300	WAG
Develop patient held registration card	£5,000	£2,000	£2,050	Velindre
Develop single contact point for patients (0800 number)	£5,000	£35,000	£38,000	Velindre / Marie Curie
End of life care pathway audit expansion	£15,000	£30,000	£33,000	North Wales Board
CaNISC development (Palliative Care module clinical record system)	£100,000		this year	IHC
CaNISC training of hospice staff and support at helpdesk	£37,000	£78,000	£82,000	IHC
2 Gwent locum consultants (part time 0.6 wte each) & Specialist Registrar	£80,000	£200,000	£205,000	Gwent Board
NHS managed community physio / O.T. to area lead units, to link with primary care	£82,000	£350,000	£380,000	7 Welsh Boards
TOTAL	£458,630	£628,000	£667,000	

Voluntary sector funding

It is very important that no funding assumptions are made by voluntary sector organisations for either new or unplanned expansion of activities. In the past there have been ad hoc developments which have not met need in the optimum way.

There is therefore a need for clear statement that in future that no new services will be eligible for NHS funding, unless there has been prior agreement with all parties with whom the service should collaborate and that such an agreement has been ratified at Board level and signed off at ministerial level.

Implementation Board recommendation on allocation of top-up transitional funding to hospices for 2008-09, by integrated Board:

	% of Welsh population	Option 3 allocation mechanism to voluntary sector (from £2m hospice fund)	Current LHB funding to voluntary sector providers eligible for hospice fund (data from hospices)	Marie Curie nursing service LHB contracts (data from Marie Curie nursing - N.B. matched funding)	Total NHS money potentially going to voluntary sector hospice services	Level of statutory funding to hospices for each Board area expressed as £/10% Welsh population
North West	10.04%	181300	555004	192142	928,446	924,747
North	12.73%	140410	591212	125053	856,675	672,958
Powys	4.43%	50360	140799	96000	287,159	648,214
Hywel Dda	12.59%	275715	735000	251273	1,261,988	1,002,373
ABM**	16.76%	65000	523004	195590	783,594	467,538
Cwm Taf*	9.71%	0	0	74163	74,163	76,377
Cf & Vale	14.93%	526210	1192308	45524	1,764,042	1,181,542
Gwent	16.49%	501500	745566	90583	1,337,649	811,188
North – Children’s hospice		175000	48124	0		
South – Children’s hospice		110000	291594	0		
TOTAL		2,025,495	4,822,611	1,070,328		

N.B.

* no voluntary sector hospice in Cwm Taf; all units are wholly NHS funded

** mostly NHS providers

The following table gives details of the aggregated funding above, broken down by individual voluntary sector hospices within each of the Integrated Board areas. It also outlines the requirements for 2008-09 to be met.

For each of the voluntary hospices the following transitional funding is recommended:

Board	Hospice	Amount in £	Key Conditions
North West	Gwynedd Hospice-at-Home	21500	As contribution to charity funding of the NHS managed service (£120,000 last year)
	St David's Llandudno	159800	For part funding of 0.8 WTE specialist medical cover + 3 CNS
North	St Kentigern's	120410	For 3 sessions consultant and 1 WTE CNS + staff training + data input officer
	Nightingale House	20000	To put in the infrastructure for CaNISC developments
	Good Shepherd Flintshire	0	Is funded for cross border by LHBs. May need increase support in future years
Powys	Severn hospice	20360	For consultant input to mid Wales
	Bracken trust	15000	To undertake complete review of service for palliative care needs of local population
	Usk house Brecon	5000	To undertake review of service & consider CNS managed from Gwent or Cwm Taf
	Ty Croeso Ystradgynlais	10000	To explore link with ABM trust and become a directly managed unit linked to Ty Olwen
Hywel Dda	Beacon of Hope	53000	To develop consultant-led service from Bronglais and CNS managed by NHS; work towards videoconferencing of MDT.
	Shalom	78600	For 2-3 sessions cons / assoc sp & 5 CNS sessions + CNS education; to work with Marie Curie to open beds. Videoconferencing for MDT across Hywel Dda
	Paul Sartori	16150	To develop as part of Hywel Dda managed cluster of services: 2 sessions consultant and 4 sessions CNS; to develop video link for MDT meetings; review of hospice at home service
	Ty Bryngwyn	127915	For 4 CNS based in NHS; plan increased consultant time to become central hub of Hywel Dda services cluster across 3 counties
ABM**	Ty Olwen	65000	To support specialist palliative care in Ty Olwen
Cwm Taf*	No voluntary sector providers		
Cardiff and Vale	Holme Tower	341210	Takes account of current consultant posts, specialist nurses and full MDT staffing in place
	George Thomas Trust	185000	For 1 WTE consultant post, data entry clerk, CNS development; subject to review when new LHB contract in place
Gwent	Hospice of the Valleys	50000	To develop consultant post jointly with Gwent, to be NHS managed
	St David's Foundation	320000	To become consultant-led clinically over next 2 years; managed through Gwent NHS Trust; hospice at home to be benchmarked against MCCC
	St Anne's Hospice	131500	For consultant / assoc. specialist sessions and closer integration with Gwent NHS Trust
Children's hospices in Wales			
South	Ty Hafan	110000	To develop links with paediatric services, staff rotation; education to CNS Paediatric Palliative Care; fund consultant input; core dataset review
North	Ty Gobaith / Hope House	175000	For staff education, links to paediatric services in N Wales; LHB funding review with Integrated Board