WELSH ASSEMBLY GOVERNMENT

TOGETHER FOR HEALTH - DELIVERING END OF LIFE CARE’- A DELIVERY PLAN UP TO 2016 FOR NHS WALES AND ITS PARTNERS - CONSULTATION

INTRODUCTION

BMA Cymru Wales is pleased to provide a response to the Welsh Assembly Governments consultation on Together for Health - Delivering end of life care.

The British Medical Association represents doctors from all branches of medicine all over the UK. It has a total membership of just over 150,000 including more than 3,000 members overseas and over 19,000 medical student members.

The BMA is the largest voluntary professional association of doctors in the UK, who speak for doctors at home and abroad. It is also an independent trade union. BMA Cymru Wales represents some 7,000 members in Wales from every branch of the medical profession.

RESPONSE TO THE CONSULTATION

BMA Cymru Wales welcomes the opportunity to comment on the draft delivery plan. We have consulted our members from across Wales and do have a number of their comments which we wish to bring to your attention.

Please do not hesitate to contact BMA Cymru Wales should you require any further information.

END OF LIFE CARE DELIVERY PLAN

We welcome the focus on ‘person centred care’ and a whole systems approach – the rise of the third sector in many areas of end of life care perhaps indicates where, what should often be essential NHS service provision, is falling short. That said, along with the NHS and other partners there is an important role for the third sector here, however it needs support and recognition for this valuable work.

BMA members strongly felt that the draft delivery plan focuses on the wrong aspects of end of life care services. Many expressed concerns about palliative care registers (such as the Liverpool Care Pathway) and the impracticalities – and questionable ethics – of deciding who should go on the pathway, which is an inexact science. It is all too easy to add someone to the register and avoid the difficult conversation and patients without the necessary consultation and conversation. It is not clear if this document is talking about the hospital orientated care pathway (LCP) or a register based more on the Macmillan Gold Standard Framework for Palliative Care.

Since the main priority has to be to provide good palliative care, whilst maintaining the respect and dignity of the patient, there should be no barriers to accessing appropriate care – particularly in relation to age and where you live - and the Delivery Plan needs to ensure that a named person, ideally the individuals GP, is coordinating the care pathway.

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Individuals should have a clear choice where they wish to die and the system must be changeable if these initial wishes alter.

For those not wishing to die at home, there should be appropriate non-District General Hospital facilities, Community Hospital beds, Hospice beds or specifically designated nursing home beds available. Any non-home care patients should be close to their home to facilitate visiting by, often elderly, relatives. As such, there is scope for the use of cottage hospital and nursing home beds here in a much more imaginative way that happens at present.

Whilst effective palliative care training is vitally important and can always involve a wider group of clinicians the role of out of hours care and supervision is something that many people need. Likewise, there is a lack of clarity for relatives on whom to approach for advice and guidance.

Staffing levels are a real barrier to improvement in this area – particularly in out-of-hours – and investment is needed in providing adequate medical and nursing staff to deliver an effective service. General nursing levels (i.e. not necessarily 24/7 access to specialist nurses) are particularly important in the provision of the essential components of support and care provision – and whose numbers desperately need increasing in this area. Improved care cannot be delivered by an overstretched, or in some areas skeleton, workforce.

Overall our members felt that this document focuses on the wrong aspects of palliative care; and that there needs to be a realignment of funding and investment if we have any chance of realising its aims.

THE PALLIATIVE CARE TEAM

Frequent, timely and accurate communication is needed between Primary Care and Secondary Care this will improve by providing the implementation of the Individual Healthcare Record. The focus of this Plan seems to be on providing day time palliative care teams but there needs to be focus on the OOH organisations ensuring there are adequate resources to provide the care needed.

The fulcrum of care must be the doctors and nurses of the Palliative Care team (ideally working from the same site) supplemented by specialist services as needed. A parallel specialist service is completely unaffordable and risks fragmenting the existing provision.

At present the OOH staffing levels are far too low and are not funded to provide the level of care needed, there must be sufficient investment in the OOH service to ensure sufficient doctors and nurses are available to keep the terminally ill in their homes – if that is their choice.

There must be sufficient investment in basic nursing care, for example: often a Marie Curie nurse is all that is needed for night support. Investment in highly qualified, but only office hour’s, style specialist nurses is not the answer.

Monthly palliative care meetings between all team members including hospice nurses are vital to ensure all aspects of the care plan are shared. Many of our members reported that palliative care meetings, which usually take place in the GP surgery, are vital for all team members to know what each is doing, that care needs and wishes are known, and that care provision is coordinated.

DISCHARGE PLANNING

Discharge planning needs to be improved, ideally all relevant parties informed 24hrs before discharge into the community.

Members reported issues of transport, many said that hospices need their own dedicated transport to ensure expediency of patient transfer. Others noted that avoiding evening or late Friday discharges from hospitals where possible is useful, unless it can be guaranteed that information is sent to practices and all other bodies are informed (e.g. hospital, district nurses and OOH organisations).
Some members reported that named cancer key workers is a process that is not working as well as it could, with communication / effectiveness and discharge planning falling short. Access to specialist advice for non cancer patients needs consistency across all palliative care providers.

RESOURCES

As noted above, there needs to be a substantial amount of monies invested to ensure a first class service can be delivered.

Palliative Care is predominately led by primary care where additional funding in this area is needed.

Where aid resources and syringe drivers are needed for the patient at home it should be ensured that these are in place at least 24hrs before discharge.

There also needs to be improved access to palliative care drugs in case of emergencies.

DEATHS

All deaths should be reported to be patient’s GP within 24hrs

The suggested Palliative Care Register should be amended to six months rather than twelve months to tie in with the patient’s requests following death to comply with the DS1500 rules.