



Aneurin Bevan University Health Board

Byw Nawr: Live Now

Purpose of the Report:

The purpose of this report is to inform Monmouthshire Council of the development of Aneurin Bevan University Health Board and its partners as a Beacons site for the development of Byw Nawr.

Byw Nawr is the Welsh equivalent of Dying Matters. This was set up by the National Council for Palliative Care to support the End of Life Care Strategy. The aim of which is to raise public awareness about the importance of talking more openly about dying, death and bereavement and of making our wishes known.

The paper gives an overview of Byw Nawr and describes some of the actions that have taken place to date.

Recommendation,

Monmouthshire Council is asked to:

- Note the contents of this paper.
- Agree the Health Board will support this campaign.

Report Author: Bobby Bolt, Deputy Chief Operating Officer

1 Introduction:

The Byw Nawr (Live Now) partnership was established in 2014 to help generate a conversation in Wales about how we can live well, yet make preparations in advance for the End of our Lives. The partnership supports the Welsh Government End of Life Care Delivery Plan by promoting 'a healthy realistic approach to dying, adopting healthy lifestyles, while being informed and supported to make arrangements in advance for the end of life.' It was launched by the Minister for Health and Social Services during Dying Matters Awareness Week on 21 May, 2015.

Talking about dying and planning ahead may not be easy, but it can help make the most of life and spare loved ones from making difficult decisions on our behalf when we become incapacitated or dealing with the consequences of us dying without making a will.

2 Attitudes to Death and Dying in Wales

Byw Nawr works in association with Dying Matters.org which is a programme of work undertaken by the National Council for Palliative Care.

A survey undertaken in 2014 by Dying Matters found that:

- Although almost a third of people in Wales (31%) think about dying and death at least once a week, 73% believe that people in Britain are uncomfortable discussing dying, death and bereavement.
- Only 32% of adults in Wales say they have written a will, 33% that they have registered as an organ donor or have a donor card, 30% that they have taken out life insurance, 26% that they have talked to someone about their funeral wishes and 7% that they have written down their wishes or preferences about their future care, should they be unable to make decisions for themselves.
- Just 18% of people in Wales say they have asked a family member about their end of life wishes.

Despite this failure to talk about dying and plan ahead, 70% of the Welsh public agree that if people in Britain felt more comfortable discussing dying, death and bereavement it would be easier to have our end of life wishes met.

The research also found that:

- The majority of people across Wales (77%) agree that quality of life is more important than how long they live for.
- The most common age at which people would like to die is 81-90 (24%).
- Almost three-quarters of people (73%) agree that providing end of life care should be a fundamental part of the work of the NHS.

3 Welsh Government Support

The previous Minister for Health and Social Services Professor Mark Drakeford has stated publicly how important it is to ensure people in Wales plan ahead for their end of life care needs and fully supports the

work of Byw Nawr, to the extent that Welsh Government funding has been made available to support the Byw Nawr partnership through the production of bi lingual Dying Matters literature and in the development of bi lingual Byw Nawr and 'Find me help' websites.

4 The Byw Nawr Partnership

The partnership is a broad and inclusive community. It aims to engage individuals and organizations throughout Wales, across a range of sectors who wish to support this work by engaging in the Big Conversation around 'living and dying well' in their communities.

A simple five step approach is promoted, encouraging people in Wales to:

1. Make a will

Will making is important if you care what happens to your property after you die, particularly if you are neither married or in a civil partnership. The law does not recognise co habitees as having the same rights as spouses and civil partners.

2. Tell your loved ones your wishes

Cicely Saunders (1918-2005) reminded us that 'How people die remains in the memory of those who live on'. Yet sometimes, through trauma or sudden illness, death occurs without time to say goodbye, plan or prepare. Knowing that we have made public our wishes and shared precious memories in advance when we are fit and well will support those left behind as they go through the bereavement process. They will be consoled knowing that having already had those conversations, they were not unprepared when the time came.

3. Register as an organ donor

The Welsh Government Organ Donation Team state that someone dies every ten days waiting for an organ transplant in Wales. Whilst 90% of us support organ donation not enough of us have told our loved ones whether we want to be a donor or not. Every missed chance for someone to become organ donor is a tragedy.

In Wales, from 1 December 2015 organ donation will be easier. Even with this change it is still important that you tell your friends and family about your wishes as under the new system your loved ones will still be asked if they knew your decision on organ donation.

4. Record your funeral wishes

Documenting your funeral wishes is an opportunity to ensure the funeral reflects your life and gives your family and friends the opportunity to say goodbye. Grieving relatives can also gain comfort from knowing that they will be taking practical steps to give you the funeral you desired.

5. Plan your future care and support

People who are coming to the end of their lives state the value of friends and professionals during the end of life; to just be there, offering practical support and a listening ear and supporting them to make important choices, such as how and where to be cared for. The 'Find me Help' section on the Dying Matters website offers links to local services, information and supportive online communities.

5 Local Actions

The Health Board has adopted the campaign and is launching a local partnership with other health and social care professionals, voluntary organisations and care homes. The aim of which is to raise awareness of the need to plan for the end of our lives and ensure we all have the Big Conversation.

This has included a formal launch. Also planned are links on organisational websites, information in health care premises, care home etc. encouraging the Big Conversation through community venues and with community groups.

Previous discussions have taken place at Monmouthshire Adult Health and Social Care Select Committee about end of life care. Following that discussion, the Deputy Chief Operating Officer and Chair of the Select Committee met with Veronica Snow, who is leading implementation of the End of Life Care Plan and co-ordinating the work of Byw Nawr across Wales. As a result there was enthusiasm to launch this locally, with the potential of asking the various 50+ groups to support this work.

The Gwent area has been identified as a Beacon site for the development of Byw Nawr in Wales. One of the aims of this is to develop formal partnerships with Local Authorities and other key partners and it is hoped that Monmouthshire Council will be the first Council in Wales to formally adopt Byw Nawr. The exact format of this is to be determined and we are in a unique opportunity to shape this and be at the forefront of improving end of life care through encouraging people to plan for their death and talk to their loved ones about their wishes so that their last days can be as peaceful as possible.

6 Recommendation:

Monmouthshire Council is asked to:

- Note the contents of this paper.
- Agree the Council will support this campaign.
- Agree the Council will collaborate with the Health Board in developing a formal partnership.

Bobby Bolt

**Associate Director Efficiency and Effectiveness
Aneurin Bevan University Health Board
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