



Welsh Government

Together for Health – Delivering End of Life Care

A Delivery Plan up to 2016 for NHS Wales and its Partners

The highest standard of care for everyone at the end of life

Wales is aiming for our health and health care services to match the best in the world.

For palliative care, this requires the Welsh Government, the NHS, charities, hospices and the public to work together across Wales. The plan says what we must do together between now and 2016.

Overview

This consultation invites views and comments on the Welsh Government's draft strategy for a National End of Life Care Delivery Plan.

How to respond

Please respond by **5 December 2012**.

Response forms can be sent to the following address:

Adult and Children's Health
Medical Directorate
Welsh Government
Cathays Park
Cardiff
CF10 3NQ

Or completed electronically and sent to e-mail:
adultsandchildrenshealth@wales.gsi.gov.uk

Further information and related documents

Large print, Braille and alternate language versions of this document are available on request.

Contact details

For further information:
Adult and Children's Health Services Branch
Medical Directorate
Health and Social Services Directorate
Welsh Government
Cathays Park
Cardiff
CF10 3NQ

e-mail:
adultsandchildrenshealth@wales.gsi.gov.uk

Tel: 029 2082 5922

Data protection

How the views and information you give us will be used.

Any response you send us will be seen in full by Welsh Government staff dealing with the issues which this consultation is about. It may also be seen by other Welsh Government staff to help them plan future consultations.

The Welsh Government intends to publish a summary of the responses to this document. We may also publish responses in full. Normally, the name and address (or part of the address) of the person or organisation who sent the response are published with the response. This helps to show that the consultation was carried out properly. If you do not want your name or address published, please tell us this in writing when you send your response. We will then blank them out.

Names or addresses we blank out might still get published later, though we do not think this would happen very often. The Freedom of Information Act 2000 and the Environmental Information Regulations 2004 allow the public to ask to see information held by many public bodies, including the Welsh Government. This includes information which has not been published. However, the law also allows us to withhold information in some circumstances. If anyone asks to see information we have withheld, we will have to decide whether to release it or not. If someone has asked for their name and address not to be published, that is an important fact we would take into account. However, there might sometimes be important reasons why we would have to reveal someone's name and address, even though they have asked for them not to be published. We would get in touch with the person and ask their views before we finally decided to reveal the information.

PERSON CENTRED CARE



REDUCING
distress in the
terminal phase
for the patient
and their family

DETECTING
and identifying
patients early

TARGETING
research

DELIVERING
fast, effective
person centred
care

IMPROVING
information

SUPPORTING
living and
dying well

Message from Lesley Griffiths AM, Minister for Health and Social Services

This document sets out my ambitions for what the NHS, working with its partners, will achieve to improve inequalities in the end of life care up to 2016.

The Palliative Care Implementation Board was established in July 2008 to deliver the recommendations of the Palliative Care Planning Report (Sugar) following its publication by the Welsh Government in 2008. The Report set out recommendations for palliative care provision in Wales with clear actions up to 2011. We have made good progress in delivering on the actions in the Sugar Report. This plan builds on these achievements and is aligned with Government's overall policy on health and health services, as set out in our *Programme for Government* and *Together for Health*.

The Programme for Government places a clear and serious responsibility on Local Health Boards, with our NHS Trusts, to promote and protect the health of people in Wales and plan and deliver high quality end of life care services.

While the NHS must take a lead, others too need to play their part. There is a very important role for Local Government in working collaboratively with NHS Wales and third sector providers to deliver integrated and supportive family centred care.

We are building on a record of success. The achievements to 2011 place Wales as a leading Nation in the delivery of end of life care in the United Kingdom and beyond. However, there is more to be done, we have to continually change and improve to remain a world leader.

A. *Our Vision*

The outcome the Welsh Government wants for the population of Wales for the highest standard of care for everyone at the end of life is set out below.

For our population, we want:

- People in Wales to have a healthy, realistic approach to dying, planning appropriately for the event
- Patients dying in Wales to have access to high quality care wherever they live and die whatever their underlying disease or disability, devoid of any prejudice in relation to their personal situation

We will use the following indicators to measure success:

- Number of individuals in Wales who die intestate
- % of people with palliative needs on a primary care practice Palliative Care Register six months prior to death
- % of patients with an advanced care plan
- Number of complaints to NHS Wales regarding end of life care

B. **How well are we doing in Wales in end of life care?**

The Palliative Care Implementation Board has worked with Local Health Boards, Trusts and third sector providers to strengthen existing services. Education programmes, quality standards, and information systems have all been developed to improve the service provided.

Patient feedback is taken on a regular basis through the Dying Well Matters Initiative in which patients and their families are invited to tell their story of their care; this patient feedback is informing further service developments.

All the evidence and research tells us we must focus all our efforts on:

- **Supporting** Living and Dying Well
- **Detecting** people with palliative care needs early
- **Delivering** fast, effective person centred care
- **Reducing** distress in the terminal phase
- **Improving** information
- **Targeting** research

So this is where we want the NHS to take the lead and to focus efforts to make significant improvements next.

C. *What will NHS Wales's services look like in 2016?*

To make real and substantial progress towards achieving our vision and for people to be healthier as a result, we want to see the following things from NHS end of life care by 2016.

Annex 1: Summary of Outcomes expected by 2016

Outcome 1 – Supporting Living and Dying Well

People in Wales have a healthy realistic approach to dying. They are encouraged to adopt healthy lifestyles, yet are informed and supported to make arrangements in advance for the end of life.

- training opportunities for primary care teams to encourage patients to have in place plans for the end of life
- improved communication skills of health professionals to talk to patients regarding End of Life plans
- greater public awareness of the need to have arrangements in place for the end of life, including making a will, addressing their financial matters and making a plan for their wishes at the end of life
- bereavement support is provided in society in particular within local communities

Outcome 2 – Detecting and identifying patients early

People with palliative care needs are identified early to enable the best care to be planned in advance.

- patients early identification in last year of life
- professionals recognise patients are entering the palliative phase of illness and communicate with the patient and colleagues' regarding future care
- Increase in Primary care practices holding regular monthly Multidisciplinary team meetings to discuss patients on a palliative care register and generating active care plans
- ensuring patients and their families understand their condition, what to look out for and what to do, including when to seek additional help
- patients and families know who is leading their clinical care at all times
- generalist clinical teams know how to access support and advice from specialist palliative care services
- timely transport is available for those patients who need to be moved for their care
- information is available by telephone and on-line to support care at home;
- people's views on services are sought regularly and acted on to ensure continuous service improvement

Outcome 3 – Delivering fast, effective person centred care

People receive fast, effective person centred care in order to maintain quality of life for as long as possible. Patients and their families have their needs identified and met so they feel well supported and informed, able to manage their illness.

- dignity and respect are maintained at all times
- systems to assure high quality palliative care provision through good communication between all those involved in providing health and social care
- seamless integration of specialist palliative care across NHS and Third sector providers and integration with other specialist and generalist services
- specialist palliative care support to other clinical services is available 24 hours a day, 365 days a year, with access to specialist services for patients in whom symptoms are not responding to treatment by generic teams
- specialist palliative care centres of excellence that match or surpass the best and are seamlessly connected with local service providers
- people's clinical and non clinical needs at the end of life are assessed and recorded using an Integrated Care Priorities Approach, with services designed around meeting those needs

Outcome 4 – Reducing distress in the terminal phase for the patient and their family

Patients entering the terminal phase of their illness and their families feel well cared for and are pain and symptom free. Symptoms and problems that are likely to arise are addressed appropriately and promptly.

- patients and their families have access to information and support services
- care is planned using an Integrated Priorities Approach
- more people receiving palliative and end of life care have access to support on a 24/7 basis
- specialist palliative care nursing is available 7 days a week
- families facing bereavement particularly those with children are supported in coming to terms with their impending loss, with additional support in bereavement where needed
- people's needs and wishes, and those of their family, are clarified, clearly recorded and are a key guide to care provided
- rapid response to all causes of distress in the patient (physical, emotional, psychosocial and spiritual) and support to their family and close carers;
- careful monitoring of patients with referral to specialist palliative care advice whenever there is no improvement in a short time frame (a standard of 48 hrs has been set)

- key information on all patients seen by the specialist palliative care team is recorded on CaNISC and accessible to others who have clinical responsibility for the patient
- a reduction in patients being admitted unnecessarily to hospital

D. *What will we do to get there?*

The Welsh Government, the NHS, local government, cardiac charities and the public all have a role to play together in end of life care. Over the coming years up to 2016 –

The Welsh Government will:

- encourage people in Wales to adopt healthy lifestyles and provide support to make arrangements in advance for the end of life
- work with partners to ensure people with palliative needs are identified early to enable the best care to be planned in advance
- raise public awareness of the need to have arrangements in place for their death eg. making a will and making a plan for their wishes at the end of life
- issue a National End of Life Care Delivery Plan for the NHS
- ensure patients and their families have access to information and support services
- hold the NHS to account on how well it cares for the people at the end of life

The NHS, working with local government, palliative care charities and hospices will:

- help people to have an informed and realistic approach to dying
- ensure appropriate drugs are available out of hours
- support palliative care research to ensure better care is provided in the future
- ensure the delivery of local services to help people at the end of life receive equitable, planned care, appropriate to their need wherever they live in Wales
- develop end of life care delivery plans
- ensure dignity and respect are maintained at all times
- promote public awareness of the need to have arrangements in place for their death, including making a will
- promote a strong culture of research
- publish regular and easy to understand information about the effectiveness of end of life care services

We will all help everyone in Wales to:

- adopt healthy lifestyles and plan effectively for the end of life
- receive fast, effective person centred care in order to maintain quality of life
- improve support to those bereaved
- ensure their needs will be addressed at the end of life
- ensure patients and their families have their needs identified and met so they are able to manage their illness

E. How will we know we are succeeding?

Each year, starting in September 2013 the Local Health Boards will publish clear concise information about end of life services where you live.

The NHS will ask people about the services they receive and publish and act on the results.

By working together, focusing on the needs of people and by being open and honest about how we are doing, we will make the difference we want.

We have made improvements. Working together to improve end of life care, we can do even better.