



Llywodraeth Cymru
Welsh Government

Palliative and End of Life Care Delivery Plan

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Foreword

As chair of the End of Life Care Board and National Clinical Lead for End of Life Care, we would like to acknowledge the work undertaken to improve end of life care which began with the Sugar Report in 2009. The progress to date has relied on strong clinical leadership and effective co-productive working between NHS Wales and our third sector partners. As a Board, we are resolved to ensure that this updated delivery plan capitalises on the success achieved to date and maintains a collegiate approach to improving end of life care in Wales.

Our End of Life Care Board is supported by a well-established Adult Palliative Care Clinical Implementation Group, chaired by Dr Mel Jefferson, and an all-Wales Paediatric Palliative Care Network and Implementation Group, chaired by Dr Richard Hain, which enables a one Wales approach, providing peer support and acting as an effective information sharing platform.

Our aim is for People in Wales to have a healthy, realistic approach to dying, and to be able to plan appropriately for the event. We want them to be able to end their days in the location of their choice – be that home, hospital or hospice and we want them to have access to high quality care wherever they live and die, whatever their underlying disease or disability.

The role of the End of Life Care Board is to drive forward the national plan and support health boards to deliver their local plans. This will be delivered by building on the relationships, systems and procedures already in place to make the most of their potential. Our collaborative approach will use the Palliative Care Clinical Implementation Group and other relevant Implementation Groups to work with the NHS and third sector partners to effect change.

The all-Wales Paediatric Palliative Care Network and Implementation Group was developed to ensure improvements in care for those with life limiting conditions from birth, through childhood and into teenage years. This is delivered by working with the children's hospices, Tŷ Hafan and Tŷ Gobaith/Hope House, to find service solutions to meet paediatric palliative care needs in each health board area.

Providing good care for patients at the end of life is of primary importance. We also know that good care facilitates a healthy grieving process for the bereaved. Appropriate bereavement care is important and we will continue to work to promote services for those who need ongoing support after a death.

We will consider how we can better engage with patients and gain an insight into their experience, both nationally and locally, to ensure services are genuinely co-produced with structured and broad input. We will develop outcome measures that more accurately reflect the experience of the patient and those close to them.

Given the intense pressure on acute hospital beds, there is a need for a wider range of care interventions to be delivered directly to patients in their own homes. There is also a need for greater teaching of relatives/proxy on aspects of care, including basic moving and handling, tailored to the individual's needs. It is

unsustainable in the long term to continue to move patients reaching the end of their lives to hospital for interventions and serious consideration must be given to ways of delivering more interventions in the community for patients of all ages.

We have also committed to supporting a programme of education which includes our Workforce Leadership Programme which is helping to develop future leaders into 2020 and beyond. Through Advance Care Planning we are working to understand the legal framework around decision-making on behalf of those who lack mental capacity for that decision at that time, and exploring ways to communicate such decisions across all sectors. In addition we are improving communication with patients through the continued roll out of our Facilitating 'Serious Illness' conversations training programme which is equipping staff with ways to open, pursue and close such difficult conversations.

Increasingly digital technology is also being used to support patients and enable them to play a part in their own care. We will make appropriate use of digital, telehealth and telemedicine wherever possible to help patients deliver self care.

We all have a part to play in achieving the ambitions of this plan, including local communities and individuals. People do not choose to develop or indeed to be born with an incurable condition. Through the gradual ageing process, we will all reach a point where life expectancy is limited. People can however choose to minimise risk through lifestyle choices and such measures can significantly impact on people's health. A healthy approach to dying, planning ahead and informing family and friends of their wishes can result in improved person centred, tailored care at the end of life. This is judicious, prudent health and social care at its best.

There are still many challenges that remain and stakeholders must continue to work together to build on the significant progress that has been achieved to date. Health Boards must continue to work closely with their third sector partners to deliver the best possible end of life care throughout Wales.

Steve Ham
Chair End of Life Care Implementation Board
CEO Velindre NHS Trust

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National Clinical Lead End of Life Care

Introduction and Context

It is estimated that 0.75% (23,000) of the overall population in Wales have palliative care needs at any one time¹ and the number of people dying each year continues to increase. This means that we will see more people living with multi-morbidity and frailty, not necessarily following a typical or predictable trajectory towards death.

A recent Marie Curie Report: *'Palliative care and the UK nations - an updated assessment on need, policy and strategy'* (2015)² reported that the work to implement the recommendations of the Sugar Report has put Wales as a nation 'ahead of the game'. Wales was the first of only two nations in the United Kingdom to have a current and overarching delivery plan for palliative and end of life care. The Marie Curie Report also identified that increased need can be found within the growing number of deaths recorded with Alzheimer's, dementia and senility as the underlying cause; and an increase in the number of deaths attributed to heart and renal disease.

Reports published during the term of the first End of Life Care Delivery Plan also highlighted areas where improvement is required. Living and Dying with Dementia in Wales: Barriers to Access' Alzheimer's Society Wales Marie Curie 2015³ and People with a Learning Disability 'A Different Ending: Addressing Inequalities in End of Life Care' Care Quality Commission 2016⁴ identified barriers including access to care for people living with learning disabilities and dementia, and a lack of effective advance care planning and timely diagnosis for both groups.

The need to improve access to palliative care services for Black, Asian and Minority Ethnic (BAME) and Lesbian Gay Bisexual Transgender (LGBT) communities were highlighted in South East Cardiff' Marie Curie (2014)⁵ and "Hiding who I am" 'The reality of end of life care for LGBT' people Marie Curie (2016)⁶ respectively.

There is a need to adopt a combined approach of Advance Care Planning, shared decision making and training for healthcare professionals in this field to support these patients and their families and carers, and to learn the best ways to meet the individual's needs.

¹ This figure is in accordance with Murtagh et al. [2014], Gómez-Batiste et al. [2012], and Marie Curie's End of Life Care Atlas (from 2011-2012 data) [2012].

² <https://www.mariecurie.org.uk/globalassets/media/documents/policy/marie-curie-reports/state-of-the-nations-mariecurie-report-england.pdf>

³ <https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/february-2015/living-and-dying-with-dementia-in-wales.pdf>

⁴ http://www.cqc.org.uk/sites/default/files/20160505%20CQC_EOLC_OVERVIEW_FINAL_3.pdf

⁵ <https://www.mariecurie.org.uk/globalassets/media/documents/who-we-are/plans-reports-and-policies/diversity-and-inclusion/improving-access-in-cardiff/improving-access-bame-cardiff.pdf>

⁶ <https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/june-2016/reality-end-of-life-care-lgbt-people.pdf>

This plan covers all aspects of palliative and end of life care, delivered by both primary and secondary care, and also involves specialist palliative care services delivered by the NHS or third sector providers. Such care also involves recognition of the needs of those experiencing bereavement. It builds on the success of the first and is set out in a similar structure, maintaining the original themes with an additional education theme.

The workforce is a critical element of both the NHS and the third sector, and is a key determinant to the success of any organisation. An engaged, sustainable and skilled workforce is essential to delivering high standards of care and transforming the way services are delivered to meet the many challenges faced by the NHS in Wales today.

There are a number of common themes running across many of the Welsh Government major health conditions delivery plans and almost all will have links to the Delivering Palliative and End of Life Care Plan. These include, but are not limited to, the respiratory, stroke, cancer, heart and liver delivery plans.

Since the publication of the first delivery plan, there have been a number of strategic and legislative changes that have impacted upon policy and are reflected in this updated plan. A summary of these changes is included at Annex 1. The relevant links are included at Annex 2.

End of Life Care Implementation Board

The End of Life Care Implementation Board provides national leadership and support and acts as a forum to drive forward change and oversee health boards' efforts to deliver the Welsh Government's vision for improving end of life care in Wales. The Board will be reconstituted to include representation of all those involved in the delivery of end of life care, including ensuring the voice of patients and their families are at the centre of service planning and delivery.

To plan effectively for their populations, local health boards must build and lead coalitions with NHS Trusts, locality networks, GPs, nursing homes, pharmacists, dentists, opticians, social services, prison services and the Third Sector voluntary bodies. Palliative care charities and independent hospices are essential in meeting the needs of people approaching the end of life. These services need to be part of an integrated end of life care service.

Patient Voice/Experience

Understanding the experiences of people at the end of their lives and their families is fundamental for patient-centred, co-productive services. This understanding is also key to measuring the effectiveness of services.

If care is going to improve for all dying patients, then this will need to be co-ordinated within generalist and specialised services. This should include consideration of when specialist palliative care advice should be sought and/or when such services are the lead in care delivery, for instance in hospices. In

addition, the health and wellbeing of the bereaved will be affected by their own personal experience of how their family, partners and friends have been cared for at the end of life.

To date user feedback has been collected through the iWantGreatCare programme and from users on the End of Life Care Implementation Board. This focus must continue and also build on aspects that have emerged as priorities during the course of the first plan. These included supporting professional colleagues to recognise that patients are entering the end of life phase and equipping them with skills to initiate Serious Illness Conversations.

The charity Byw Nawr (Live Now) was established in 2014 in Wales to drive forward the public conversations around death and dying and to help people to openly discuss their concerns. This allows individuals and those representing them to plan appropriately for their physical deterioration and to be able to enjoy whatever time they have left, unencumbered by fears and anxieties over what lies ahead for them, and for their dependents. Byw Nawr aims to inform and educate the public about death and dying in society today, to allay fears and to improve behaviours in terms of patients planning for the reality of their own mortality.

Primary Care and Acute Care

Generalists and non-palliative care specialists (GPs, physicians, geriatricians, community nurses, paramedics and condition specific specialist nurses) have a key role in identifying and supporting these individuals, and ensuring that a palliative care approach is adopted, where appropriate, from an early stage. This will support the delivery of good end of life care.

Maintaining patients in their usual place of residence, when appropriate, is an important goal. We need to ensure people are not being admitted to hospital as emergency admissions unnecessarily into hospital towards the end of life.

Professionals in all settings caring for patients during the last days of life should be able to adopt an approach to care as defined within the Care Decisions for the Last Days of Life⁷. Training to support Care Decisions should be available.

Building and developing the skills (communication skills, serious illness conversational skills, early identification of patients with palliative care needs and symptom control needs) in the generalist workforce in primary care, secondary care and in the community, is *essential* to the overall aim of delivering equitable and high quality palliative and end of life care to the people of Wales.

Health boards need to have in place a succession planning strategy that supports staff to develop skills and qualifications in palliative and end of life care. Opportunities to adopt new models of delivery, incorporating roles such as the Advanced Nurse Practitioner, Staff and Associate Specialist doctors, Physician

⁷ <http://wales.pallcare.info/files/CDLDoL%20Care%20Decisions%20V5.3.pdf>

Assistants, and the changing role of the community pharmacist, should be considered.

Advance Care Planning (ACP) is a process that supports people to plan ahead and make decisions and state preferences in the event of losing capacity. Since the commencement of the National Mental Capacity Forum in September 2007 implementation of the Mental Capacity Act 2005 has improved across Wales. As part of this improvement, a consultation on all aspects including advance decisions to refuse treatment has been ongoing since the publication of Public Policy Institute for Wales report 'Increasing Understanding and Uptake of Advanced Decisions in Wales' (2015)⁸. The report recommends encouraging the public in planning for potential future loss of capacity.

Children and Young People

The Welsh Institute for Health and Social Care (WiHSC) report: Palliative Care for Children and Young People in Wales⁹ acknowledges that identifying the number of children and young people who actually require palliative care is difficult, in part because it is defined primarily by the needs of an individual child and family. The report suggests an estimated prevalence rate for children and young people likely to require palliative care services as 15 per 10,000 population aged 0–19 (excluding neonates).

In Wales there are 3,200 children with life-limiting conditions (LLC) as categorised by one or more of the children's charity Together for Short Lives and the Royal College of Paediatrics and Child Health below:

- I - conditions that are life-limiting but might have a cure (e.g. cancer)
- II – palliative conditions, which there is a period of normality first (e.g. Muscular Dystrophy)
- III - conditions that will cause death after a long period of relentless deterioration (e.g. Tay Sachs disease)
- IV - conditions that will cause premature death in childhood but whose course is unpredictable (e.g. severe cerebral palsy).

Children and young people with conditions in groups II, III and IV typically experience three or four 'end of life' episodes, often separated by several months, from which they may unexpectedly recover. Each of these is properly considered as an end of life episode. Each differs from the final end of life episode only in its ultimate outcome, and all require the same palliative care support. Each year around 200 Welsh children die. At least half of those have an LLC and so would potentially benefit from palliative care. The numbers are, as expected, small compared with other age groups. That does not mean, however, that the need for palliative care is proportionally small. A simple pro rata extrapolation from other age

⁸ <http://sites.cardiff.ac.uk/ppiw/files/2016/02/PPIW-Report-Increasing-the-awareness-and-uptake-of-Advance-Decisions.pdf>

⁹ <https://www.tyhafan.org/uploads/Documents/Ty-Hafan-WiHSC-Report-2016.pdf>

groups relies on a paradigm that is not accurate in children and young people. An appropriate model must take into account the following:

Prevalence: The number of children and young people suffering from a LLC at any one moment is many times the numbers that actually die each year.

An integrated management model: The primary care team is not usually involved with day-to-day care of the dying child or young person at home. Medical care of children and young people often involves off-label and/or off licence prescription of medications, and in paediatric palliative care such unorthodox prescription is the rule. Primary Care teams may be uncomfortable managing the child or young person with an LLC, and it usually means that the specialist palliative care team delivers bedside care to the family at home. Most families caring for children and young people with LLC have some form of 'open access' arrangement with the local paediatric unit that represents access point into healthcare.

There will be some patients with LLC on the caseload of most paediatricians. At any given time, the majority of those patients do not require specialist Paediatric Palliative Care (PPC) support. When they do need it, PPC is delivered through an all-Wales clinical network, which comprises three elements:

- Within each health board a local team of specialist PPC nurse and paediatrician.
- A tertiary team who support local teams clinically, through joint clinics and multi disciplinary team discussions, where necessary by videoconference.
- Third sector providers, particularly the Children's Hospices that serve Wales. PPC is delivered by way of a hub-and-spoke model through ten different satellite clinics across Wales, domiciliary visits and electronic communication. The model is integrated between home-based and inpatient services, allowing the same specialist team to provide continuity in support.

National all-Wales agreed referral and care pathways, with developments such as the Paediatric Advance Care Plan (similar to advance care plans in adult care) should reflect the distinctive needs of dying children and their families. Communication between all care sectors needs to be exemplary, and tools and pathways need ongoing evaluation in practice.

Transition from paediatric to adult services in palliative care requires careful planning, close collaboration between services, and support for parents facing a changed legal framework. These young people often become gravely ill and then make an unexpected recovery on several occasions before their death. Such episodes can be months apart, making the workload pattern different from adult care.

If there are health issues falling across different specialist areas, the handover of care from paediatric services should identify who will take lead clinical responsibility for coordination of care. All primary and community care, palliative care, and

specialty services must ensure they are skilled and competent to deal with the full range of conditions that may occur during this period of a service user moving from being a young person to a young adult. This must include attention to consent in health care, including Mental Capacity Act 2005 assessment and Best Interests decisions where appropriate. Multi agency planning should include services for young adults up to the age of 25, in line with the Social Services and Well Being Act 2014 and the Additional Learning Needs Bill.

Measuring Success

We know that a good service will be different for patients, dependant on individual need and circumstance. To be able to provide the appropriate service, at the right time, we need to understand from the patient and carer perspective what good looks like from their point of view. The iWantGreatCare patient surveys have provided valuable feedback to services across Wales and have evaluated well, but looking to the future, we want to have a greater understanding of what excellence looks like for patients, their families, partners and carers. Developing patient reported quality outcome measures will be a priority. We will use the following outcome indicators to measure success in all patients, irrespective of age:

- Patient reported outcomes during their care covering specific symptom distress scores and their overall evaluation of the quality of any specialist palliative care service they have encountered
- Data from service delivery to monitor the responsiveness of specialist palliative care services, peer review findings year on year, will include a review of complaints and compliments
- Family reported evaluation of the care received; the current pilot in Cwm Taf will guide the timing and method of gaining such information
- GP palliative care registers as a marker of awareness of this patient population
- As the Advance Care Planning processes (adult and paediatric) become incorporated in NHS Wales' IT systems, then the number of such plans that are up to date and logged with the NHS Wales Informatics Service (NWIS) clinical portal, will give a surrogate marker of serious illness conversations that have occurred.
- proportion of patients who are cared for in one of their stated places of preference

Good end of life care services are best delivered by a team of well trained professionals, coupled with good social and carer support. The quality and responsiveness of these services will be measured through the Peer Review process, information systems and health board reports. An all-Wales peer review framework will be published during 2017.

The peer review process for specialist palliative care services has already been very informative, helping services develop in the light of feedback to be able to better meet the needs of their local population. As services move to take more non-

cancer patients, the sharing of their experiences of novel service development will become increasingly important.

This plan recognises that good end of life care can be delivered in a variety of settings by a variety of care deliverers, ranging from highly specialist palliative care teams, generic acute hospital teams to health care support workers in the community and care home setting.

Research

Palliative care research has been identified as a priority area in Wales. Infrastructure has developed significantly in Wales over the last five years with significant investment by Marie Curie in the Marie Curie Palliative Care Research Centre at Cardiff University, with additional research active teams supported by higher education establishments including Cardiff, Swansea and Bangor Universities.

More recently palliative and supportive care has been established as a key work stream of the Health and Care Research Wales (HCRW) funded Wales Cancer Research Centre (WCRC).

To deliver evidence-based care and improve future outcomes, greater coordination of resources and engagement with the clinical workforce and patients is required across NHS organisations, higher education establishments and the third sector. The overarching aim of this plan is to undertake high quality research directly relevant to patient and carer needs and readily translated into improvements in care.

Key objectives to achieve this include:

- **Research leadership:** continued development of multi-professional leadership attracting high value external research funding into Wales and the UK as project leads; also as co-applicants and key collaborators on studies led from elsewhere. This requires cross-institutional collaboration and commitment to create a sustainable environment for clinician engagement in research activities and the development of both portfolio and pathway to portfolio studies.
- **Capacity building:** using established clinical and academic leadership to further build capacity for supportive and palliative care research in Wales. This will be across disciplines and levels of seniority and will rely on collaboration and coordination across institutions. Clinical organisations should support and encourage protected research time for clinically-active staff of all disciplines.
- **Patient and Public Involvement:** demonstrating continued national leadership and innovation in embedding unique model of Patient and Public Involvement (PPI) at all stages of study design, implementation and

evaluation as evidenced within WCRC and the Marie Curie Research Centre.

- Participant recruitment: continuing to increase the numbers of patients and carers offered access to well designed studies across care settings. This will require close collaboration with HCRW workforce and University Health Board research and development departments. Recognition should be given to the resource implications of undertaking trials of complex interventions, including data capture in home settings, with consideration to adjusted weighting for these studies.
- Impact: developing opportunities to mobilise new research findings into practice at pace. This will require collaboration across academic and clinical organisations to mobilize palliative care evidence based practice across the multi-professional undergraduate and postgraduate workforce, and targeting of key guidelines groups including NICE and End of Life Care Board. The Palliative Care Evidence Review Service (PaCERS) at WCRC will also be utilized to support rapid transfer of research evidence into practice.

Implementing the Delivery Plan

Health boards are required to identify, monitor and evaluate action in their area that is required to deliver this Palliative and End of Life Care Delivery Plan in the health board integrated medium term plan.

The Welsh Government will hold the NHS to account to ensure that the actions in this plan are delivered and the desired outcomes achieved. The lines of accountability will be through the Chairs of the health boards and trusts to the Cabinet Secretary for Health, Well-Being and Sport, and, with the Chief Executives of the health boards and trusts reporting to the Chief Executive of the NHS Wales, who is also the Director General of the Welsh Government's Health and Social Services Group.

Health boards are responsible for planning, securing and delivering local services to ensure that those people who are at the end of their lives can access the right care at the right time and place. Each health board has a local planning and delivery group. The local groups will need to plan services effectively for their population and build and lead coalitions with Welsh Ambulance Service Trust, other health boards in Wales and England, primary care, local government and the third sector voluntary bodies.

The End of Life Care Board will support health boards and their local delivery groups through the provision of strong and joined-up leadership and oversight. They will co-ordinate national priorities and actions in a strategic way.

Theme 1: Supporting Living and Dying Well¹⁰

Delivery Aspirations:

People in Wales have a healthy realistic approach to dying. They are encouraged to talk openly about the uncertainties in serious illness, and are informed and supported to make plans for the last phase of their life.

Whenever an adult or child is dying, services must consider the needs of (other) children affected by the death, applying the adage 'think patient, think child'.

Specific Priorities 2017-2020

Health Boards to:

1	Work with NWIS to develop an all-Wales advance care planning record, to enable advance care plans (adult and paediatric) to be shared across all care settings within Wales.
2	Ensure training is available for primary care teams to facilitate patients to express their wishes about their care, and provide palliative care in community settings. (Adult)
3	Maintain sufficient community paediatric services to provide care in community settings and support families in their preferred places of care. (Paediatric)
4	Have in place named pharmacists in each health board to support improvement of medicine management for seriously ill and dying patients.
5	To consider putting in place a lead paediatric pharmacist at the Children's Hospital of Wales with palliative care training to support improvement of medicine management for children with life-limiting conditions in hospital, community and children's hospice settings. (Paediatric)
6	Provide a single point of contact, 24/7 for families caring for a person at home whose death is likely to be imminent, tailored to the individual's needs, even if not apparently immediately required.
7	Promote public awareness of the need to have arrangements in place for their death, including making a will, addressing their financial matters and a plan for their preferences. (Adult)

Clinicians and service managers to:

8	Identify patients with changing care needs towards the end of life at an early stage, through the use of palliative care registers and regular multidisciplinary team meetings involving primary and social care.
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All clinical departments to:

9	Ensure all clinical departments have a programme to ensure family carers are taught basic principles of the care provision to the patient in their place of residence, including lifting and safe transfers, and medication administration, such as urgent pain relief.
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¹⁰ Where priorities are not categorised as Adult or Paediatric, they refer to both.

Theme 2: Detecting and identifying patients early

Delivery Aspirations:

People with palliative care needs are identified early to enable the best care to be planned in advance, using age appropriate tools.

Specific Priorities 2017-2020

Health Boards to:

1	Identify, through various feedback mechanisms, health professionals who would benefit from training in initiating serious illness conversations with patients and their families, and provide such training. (Adult)
2	Ensure generalist teams know how to and are able to access 24/7 support from adult and paediatric specialist palliative care services, including those with learning disabilities.
3	Identify a Clinical Lead for Advance Care Planning.
4	Validate, as part of the QOF process, or subsequent arrangements, that GPs maintain Palliative Care Registers for patients of all ages and across all disease categories, with less than one year life expectancy.
5	Verify as part of the QOF, or subsequent arrangements, that regular multi-disciplinary team meetings take place to discuss patients in acute, primary and community settings, and that these involve a member of the specialist palliative care team.

Theme 3: Delivering Fast, Effective Care End of Life Care

Delivery Aspirations:

People receive fast, effective person centred care 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.

Specific Priorities 2017-2020

Health Boards to:

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| 1 | Review existing specialist palliative care workforce capacity and skills and have in place short and long term workforce plans to address future need, recognising diversity and co-existing need. |
| 2 | Review the capacity of existing bereavement services and settings in which they are delivered to ensure that needs of all bereaved families and carers are being met. |
| 3 | Have in place active mechanisms to facilitate rapid transfer of patients to meet patients care needs and wishes. |
| 4 | Continue to participate in relevant national clinical audits and peer review programmes, using findings to drive continuous service improvement. |
| 5 | Maintain delivery of evidence based specialist palliative care services through well organised multidisciplinary teams, with clear funding streams for specialist palliative care services in line with national guidelines. |
| 6 | Take account of all relevant evidence and guidance, including the National Institute for Health and Care Excellence (NICE) guidelines and quality statements when developing clinical pathways for end of life patients. |

Health Boards working with care home and other residential providers to:

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| 7 | Ensure that staff who have responsibility for patients residing in care homes, nursing homes and other institutional settings, including prisons, are able to access support from specialist palliative care teams to provide appropriate end of life care. (Adult) |
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Health Board inpatient and emergency services, the ambulance service, primary care and third sector providers to:

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| 8 | Work with the End of Life Care Implementation Board to evaluate systems and ways of working that aim to decrease avoidable admissions. (Adult) |
| 9 | Ensure secure, effective and real-time sharing of patient information between services. |

All Specialist Palliative Care providers must:

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| 10 | Ensure that all patients and families have the opportunity to provide feedback on their experience of care, through mechanisms that report back to the End of Life Care Implementation Board. These mechanisms should include (but not limited to) the Patient Experience Outcome Measures (PREMS) and the Patient Related Outcome Measures (PROMS). |
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Health Inspectorate Wales in conjunction with all providers to:

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| 11 | Ensure that all relevant inspections include specific review of care of patients at the end of life, including responsiveness to pain and also serious illness conversations with patients and those close to them. |
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Theme 4: Reducing the distress of terminal illness for the patient and those close to them

Delivery Aspirations:

Patients in the terminal phase of their illness and dying, and those close to them, including children affected by their dying, feel well cared for. Symptoms and other problems are addressed appropriately and promptly in line with the All Wales Palliative Care Standards¹¹ and the All Wales Care Decisions Guidance for the Last Days of Life.

Specific Priorities 2017-2020

Health Boards to:

1	Deliver well co-ordinated palliative and end of life care on a 24/7 basis in line with published guidance, including: 7-day multi-professional specialist palliative care services that respond rapidly to urgent referrals, and 24/7 specialist advice available to health and social care professionals.
2	Support all providers who care for dying patients to participate in the All Wales audit of the care decisions documentation.
3	Ensure that advice can be rapidly sought by professionals across disciplines in the management of patients with multiple comorbidities.
4	Ensure all services providing care to patients with serious and potentially life threatening illness have suitable calm places of privacy for conversations with patients and those close to them.
5	Work with Health Inspectorate Wales and Care and Social Services Inspectorate Wales to agree markers of the quality of end of life care against which they routinely report to allow benchmarking of services across all sectors, for example ensuring that all services providing care to patients with serious and potentially life-threatening illness have suitable calm places of privacy for conversations with patients and those close to them.

Health Boards in conjunction with adult and paediatric specialist palliative care service providers to:

6	Ensure appropriate transition arrangements from child to adult palliative care services are in place.
7	Establish a 24-hour paediatric palliative care telephone advice rota. (Paediatric)
8	Work with Byw Nawr to hear the voice of the user at all levels. (Adult)
9	Ensure that all non-specialist palliative care staff are aware of the need to respond rapidly to pain and distress in terminally ill patients, and that pain is routinely and regularly monitored, along with other symptoms and individual needs.
10	Ensure participation in surveys of the experience of palliative care for patients and their families.

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<http://www.wales.pallcare.info/files/All%20Wales%20Palliative%20Care%20Standards%20for%20Children%20and%20Young%20People%20Specialised%20Healthcare%20Services.pdf>

Theme 5: Improving Information

Delivery Aspirations:

Important information about a patient, including their needs and desires, should be easily and rapidly accessible to those providing care, to ensure care is joined up, efficient, timely and reliable.

Data about care processes can be rapidly compared between services to provide dynamic audit of services.

Specific Priorities 2017-2020

Health Boards to:

1	Ensure all written information is available in formats that are understandable to the relevant patient and family populations, e.g. easy read formats.
2	Provide an annual statement of assurance to Chair of the End of Life Care Implementation Board.
3	Through the End of Life Care Implementation Board, explore and evaluate innovative ways of staff working, recording patient data and supporting patients and families at home, through different models of care (e.g. delivering subcutaneous fluids, blood transfusion etc. at home; teaching families to administer medication including breakthrough doses as appropriate) and through IT solutions.
4	Publish transparent information on the performance of NHS and voluntary sector providers including safety, effectiveness and patients' views.
5	Work with NWIS and voluntary sector teams to ensure rapid and secure IT communications links are in place to support clinical care.

Public Health Wales and NWIS to:

6	Provide Health Boards with trend and analysis of mortality, place of death and other relevant information to monitor local service performance.
7	Provide an effective palliative care clinical information infrastructure.
8	Analyse and benchmark information to facilitate and inform Health Board's participation in national clinical audit and peer review.
9	Develop and maintain good IT links to NHS and non-NHS providers to promote integrated care delivery.
10	Work with the End of Life Care Implementation Board to explore and evaluate innovative ways of staff working, recording patient data and supporting patients and families at home, through different models of care and through IT solutions that capture data on both processes and outcomes of care.
11	Ensure NHS Wales clinical record systems are accessible and link with other relevant IT systems e.g. GPs and ambulance systems.

Theme 6: Targeting Research

Delivery Aspirations:

Research processes should be embedded across health and social care delivery to provide evidence to inform improvements in the delivery of healthcare and future service plans.

Specific Priorities 2017-2020

The specific priorities requiring the co-ordinated support of NHS organizations, higher education establishments and third sector organizations are to:

1	Increase the number of well-designed palliative care and end of life care studies undertaken in Wales. Work with Health and Care Research Wales researchers and centres to increase the number of Wales-led studies in addition to those undertaken in Wales but led from elsewhere.
2	Increase the number of individuals actively taking part in palliative care and end-of-life research across all health and social care sectors. Work with Health and Care Research Wales Support and Delivery Service to develop the additional infrastructure required for the delivery of complex intervention studies across care settings, including home. This includes ensuring that patients and carers have access to well-design studies across Wales and across care settings whilst minimising the impact on their daily lives.
3	Increase the number of members of the public (to include patients and carers) involved and engaged in research activity by creating a robust and meaningful process for involvement of patients and carers with palliative care needs at all stages of research activity, from study design to implementation and dissemination.
4	Ensure arrangements are in place for research to feed into organisations' mechanisms for uptake of best practice and service change, improving clinical practice and patient outcomes.
5	Ensure a research and development lead is identified and provides visible R&D leadership for the Delivery Plan.
6	Promote the importance of research and development through participation in studies, and recognition and understanding by all NHS and other staff of the role that research plays in increasing and delivering good quality care, including staff recruitment, retention and development.

Theme 7: Education

Delivery Aspirations:

Professionals caring for people with palliative and end of life care needs are equipped in all health care settings to support patients and their families to make informed choices over their care and supported to cope with uncertainty.

Specific Priorities 2017-2020

Health Boards in conjunction with all providers to ensure that:

1	All appropriate staff in all settings are aware of the five principles of the Mental Capacity Act 2005 and their duties of care through mandatory training. (Adult)
2	All appropriate staff are aware of the need to ensure that children affected by a relative who is ill or dying are given honest information and support as appropriate to their age and development. (Paediatric)
3	Staff who have serious illness conversations with patients understand the importance of recording patients' wishes for their future care, as part of a dynamic ongoing conversation. (Adult)
4	All appropriate staff receive mandatory training in the need to monitor pain and respond to distress, identifying pain as a vital sign.
5	An agreed programme of support and education is made available to care home staff, to ensure patients with end of life care needs receive an equitable level of care regardless of place of residence. (Adult)
6	All appropriate staff in all settings recognise palliative care needs in children and young people and know how to access appropriate specialist services. (Paediatric)
7	Programmes such as Byw Nawr are supported to facilitate a national conversation on serious illness and preparing the population to face end of life care.(Adult)
8	All appropriate staff will undertake peer reviews of the quality of healthcare to support and inform the planning and delivery of services.

STRATEGIC AND LEGISLATIVE CHANGES SINCE FIRST END OF LIFE CARE DELIVERY PLAN WAS PUBLISHED IN 2013

Since the publication of the first delivery plan there have been a number of strategic and legislative changes that have impacted upon policy and need to be reflected in this delivery plan.

New Programme for Government and the NHS Plan

The Welsh Government's new Programme for Government *Taking Wales Forward 2016-21* and NHS Plan set out a programme for health and wellbeing in Wales focussing on improving our healthcare services; our healthcare staff; being healthy and active; our mental health and wellbeing; the best possible start for children and care for older people.

The Health and Care Standards – April 2015

The Health Care Standards are designed so that they can be implemented in all health care services, settings and locations. They establish a basis for improving the quality and safety of healthcare services by providing a framework which can be used in identifying strengths and achieving excellence.

Achieving Excellence: The Quality Delivery Plan for the NHS in Wales for 2012-16

The quality delivery plan outlines actions for quality assurance and improvement and for the delivery of a quality-driven NHS that provides services which are safe, effective, accessible, and sustainable, and that comes with an excellent user experience. This plan is currently being reviewed.

Well-being of Future Generations (Wales) Act 2015

The Welsh Government published the Well-being of Future Generations (Wales) Act in April 2015 to improve the social, economic, environmental and cultural well-being of Wales. It aims to make public bodies think more about the long-term, work better with people and communities and each other and look to prevent problems and take a more joined-up approach. The Act sets out seven well-being goals, and five ways of working in order to support the implementation of these goals:

- a prosperous Wales
- a resilient Wales
- a healthier Wales
- a more equal Wales
- a Wales of cohesive communities
- a Wales of vibrant culture and thriving Welsh Language
- a globally responsible Wales

The Act also establishes Public Services Boards (PSBs) for each local authority area in Wales who must prepare and publish a local well-being plan setting out its

objectives and the steps it will take to meet them. It is expected that these plans inform local priority setting.

Social Services and Well-being (Wales) Act 2014

A number of actions in this delivery plan have been developed to further embed the requirements of the Social Services and Well-being (Wales) Act 2014 which came into force on the 6 April 2016. The Act places a duty on health boards and local authorities to jointly undertake an assessment of the local population's care and support needs, including the support needs of carers. The population assessment is intended to ensure that health boards and local authorities produce a clear and specific evidence base to inform various planning and operational decisions, including Integrated Medium Term Plans.

Population Needs Assessment

Population needs assessments are critical to the development of good long-term strategies. The Well-being of Future Generations Act makes it clear that this needs to be done in conjunction with other public service bodies, such as local authorities, education and housing. Population needs assessment should underpin the local well-being plan, developed by public service boards.

The 64 primary care clusters are the mechanism for this collaborative approach to integrated service planning and delivery. Making best use of available financial, workforce and other resources, not just those of the NHS but of local authorities, the third and independent sectors and the assets of local communities.

Prudent Healthcare

In addition, the plan has also been underpinned by the principles of Prudent Health and Care. The way in which services have been shaped and delivered in recent years provide good evidence of prudent health and care in practice and this delivery plan aims to strengthen that approach through a greater emphasis on prevention, integration and long term sustainability. Placing the needs of service users at the heart of service design, co-production in care and treatment planning and delivering services by professionals in both the statutory and third sector are good examples of how the prudent health and care principles underpin service delivery.

Health and Social Care Inequalities

Delivering the actions set out in the plan will make a positive contribution to the Welsh Government's equality agenda objectives through a commitment to identify and meet the needs of all groups in relation to stroke, including those from disadvantaged backgrounds who are statistically more likely to be living in poverty and be at greater risk of heart disease. This has also included consideration to the articles contained within the United Nations Convention on the Rights of the Child (UNCRC). The latest CMO Annual report focusses on rebalancing healthcare – working in partnership to reduce social inequity and exploring the effects of the social gradient on the people of Wales, and what can be done to address it.

Informed health and care – A digital health and social care strategy for Wales

It outlines the commitment to providing access to the best possible services to the public by enabling health professionals to access the most up-to-date technology in its digital health strategy published in 2015. This provides the driver for development and innovation in the use of information technology in cardiac care for the benefit of patients.

Building a Brighter Future

Building a Brighter Future is a coordinated programme to ensure that children have the best possible start in life through early intervention, family support and integrated services, focusing on achieving better outcomes and reduced inequality for children.

Welsh Language

The objectives of 'More than just words' the Welsh Government's strategic framework for Welsh language services in health, social services and social care have also been embedded into the plan through actions that make it clear all organisations associated with service delivery must ensure that such services are available to those who wish to communicate in Welsh.

Developing a Skilled Workforce

The workforce is the most critical element of both the NHS and the third sector and is the key determinant to the success of any organisation. An engaged, sustainable and skilled workforce is essential to delivering high standards of care and transforming the way services are delivered in order to meet the many challenges faced by NHS Wales today. Workforce must be planned and developed around the prudent healthcare principles (i.e. how is the profile of your workforce going to change to allow professionals to concentrate on where they can add the greatest value).

Website Links:

Delivery plan for the critically ill

<http://gov.wales/topics/health/nhswales/plans/delivery-plan/?lang=en>

Heart Condition Delivery Plan

http://gov.wales/topics/health/nhswales/plans/heart_plan/?lang=en

Diabetes Delivery Plan

<http://gov.wales/topics/health/nhswales/plans/diabetes/?lang=en>

Congenital Heart Disease Services Standards

<https://www.england.nhs.uk/commissioning/spec-services/npc-crg/chd/>

Sentinel Stroke National Audit Programme

<https://www.strokeaudit.org/>

National Confidential Enquiry into Patient Outcome and Death: Time to Intervene (2012)

<http://www.ncepod.org.uk/2012cap.html>

Cochrane

<http://www.cochrane.org/what-is-cochrane-evidence>

SSNAP website: <https://www.strokeaudit.org/>

Programme for Government

<http://gov.wales/about/programme-for-government/?lang=en>

Embedding of the prudent healthcare principles

<http://gov.wales/topics/health/nhswales/prudent-healthcare/?lang=en>

Securing Health & Wellbeing for Future Generations- February 2016

<http://www.prudenthealthcare.org.uk/securing-health-and-wellbeing-for-future-generations/>

Health and care standards (April 2015)

<http://gov.wales/topics/health/publications/health/guidance/care-standards/?lang=en>

Achieving excellence - The quality delivery plan for the NHS in Wales

<http://gov.wales/topics/health/nhswales/plans/excellence/?lang=en>

NHS Wales Planning Framework

<http://gov.wales/topics/health/nhswales/organisations/planning/>

Primary Care Services Plan

<http://gov.wales/topics/health/nhswales/plans/care/?lang=en>

Well-being of Future Generations (Wales) Act 2015

<http://gov.wales/topics/people-and-communities/people/future-generations-act/?lang=en>

Social Services and Well-being (Wales) Act 2014

<http://gov.wales/topics/health/socialcare/act/act-nhs/?lang=en>

Informed health and care – A digital health and social care strategy for Wales

<http://gov.wales/topics/health/nhswales/about/e-health/?lang=en>

Health and Care Research Wales Strategic Plan 2015

https://www.healthandcareresearch.gov.wales/uploads/Policy%20&%20Strategy/Health_and_Care_Research_Wales_Strategic_Plan_2015_2020.pdf

Public Health Outcomes Framework

<http://gov.wales/topics/health/publications/health/reports/public-health-framework?lang=en>

More than just words.... Follow-on strategic framework for Welsh language services in health, social services and social care

<http://gov.wales/topics/health/publications/health/guidance/words/?lang=en>

Framework for Assuring Service User Improvement and Core Questions

<http://www.wales.nhs.uk/governance-emanual/public-and-patient-involvement>

***Safe Care, Compassionate Care*: National Governance Framework to enable high quality care in NHS Wales**

<http://www.wales.nhs.uk/sitesplus/documents/888/Appendix%20Item%206%20Safe%20Care%2C%20Compassionate%20Care.pdf>

Delivering Local Integrated Care

<http://gov.wales/topics/health/publications/socialcare/strategies/integration/?lang=en>

A framework for delivering integrated health and social care for older people with complex needs

<http://gov.wales/topics/health/publications/socialcare/strategies/integration/?lang=en>

Children and young people's continuing care guidance

<http://gov.wales/topics/health/publications/socialcare/guidance1/care/?lang=en>

Self care and care plans

<http://gov.wales/docs/dhss/publications/100102frameworkselfcareen.pdf>

<http://gov.wales/topics/health/nhswales/healthservice/chronic-conditions/?lang=en>

Patient Consent

<http://www.wales.nhs.uk/sites3/page.cfm?orgid=465&pid=11930>

All-Wales Policy on Do Not Attempt Cardiopulmonary Resuscitation

<http://www.wales.nhs.uk/news/35793>

Lasting Power of Attorney

<http://www.olderpeoplewales.com/en/Publications/pub-story/16-01->

[04/An_easy_guide_to_lasting_powers_of_attorney.aspx#.VoprfWcqXcs](http://www.olderpeoplewales.com/en/Publications/pub-story/16-01-04/An_easy_guide_to_lasting_powers_of_attorney.aspx#.VoprfWcqXcs)

NHS Wales Workforce Review

<http://gov.wales/topics/health/publications/health/reports/workforce/?lang=en>

Health and Care Research Wales Performance Management Framework

<http://www.healthandcareresearch.gov.wales/performance-management/>

Industry Engagement in Wales

<http://www.healthandcareresearch.gov.wales/industry-engagement/>

Delivery Framework for the Performance Management of NHS R&D

<http://www.healthandcareresearch.gov.wales/nhs-randd-funding-policy/>

The Nurse Staffing Levels (Wales) Act 2016

<http://www.legislation.gov.uk/anaw/2016/5/enacted>

Palliative and End of Life Delivery Plan, Indicators and Assurance Framework (to inform individual Health Board)

Vision	Outcome Indicators
<p>People in Wales to have a healthy, realistic approach to dying, planning appropriately for the event</p> <p>People dying in Wales to have access to high quality care wherever they live; and, whatever their underlying disease or disability, spend their dying months devoid of any prejudice in relation to their personal situation</p>	<p>A fall in complaints, especially those where people and those close to them were not listened to when expressing their needs and preferences.</p> <p>Schools report knowing how to access support for children with severe life limiting conditions at times of deterioration and death.</p>

Theme 1: Supporting Living and Dying Well	Theme 2: Detecting and identifying patients early	Theme 3: Delivering fast, effective person-centred care
<p>Overarching Indicators Serious illness conversations occur appropriately and empower patients to take informed decisions</p> <p>Performance (Assurance) Measures Staff training logs show an increase of at least 20% of staff having undertaken communication skills training in serious illness conversations</p> <p>Patients and families report: Being taught basic principles in safe mobility Knowing who to contact at all times when a person is dying at home Being able to obtain medication without delay</p>	<p>Overarching Indicators Patients with serious progressive illness who have palliative care needs are identified early</p> <p>Performance (Assurance) Measures GP registers show an increase in the numbers of patients identified as needing palliative care. These patients are regularly reviewed and over time, the length of time patients are on the register increases.</p> <p>Training logs record the numbers and grades of staff who have undertaken specific training in serious illness conversations with patients and families</p>	<p>Overarching Indicators Patients and families report experiencing care that meets their needs and preferences.</p> <p>Performance (Assurance) Measures Fall in hospital admissions rates for patients known to be nearing the end of life, with more being cared for in one of their preferred places of care. Patient and family feedback on their experience of care. HIW inspection and peer review reports on facilities and quality of care. NHS Wales clinical record systems data on service responsiveness / patient outcome scores</p>

Theme 4: Reducing distress in the terminal phase for the patient and their family	Theme 5: Improving Information
<p>Overarching Indicator Patients and those close to them including children report feeling supported at all stages and by all staff</p> <p>Performance (Assurance) Measures Minimum Data Set reports show adequate specialist palliative care staff working in line with recommendations of the End-of-Life Implementation Board Transitional care arrangements are evidenced at peer review IT systems allow access to key information across all providers Bereavement support services and a referral process is in place HIW and CSSIW inspections find evidence of pain being responded to with urgency HIW and CSSIW inspections find the premises of care provide appropriate privacy</p>	<p>Overarching Indicator Patients and their families have the information they need to make decisions. Routinely collected NHS data highlight quality of care, service performance and complaints</p> <p>Performance (Assurance) Measures Processes of care reveal no delays in access to urgent treatment with patients present with symptoms suggestive of a medical emergency Urgent referrals to specialist palliative care are seen within a maximum of two days, with the majority seen within 24 hours or less NWIS data provides clinical information relevant to patient care Changes in symptoms and distress scores are routinely collated from specialist palliative care records.</p>

<p>Theme 6: Targeting research</p> <p>Overarching Indicator</p> <p>An increase in research into palliative care problems</p> <p>Performance (Assurance) Measures</p> <p>A Research and Development lead is for End of Life Care is identified in each Health Board</p> <p>An increase in the number and type of research projects being undertaken nationally with the support of the Marie Curie Research Centre</p> <p>Increase in the number of patients and their families in Wales who have access to and participate in palliative care research</p> <p>Report on Key performance indicators set out in the Delivery Framework for the Performance Management of NHS R&D that are relevant to the Delivery Plan.</p>	<p>Theme 7: Targeting Education</p> <p>Overarching Indicator</p> <p>Professionals caring for people with palliative and end of life care needs are equipped in all health care settings to support patients and their families</p> <p>Performance (Assurance) Measures</p> <p>Evidence of events to promote national conversation to increase public awareness around advance care planning for end of life</p> <p>Evidence of all appropriate staff receiving mandatory training in the need to monitor pain and respond to distress, identifying pain as a vital sign.</p> <p>Evidence of an agreed programme of support and education is made available to care home staff, to ensure patients with end of life care needs receive an equitable level of care regardless of place of residence.</p> <p>Evidence of training available to all appropriate staff in all settings regarding the five principles of the Mental Capacity Act and their duties of care to patients.</p>
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