

Palliative and End of Life Care

A Wales Cancer Alliance Policy Paper

Summer 2017



Palliative and end of life care: Overview

There have been real improvements in the provision of palliative and end of life care in Wales over the past decade. However, we know that some people with cancer who need this care and support still do not receive it, or are not given support early enough. Age can be a key factor in determining whether someone is likely to access care.

Cancer Delivery Plan¹ and End of Life Care Delivery Plan²

The Welsh Government recognises the importance of end of life care in the *Cancer Delivery Plan* with 'Caring for people with cancer at the end of their life' as one of the 7 chapters in the Plan, along with associated 'Key actions' as well as the refreshed Palliative and End of Life Care Delivery Plan published in March 2017, which provides additional national policy and guidance on how the NHS and its partners can provide a high standard of person-centred care for everyone at the end of life. There is much to welcome in the Cancer Delivery Plan on end of life care. The Key Actions (p. 15) include the requirement for 'Health Boards to plan, secure and deliver well co-ordinated palliative and end of life care on a 24/7 basis' (Key Action 42); and for them to 'have clear funding streams for specialist palliative care services which are above the minimum level advised by the End of Life Board' (Key Action 45).

The Wales Cancer Alliance believes that the only way to improve patient-centred care is to involve patients and their relatives, friends and carers. We welcome the Welsh Government's commitment to further understand the needs of patients and welcome the work done to date of the End of Life Care Implementation Board and the iWantGreatCare (iWGC) programme.

Background

Palliative care is a holistic approach to care which aims to improve quality of life by treating or managing pain and other physical symptoms. It also helps with any psychological, social or spiritual needs that a patient and their family may have. It can be delivered by a wide range of professionals across a variety of settings. Specialist palliative care is that delivered by professionals who have received specialist training in palliative care.

Palliative or hospice care is not necessarily just for people who will die soon. It can be relevant at any stage in a person's illness. However, it is particularly appropriate for people with metastatic and terminal cancer for whom curative treatments are no longer a suitable option. Someone with metastatic or terminal cancer may live for weeks, months or years after their diagnosis and may have many episodes of need for palliative care over this time.

End of life care typically refers to the care and support that is given to people in the final year of life. End of life care includes palliative care as well as support for families and carers.

- 8,903 people died from cancer in Wales in 2014³.
- Between 2001 and 2014, there was a large increase in the number of cancer deaths for people aged 85 years and over⁴.

¹ Wales Cancer Network (2016) Cancer Delivery Plan for Wales 2016 – 2020: The highest standard of care for everyone with cancer. Available from: <http://gov.wales/docs/dhss/publications/161114cancerplanen.pdf>

² End of Life Care Implementation Board (2017) Palliative and End of Life Care Delivery Plan. Available from <http://gov.wales/docs/dhss/publications/170327end-of-lifepen.pdf>

³ Welsh Cancer Intelligence & Surveillance Unit (2014) Cancer in Wales: a summary report of population cancer incidence, mortality and survival, Wales: WCISU / Public Health Wales.

Calls for Action

The Wales Cancer Alliance calls for:

1) Access to the full range of support services, including palliative care, for all those who need it following initial diagnosis and routine holistic assessment going forward

The WCA is calling for people who have been given a non-curative diagnosis to be made aware of the full range of support available to them, including what can be achieved through palliative care. Healthcare professionals should be aware of available holistic assessment tools which may aid them in this process, such as the Sheffield Profile for Assessment and Referral to Care (SPARC) self-assessment questionnaire⁵.

Someone with metastatic or terminal cancer may live for years after their diagnosis and may have many episodes of need for palliative care over this time. Introducing palliative interventions shortly after diagnosis for patients with metastatic lung cancer can lead to less aggressive care, better quality of life and longer survival⁶. When appropriate, and when the patient chooses this approach is in tune with the Welsh Government's prudent healthcare agenda.

2) Consistent, timely support from trained professionals for people to have conversations about their options and preferences

The WCA is pleased that the importance of engaging a person in conversations about their treatment options and wishes towards the end of their life is recognised in the Cancer Delivery Plan (Key Action 47)).

It should be recognised however, that a person may live for years with a metastatic or terminal cancer diagnosis so these conversations should not be restricted to the final 12 months of a person's life. Helping patients and their families to understand the nature of their illness and expected prognosis is important. It enables patients and families to set realistic goals and priorities during the last phase of their lives, which healthcare professionals can then coordinate care around.

Appropriate professionals, such as general practitioners, should be trained to have the skills and experience to engage in these on-going conversations sensitively and in a patient-led manner. It is important that they can readily access information regarding local and national sources of support in a variety of formats so they can make this available to patients.

3) Better public and professional understanding of palliative care

The exact nature of palliative care is often misunderstood by patients and professionals alike. Many patients understand it to be the giving up of treatment and an indication of imminent end of life. As a result they opt out of support that could make a real difference to their quality of life. Research has shown that final year nursing students in Wales have also been found to have only a superficial understanding of palliative care, associating it with the imminent dying phase⁷.

It is recommended that healthcare professionals who are involved in the care of people with metastatic or terminal cancer should understand what palliative care is and what it can achieve so

⁴ Welsh Cancer Intelligence & Surveillance Unit (2014) Cancer in Wales: a summary report of population cancer incidence, mortality and survival, Wales: WCISU / Public Health Wales.

⁵ Wilcock, A., Klezlova, R., Coombes, S., Rawson, A., Bentley, R., Hooper, D. & Maddocks, M. (2010) "[Identifying supportive and palliative care needs in people with a recent diagnosis of thoracic cancer: acceptability of the SPARC questionnaire](#)", *Thorax*: Online First.

⁶ Temel, J., Greer, J., Muzikansky, A., Gallagher, E., Admane, S., Jackson, V., Dahlin, C., Blinderman, C., Jacobsen, J., Pirl, W., Billings, J. & Lynch, T. (2010) "[Early palliative care for patients with metastatic non-small-cell lung cancer](#)", *New England Journal of Medicine*, no. 363, pp. 733-42.

⁷ Watts T. (2014) "[Final year nursing undergraduates' understanding of palliative care](#)". *International Journal of Palliative Nursing*. IJPN website.

they can effectively communicate this to their patients and their families. Training and education programmes should reflect this.

4) Action to tackle inequalities in access to palliative and end of life care

Action needs to be taken to explore the effects of and deal with existing inequalities in relation to access to appropriate palliative care depending on factors such as cancer site⁸ and age. Better data will be integral to achieving this.

Gaps in palliative and end of life care services in the community may also exist for 16-18 year olds, whose care often falls outside of children's services but who are not old enough for adult services to be appropriate⁹. Although their numbers are small, it is important that people in this age group have access to age-appropriate information and services.

Data shows that only a third of people aged 85 years and over who died from cancer in Wales in 2012 received specialist palliative care, compared to over 55 per cent of people aged 64 years and under¹⁰. Although the palliative care needs of the older group may have been looked after by health professionals who aren't specialists in palliative care, such as oncologists, geriatricians or their primary health care team, we cannot be sure of this from the data available. As the number of cancer deaths has increased by almost one third for people aged 85 or over since 2003, it is important to get a better understanding of this situation and target improvements as necessary¹¹.

5) Increased emphasis on providing services in a community setting with appropriate resources to achieve this

Over half of deaths from cancer in Wales take place in hospital, yet most people say this is the place they would least like to be. Although people's preferences for place of care at the very end of life do sometimes change depending on their symptoms or level of need, community services can support people to remain in the familiar surroundings of their home or care home for as long as possible. Investing in and improving the quality of palliative care delivered by generalists and specialists in the community could help to alleviate pressures on secondary care services and provide people with care more appropriate to their needs and wishes. The WCA therefore strongly endorses Key Action 49: 'Health Boards to establish and prioritise people's preferences for place of death'.

Data from the National Survey of Bereaved People (VOICES) in England shows that overall care was more likely to be rated as Outstanding or Excellent (63 per cent) for people who died from cancer at home than for any other cause and place of death. Wales does not currently have this sort of national-level data; collecting it would help to benchmark how well services are meeting people's needs and help to identify areas for improvement based on clear evidence.

6) Greater integration of support between the NHS, local authorities and the third sector

Enabling people to live at home towards the end of their life can involve a great number of people from different organisations, such as the NHS, local authorities and the third sector and this should be consistent across Wales. When this support is not well coordinated, people can feel confused and frustrated. They may not be able to die at home because a package of care has not been organised quickly enough to ensure they can be discharged. Continuity and coordination of care should be key standards for service delivery and the effective use of information-sharing systems is an important aspect of this. A simple 'one stop shop' service offering practical support should ideally be available.

⁸ Marie Curie (2014) *Death and Dying in Wales*, Wales: Marie Curie / Bevan Foundation.

⁹ Grinyer, A. & Barbarachild, Z. (2011) *Teenage and Young Adult Palliative and End of Life Care Service Evaluation*, Teenage Cancer Trust / Lancaster University.

¹⁰ Marie Curie (2014) *Death and Dying in Wales*, Wales: Marie Curie / Bevan Foundation.

¹¹ Welsh Cancer Intelligence & Surveillance Unit (2014) *Cancer in Wales: a summary report of population cancer incidence, mortality and survival*, Wales: WCISU / Public Health Wales.

7) Support for Carers

It is also crucial that carers can access the support they need to help them in their role. At the UK level, only 8 per cent of those caring for someone at the end of life have received a formal Carer's assessment¹². Action from health boards and local authorities is needed to ensure that carers' needs are identified and services are planned to accommodate them.

8) Promotion of the palliative and end of life care research base in Wales

Evidence shows that since 2002 the funding for cancer-related palliative and end of life care research has been consistently below 0.7% of the total spent on cancer research in the UK¹³. The Marie Curie Palliative Care Research Centre is therefore an important resource for Wales for assessing whether current practices in palliative care are effective, capturing the patient experience, and informing the design of new models of care. Local Health Boards and NHS Trusts should therefore be encouraged to promote its use as a key research facility. This should include helping to identify potential participants for research studies so that the patient's experience of care can guide future practices, yet numbers of participants have historically been very low.

9) A national data set to benchmark experiences of care at the end of life

Other resources such as the iWantGreatCare (iWGC) survey for specialist palliative care services should be implemented as effectively as possible nation-wide. This should be complemented by a national data set such as the data generated by the VOICES survey used in England, which would provide a rich evidence base from which to assess the suitability of services across Wales.

10) Advanced Care Planning and open discussions

A simple and cost-effective way to improve end of life care for patients is to encourage individuals to openly discuss their own wishes with friends and loved ones before it is too late and for Advanced Care Plans (ACP) to be drawn up. The Welsh Government through the charity Byw Nawr is helping drive this along with organisations such as Dead Social who help people plan and organise their online activity in order to leave a 'digital legacy.'

¹² Macmillan (2015) [Hidden at Home: The social care needs of people with cancer](#), London: Macmillan.

¹³ James Lind Alliance (2015) [Palliative and End of Life Care Priority Setting Partnership \(PeolcPSP\): putting patients, carers and clinicians at the heart of palliative and end of life care research](#), Southampton: James Lind Alliance.