

**HEALTH AND SPORT COMMITTEE**  
**WHAT SHOULD PRIMARY CARE LOOK LIKE FOR THE NEXT GENERATION?**  
**SUBMISSION FROM HOSPICE UK**

Hospice UK is the national charity for hospice care, working with over 200 hospice care providers in the UK. Hospice UK supports the breadth, dynamism and flexibility of modern hospice care by influencing national and local policy, improving quality of care through the sharing of good practice, and providing resources, education and training, and grant programmes. In Scotland, hospice care supports an estimated 21,000 people every year. Around 80 per cent of hospice care, by number of patients, is community based, through day, outpatient and hospice at home services.

We welcome the opportunity to contribute to the Health and Sport Committee's inquiry into the future of primary care. Our response is focused on how primary care can best meet the needs of people living with terminal and life-shortening conditions in Scotland.

**The importance of primary care for people with palliative care needs**

Primary care is often the first point of contact for people with palliative care needs. The primary care team plays a vital role in identifying people with palliative care needs, co-ordinating and delivering their care and ensuring they get access to more specialist care and advice, if they need it. The majority of palliative and end of life care is provided by generalist services through people's GP practice, community nursing and social care.

In Scotland, 58,503 people died in 2018<sup>i</sup>. It is estimated that three quarters, nearly 44,000 people, could have benefited from palliative care<sup>ii</sup>. Demographic change is bringing both increased life expectancy and an increase in the number of deaths per year. As people are living longer, they are more likely to have multiple health conditions and an increased need for health and care support. The number of people dying each year is predicted to rise to 61,600 by 2037<sup>iii</sup>. This means an increasing number of people will need palliative and end of life care, and much of this increased need will need to be met by community-based services. In 2016, the Scottish Government committed to doubling the provision of palliative and end of life care in the community by 2021.

**Hospice UK believes that for primary care to meet the needs of people in Scotland living with terminal and life-shortening conditions there needs to be:**

**(i) Early identification of people with palliative care needs**

Identifying people who would benefit from a palliative care approach is vital. Having early, open conversations with people about palliative care helps people to make informed choices about the care they want to receive at the end of life and helps staff to co-ordinate that care and support.

Identifying when someone has palliative and end of life care needs can be difficult. There has been positive work happening nationally to support this. Healthcare Improvement Scotland has published a comparator of different tools to identify palliative care needs<sup>iv</sup>, for example an electronic frailty index tool and a computer application that helps primary care teams to screen their registered patients for people who could benefit from palliative care. In addition, the Scottish Government's primary care enhanced services palliative care scheme<sup>v</sup> encourages GP practices to take a systematic approach to identifying appropriate patients for the Palliative Care register, using a combination of tools and clinical judgement, and to ensure that these patients have an anticipatory care planning approach to their care.

We need to maintain momentum in this area and ensure that national improvement work actually makes a difference to the care and support people receive. As well as identifying people, primary care teams need time to do follow-up assessments and co-ordinate the care people need. It is estimated that there are 11,000 people each year in Scotland who could benefit from palliative and end of life care, who do not receive it<sup>vi</sup>. This shows we still need to improve how we identify and support people with palliative care needs.

**(ii) Effective anticipatory care planning that is accessible across all care settings**

Anticipatory Care Planning is a vital part of palliative and end of life care. Anticipatory Care Plans (ACPs) are developed in partnership between the patient and healthcare professionals and records a person's future wishes and priorities for their care. The Key Information Summary (KIS) is a summary of a patient's care plan and preferred place of care, taken from their GP patient record, which is available to out of hours services and secondary care. Hospice care providers, for example, rely on ACPs and KIS for information to support the admission of a patient.

We support Scottish Government's commitment that everyone who needs one should have a KIS and are pleased that there has been an increase in the use and access of KIS in Scotland. There is still progress to be made in ensuring everyone who needs a KIS has one and in addressing variation in who has a KIS according to diagnosis and across different parts of Scotland. In addition, the information in ACP/KIS is not always complete and some services cannot access it, for example care homes or social care services. While hospices can access a patient's KIS, they cannot update it following an admission or visit from the hospice team. Only the GP is able to complete this information. Having one system that can be accessed and used across all services would be hugely beneficial. The new National Digital Platform being developed for Scotland has huge potential benefits, providing there is read and write access across all care settings.

**(iii) Seamless and timely care co-ordination for people with palliative care needs**

People with terminal conditions can have complex care needs and need a holistic, person-centred approach, co-ordinated through a multi-disciplinary team. There are examples of this happening well. For example, in Renfrewshire a new multi-disciplinary, holistic approach to co-ordinating community palliative care services has been introduced<sup>vii</sup>. Primary care teams categorise people on the GP palliative care register based on whether their palliative care needs are stable, changing or deteriorating more rapidly. A weekly integrated multidisciplinary meeting attended by district nursing, social work, care at home, hospice staff, and rehabilitation and reablement services, co-ordinate the care of people whose needs are changing or deteriorating.

While the majority of palliative and end of life care is delivered by generalist services in the community, there needs to be timely and seamless access to specialist care if needed. Eight out of ten hospice care providers have rapid response, out of hours and/or telephone advice for patients, carers and clinicians. Our members reported positive relationships with their primary care colleagues and appropriate seeking of advice. However, they also felt that there was room for more increased joint working and greater collaboration, supported by better use of technology.

**(iv) A resourced and supported community workforce with the right skills to support people with palliative care needs**

With the introduction of the new GMS contract, the role of GPs is now primarily focused on patients with more complex needs. It is therefore important to take a whole system approach

and ensure that the wider health and care community workforce is adequately resourced and have the skills needed to deliver high quality care for people with palliative care needs.

There are significant workforce pressures in the social care workforce and the district nursing workforce who both play a key role in delivering palliative and end of life care in the community. Care homes and care at home staff are increasingly providing palliative and end of life care, for example, 38 per cent of residents supported in independent care homes have palliative care needs<sup>viii</sup>. But care staff face recruitment and retention issues, time constraints and are not always valued for the important role they play.

The Scottish Government's recent review of district nursing emphasised their key leadership role in anticipatory care planning and palliative and end of life care<sup>ix</sup>. The Scottish Government's Primary Care Workforce Plan committed to look at the investment necessary to expand the district nursing workforce in 2018. There has been no increased investment to expand the district nursing workforce, despite high vacancy rates, a high proportion of district nurses retiring and a growing older population who require support.

As the focal point for people facing end of life, it is important that the primary care and community workforce have the right skills to support them to deliver palliative and end of life care. The NHS Education for Scotland and Scottish Social Services Council education framework for palliative care has been viewed positively as a tool to support staff in achieving competencies in palliative and end of life care. It may be helpful to do an audit to see how widespread use of the framework has been and how effective it is.

Dedicated palliative care providers, play a key role in education, with 90 per cent of charitable Scottish hospice care services providing education and training to health and social care professionals, including GPs, community teams and care home staff. Project ECHO is an international knowledge transfer model, which uses videoconferencing technology to bring together clinical specialist teams with primary care clinicians. Highland Hospice in Inverness is a Project ECHO 'superhub' and has facilitated communities of practice with care homes, remote and rural GPs, out of hours practitioners, community specialist nurses and community pharmacists, delivering tailored programmes around palliative and end of life care. They have also trained other hospice care providers to facilitate Project ECHO in their areas.

#### **(v) Support for carers and compassionate resilient communities**

Well supported carers are essential to good palliative and end of life care. Primary care staff are ideally placed to support carers, but need to do more to identify carers and promote their health and wellbeing. Staff need to be trained to know how to support carers and where to signpost people for advice and information to help them in their caring role.

We welcome that the Carers (Scotland) Act 2016 requires local authorities to provide information and advice about bereavement support and counselling to carers. However research by Hospice UK and Sue Ryder in Scotland in 2018, found that out of the 31 per cent of respondents who needed support, only 6 per cent accessed it. Those who did access bereavement support, most commonly accessed it through their GP or practice nurse.

Greater community involvement and recognition of community resources is vital, especially in the context of death, dying and bereavement. Changing demographics mean that alongside more people living and dying with multiple conditions, people will have less family support locally. Compassionate communities initiatives, such as Compassionate Inverclyde, befriending services, bereavement services and support for carers all help build community capacity and resilience.

**To achieve a primary care service that supports people with palliative and end of life care needs, there needs to be:**

**(i) Greater accountability of Scottish Government commitments around palliative and end of life care**

In 2016, the Scottish Government committed to double the provision of palliative and end of life care in the community by 2021, and committed that everyone who needs palliative and end of life care would receive it<sup>x</sup>. It is not clear what progress there has been against these commitments, how they are being measured or from what baseline they are being measured against. To make an impact, there needs to be clear accountability of national commitments to improve access to palliative and end of life care.

**(ii) A better understanding of palliative and end of life care needs in Scotland**

Currently there is no robust data on need and unmet need for palliative and end of life care in Scotland. Estimates to date are based on methodology developed to assess need in England. Although research is underway to estimate Scotland's future palliative care needs. Children's Hospices Across Scotland estimate there are over 15,000 babies, young people and children in Scotland with life-shortening conditions, with two-thirds not being known to their services<sup>xi</sup>. In addition, while we know that there are inequalities in access to palliative and end of life care, for example people with conditions other than cancer, and for some people from the LGBT community, people who are homeless and people from the traveler community, there is a lack of data and evidence specific to Scotland<sup>xii</sup>.

Having a greater understanding of palliative and end of life care need, unmet need and inequalities in Scotland, will better support strategic planning of primary care and dedicated palliative and end of life care services. Such understanding must also take into account rapid demographic change over the short, mid and longer term. This would support more people being identified, help understand what the barriers are for people not receiving palliative care when they need it and inform workforce planning.

**(iii) A focus on palliative and end of life care in strategic planning and improvement**

All people will die one day. Around 1 per cent of the population dies every year and we are high users of health and care services in our final years. Palliative and end of life care therefore should be a priority for integration authorities' joint needs assessments, strategic commissioning plans and primary care improvement plans, as well as inform integrated workforce planning. Palliative and end of life care should also be a focus for quality improvement locally within GP clusters. Making palliative and end of life care a strategic priority will support primary care services to better identify people who can benefit from a palliative care approach, will help co-ordinate multi-disciplinary care, and will improve the identification and support of carers.

**(iv) Third sector, independent sector and the public are equal partners in the planning and delivery of care**

To support transformation in primary care, and across health and social care more widely, there needs to be an equal partnership between health, social care, the third sector, the independent sector and the public/local community. All partners need to be fully engaged at every stage of needs assessment, strategic planning and delivery of palliative and end of life care in the community.

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- <sup>i</sup> General Registrar Office for Scotland, June 2019
- <sup>ii</sup> Murtagh F et al. (2014) How many people need palliative care? A study developing and comparing methods for population-based estimates. *Palliative Medicine*, Vol 28(1) 49–58
- <sup>iii</sup> Scottish Government (2015) Strategic Framework for Action on Palliative and End of Life Care
- <sup>iv</sup> <https://ihub.scot/media/2079/palliative-care-identification-tools-comparator.pdf>
- <sup>v</sup> [https://www.sehd.scot.nhs.uk/pca/PCA2019\(M\)06.pdf](https://www.sehd.scot.nhs.uk/pca/PCA2019(M)06.pdf)
- <sup>vi</sup> Health and Sport Committee (2015) A report for the Scottish Parliament by Professor David Clark: International comparisons in palliative care provision: what can the indicators tell us?, 9th Report, 2015 (Session 4)
- <sup>vii</sup> Model delivered by Macmillan Cancer Support, Renfrewshire Health and Social Care Partnership and Healthcare Improvement Scotland
- <sup>viii</sup> Scottish Care (2018) Care Homes: Then, Now and the Uncertain Future
- <sup>ix</sup> Scottish Government (2018) Transforming nursing, midwifery and health professionals roles: district nursing roles
- <sup>x</sup> Scottish Government (2016) Health and Social Care Delivery Plan
- <sup>xi</sup> McLaughlin, T and Robb, S (2018) *Children in Scotland Requiring Palliative Care (CHiSP) 2* Children's Hospices Across Scotland (CHAS)
- <sup>xii</sup> Dixon, J *et al.* (2015) Equity in the Provision of Palliative Care in the UK Marie Curie and London School of Economics