

## Written evidence submitted by Marie Curie (EPW0060)

### **Government progress on commitments on the palliative and end of life care workforce in England:**

- The Government has clearly set out its vision for the palliative and end of life care workforce in Ambition Five of its *Ambitions framework for Palliative and End of Life Care 2021-2026*.
- There is also an important new opportunity to better resource this workforce in the new legal duty for Integrated Care Boards to commission palliative care services in the Health & Care Act.
- The main employers of the specialist palliative care workforce are charitable hospices and their current funding model is neither resilient nor sustainable, with only around one third of their funding coming from statutory sources and the remainder raised largely through charitable fundraising activities.
- An increase in the numbers of deaths taking place at home is resulting in generalist palliative and end of life care workers such as GPs, district nurses, and social care workers being called upon to play an increasingly large role in end of life care, yet this workforce is also under-resourced, and many of these workers have never received any training in end of life care.
- Caring for people through dying, death and bereavement can be both rewarding and challenging, and has significant impacts on the physical health and mental wellbeing of individual workers involved in delivering this care, and their ability to ensure that everyone has the best possible end of life experience.
- With demand for palliative and end of life care set to increase by 42% in the next two decades due to our ageing population, concerted action is needed from Government to plan, resource, train and support a palliative and end of life care workforce that is fit for meeting current and future challenges.

### **Key policy recommendations:**

- Review funding for palliative and end of life care services provided by the charitable hospice sector, the main providers of this care in our health and care system, to ensure that support is resilient, equitable and fit for purpose;
- Introduce a statutory duty for an annual, independent assessment of health and social care workforce projections and a requirement on Government to respond to that assessment with a full costed plan for how these workforce needs will be met over the next 15 years;
- Introduce palliative and end of life care training as a compulsory part of initial training and continuing professional development for all health and social care workers, not just those in regulated professions, for example through inclusion on the General Practitioner and Nursing curriculum; and
- Ensure a pro-active approach to supporting health and wellbeing for all palliative and end of life care workers in every setting.

### **Definitions used in this submission**

*Palliative and end of life care* is treatment, care and support for people with a terminal illness as well as their families, friends and carers. This aims to identify and relieve the symptoms and concerns that people living with a terminal illness experience, whether that be physical experiences such as

breathlessness or pain, or emotional, social and practical concerns.

*Specialist palliative care workers* operate in multidisciplinary teams where palliative care is the main focus of their role. Specialist palliative care teams work across the community, acute hospital and hospice settings. As well as providing direct hands-on care to people living with a terminal illness and their families and carers, specialist palliative care teams have an important role in indirect care through providing education and training to health and care professionals.

*Generalist palliative and end of life care* is provided by a much broader workforce that includes a diverse range of health and care professionals both inside and outside the NHS, including clinicians, allied health professionals, general practitioners and community nurses, palliative care social workers and home care workers. As a result, every health and care professional is likely to support someone through dying, death and bereavement as part of their role.

### **Policy Area: Planning for the workforce**

#### **Government Commitment 1: Ensure that the NHS and social care system has the nurses, midwives, doctors, carers and other health professionals that it needs.**

#### **What is the commitment?**

The government's Ambitions for Palliative and End of Life care framework for local action 2021-2026<sup>1</sup> sets out a clear vision for the workforce for the next five years in chapter five. This includes acknowledgement of some of the key challenges currently faced by the palliative and end of life care workforce:

- Caring for people through dying, death and bereavement can be distressing and very challenging to staff resilience
- Most health and care staff look after people at the end of life at some point in their careers, yet most do not receive any training in palliative and end of life care.
- Often employers of health and care professionals fail to act systematically to help their staff avoid burn-out through training and support in palliative and end of life care.
- Health and care staff can only provide compassionate end of life care when they are cared for themselves.

The framework also sets out what is needed to meet these challenges;

- Healthcare professionals at all levels of expertise need to be trained, supported and encouraged to bring a professional ethos to end of life care. This involves using professional judgement, values and authority to ensure that individuals get the right care for them, and there are no obstacles to ensuring that the needs of the dying person come first.
- The traumatic nature of death and dying tests resilience, and to provide care full time requires support from organisational and professional settings. End of life care can also involve working in a range of settings from individual homes to intense hospital wards and is demanding. Staff require support for their emotional and physical health in such a demanding field.
- Clear, knowledgeable, responsible and confident professional judgement is essential to guarantee a positive end of life experience. Health and social care

---

<sup>1</sup> National Palliative and End of Life Care Partnership (2021) Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026.

- Clear, knowledgeable, responsible and confident professional judgement is essential to guarantee a positive end of life experience. Health and social care regulators must ensure staff are well-trained and receive updated, well-delivered education.
- Support must be given to ensure those delivering palliative and end of life care can make safe use of new technology in order to build relationships with and bring support to a person at the end of their lives and their families. Professionals must have assistance in adapting to new ways of interacting with people, as well as guidance in doing so.
- All providers of palliative and end of life care should understand the legislation that seeks to ensure a person-centred approach to care and comply with it. This includes safeguarding, equalities and diversity legislation. A widespread lack of knowledge around different community preferences challenges good care at the end of life.
- Organisations must have clear governance and accountability at board level for high quality palliative care in order to ensure all staff can provide the best possible care<sup>2</sup>.

### Was it funded?

The current funding model for palliative and end of life care is neither resilient nor sustainable. The cost of providing palliative and end of life care to people in the UK is currently approaching £1 billion each year, and charitable hospices are the main providers of this care<sup>3</sup>. Charitable hospices receive around only around one third of their funding from the NHS and other statutory sources, and raise the remaining two thirds from charitable fundraising and other activities such as charity shops<sup>4</sup>.

Children's hospices in the UK are funded differently to adult hospices and on average receive funding equivalent of 34% of their charitable expenditure from the statutory sources, including local NHS funding, local authority funding and a central NHS England and NHS Improvement (NHSE/I) Children's Hospice Grant.<sup>5</sup>

The Covid-19 pandemic has had a significant impact on fundraising at Marie Curie and across the whole charitable hospice sector. With 50% of the funding needed to deliver our community nursing services and 65% of our hospice funding coming from charitable donations<sup>6</sup>, the pandemic had a significant impact on our income.

This reduction in income took place at the same time as an increase in demand for palliative and end of life care services, due to the significant increase in deaths during Covid-19. Research demonstrates that this increased demand for palliative and end of life care services of all types was experienced in all parts of the UK. It also shows that the care hospices were able to provide was compromised by shortages of essential medicines, staff, PPE and other equipment that were exacerbated by not being considered 'frontline NHS'<sup>7</sup>.

£200m of emergency grant funding provided by the UK's governments has been very welcome as a short-term measure to address the impact of the crisis on the charitable hospice sector. However, it

---

<sup>2</sup> National Palliative and End of Life Care Partnership (2021) Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026

<sup>3</sup> Von Petersdorff C, Patrignani P, Landzaat W. (2021) [Modelling demand and costs for palliative care services in England: A final report for Sue Ryder](#). London Economics. P8

<sup>4</sup> Sue Ryder (2021) [England's palliative care funding challenge](#).

<sup>5</sup> Together for short lives. (2019) [Statutory funding for children's hospice and palliative care charities in England 2018/19](#).

<sup>6</sup> Marie Curie (2020) [Annual Reports and Accounts 2019/20](#) (p51)

<sup>7</sup> Marie Curie (2021) [Better End of Life 2021 report](#) (p5)

must be recognised that emergency grant funding to support the charitable hospice sector is not a sustainable and resilient funding model for this essential part of our health and care workforce.

**Recommendation:** *The Government must review funding for palliative and end of life care services provided by the voluntary sector to ensure that support is resilient, equitable and fit for funding the workforce of the future over the next 15 years.*

### Did it achieve a positive impact for patients and service users?

Although government funding for charitable hospices to pay for palliative and end of life care workers has undoubtedly had a positive impact, there remains currently significant unmet demand for palliative and end of life care in the UK. Estimates suggest that while as many as 90% of people who die in the UK may need palliative care, only around 50% of people who die actually receive it<sup>8</sup>.

Most people express a preference for home over hospital as the place of care at the end of their life<sup>9</sup>. The Covid-19 pandemic has increased the number of deaths taking place in care homes and private homes, and acted as a stress-test for the standard of care workers are able to provide in these settings<sup>10</sup>.

There is significant unmet demand for palliative and end of life care in these community settings. A recent Marie Curie survey of carers of people who died at home during pandemic found that:

- 76% said their loved one did not get all the care and support they needed
- 64% said they did not get the care and support they needed with pain management
- 61% said they did not get the care and support they needed with personal care; and
- 65% said they did not get the care and support they needed out-of-hours.

Research by Marie Curie<sup>11</sup> and others indicates that certain groups experience significant inequalities in access to and experiences of palliative and end of life care including people who are living in poverty, alone, or with dementia – as well as people with learning disabilities<sup>12</sup>, those who are homeless, poorly housed<sup>13</sup> or in prison<sup>14</sup>, BAME groups<sup>15</sup> including Gypsies and Travellers<sup>16</sup>, and LGBTQ+ people<sup>17</sup>.

---

<sup>8</sup> Von Petersdorff C, Patrignani P, Landzaat W. (2021) [Modelling demand and costs for palliative care services in England: A final report for Sue Ryder](#). London Economics.

<sup>9</sup> Marie Curie (2021). [Better End of Life 2021](#). p2

<sup>10</sup> The Kings Fund (2021) [Invisible deaths: understanding why deaths at home increased during the Covid-19 pandemic](#).

<sup>11</sup> Marie Curie (2020) [A place for everyone – what stops people from choosing where they die?](#)

<sup>12</sup> Tuffrey-Wijne I *et al.* (2009) [People with learning disabilities who have cancer: an ethnographic study](#). British Journal of General Practice; 59 (564): 503-509.

<sup>13</sup> Shulman C *et al.* (2018) [End-of-life care for homeless people: A qualitative analysis exploring the challenges to access and provision of palliative care](#). Palliative Medicine Vol 32, Issue 1

<sup>14</sup> Turner, M, & Peacock, M. (2017) [Palliative Care in UK Prisons: Practical and Emotional Challenges for Staff and Fellow Prisoners](#). Journal of Correctional Health Care, 23(1), 56–65

<sup>15</sup> Evans N *et al.* (2011). [Appraisal of literature reviews on end-of-life care for minority ethnic groups in the UK and a critical comparison with policy recommendations from the UK end-of-life care strategy](#). BMC Health Serv Res 11, 141 .

<sup>16</sup> Dixon KC, Ferris R, Kuhn I, *et al.* (2021). [Gypsy, Traveller and Roma experiences, views and needs in palliative and end of life care: a systematic literature review and narrative synthesis](#). BMJ Supportive & Palliative Care

<sup>17</sup> Almack, K *et al.* (2010) [Exploring the impact of sexual orientation on experiences and concerns about end of](#)

## Was it an appropriate commitment?

The Ambitions framework for palliative and end of life care sets out a vision for the workforce but does not adequately specify the steps that are needed to achieve that vision, especially in the context of significantly rising demand for this workforce in the next two decades. Current recommendations for the number of palliative medicine specialists equate to only 0.8 workers (FTE) per population of 100,000 people in the UK, compared to 2.2 workers in Ireland and 1.5 in Australia.

In response to a campaign led by Marie Curie, the Government recently introduced a new legal duty to commission palliative care services in every part of England through the Health & Care Act. This needs to be accompanied by clear statutory guidance designed to ensure the right workforce is in place to:

- Provide support in **every setting** including private homes, care homes, hospitals, hospices and other community settings;
- Include **hospice and other palliative care beds** when required, including **admission on an urgent basis**;
- Make specialist palliative care advice **available on a 24/7 basis**;
- Provide **support by telephone** from specialist healthcare professionals;
- Ensure a **point of contact is available** for people with palliative and end of life care needs if their usual source of support is not accessible; and
- Ensure **systems are in place to share information** about the person's needs with all professionals involved in their care, provided they give consent for this;
- Support **advance care planning** development in all services to ensure patients are able to have open conversations about their needs and concerns; and
- Enable staff to **participate in relevant research and disseminate evidence-based innovations** in palliative care.

The biggest factor driving demand for the PEOLC workforce over the next 15 years is our ageing population. As a result of our ageing population, by 2040 there will be 100,000 more people dying each year in the UK. As our population ages, more people will be living with multiple and complex conditions, and cancer and dementia will become the most common causes of death<sup>18</sup>. The number of people dying with a need for palliative care is projected to increase by up to 42% by 2040<sup>19</sup>.

There has also been a long-term trend towards fewer people dying in hospital, and more people dying in care homes and private homes. This is a significant factor in shaping demand for services over the past decade. Sustaining current trends would likely require a doubling of current end of life care provision in care homes and private homes by 2030<sup>20</sup>. This trend has been accelerated during the Covid-19 pandemic<sup>21</sup>.

In combination, these factors will result in significantly increased demand for a health and care workforce that is skilled in palliative and end of life care in all settings, especially in community settings. Resourcing of the workforce will likely need to increase by around 40% on current levels by

---

[life care and on bereavement for lesbian, gay and bisexual older people](#). *Sociology* 44(5): 908–924

<sup>18</sup> Etkind, SN, Bone, AE, Gomes, B *et al.* (2017). [How many people will need palliative care in 2040? Past trends, future projections and implications for services](#). *BMC Med* 15, 102

<sup>19</sup> Bone *et al* (2018) [What is the impact of population ageing on the future provision of end of life care? Population based projections of place of death](#). *Palliative Medicine*. 32(2): 329-336

<sup>20</sup> Bone *et al* 2018

<sup>21</sup> The King's Fund (2019). [Investing in quality: the contribution of large charities to shaping the future of health and care](#).

2014 to ensure demand for palliative and end of life care can be met.

### **A workforce to support rising numbers of dying people is urgently needed in all settings**

To sustain current trends, end-of-life care provision in care homes and the community settings needs to double by 2040.

Between 2004 and 2014, the proportions of home and care home deaths increased (18.3%-22.9% and 16.7%- 21.2%) while hospital deaths declined (57.9%-48.1%). If these trends continue, the numbers of deaths in care homes and homes will increase by 108.1% and 88.6%, with care home the most common place of death by 2040. If care home capacity does not expand and additional deaths occur in hospital, hospital deaths will start rising by 2023.

[Bone et al \(2018\)](#) projected where people will die from 2015 to 2040 across all care settings in England and Wales. The researchers used population-based trend analysis and projections using simple linear modelling. Age- and gender-specific proportions of deaths in hospital, care home, home, hospice and 'other' were applied to numbers of expected future deaths.

Setting/population: All deaths (2004-2014) from death registration data and predicted deaths (2015-2040) from official population forecasts in England and Wales.

Their results showed that annual deaths are projected to increase from 501,424 in 2014 (38.8% aged 85 years and over) to 635,814 in 2040 (53.6% aged 85 years and over). Between 2004 and 2014, proportions of home and care home deaths increased (18.3%-22.9% and 16.7%- 21.2%) while hospital deaths declined (57.9%-48.1%). If current trends continue, numbers of deaths in care homes and homes will increase by 108.1% and 88.6%, with care home the most common place of death by 2040. If care home capacity does not expand and additional deaths occur in hospital, hospital deaths will start rising by 2023.

**Recommendation:** *Introduce a statutory duty for an annual, independent assessment of health and social care workforce projections and a requirement on Government to respond to that assessment with a full costed plan for how these workforce needs will be met over the next 15 years.*

### **Policy Area: Building a skilled workforce**

#### **Government commitment 2. Help the million and more NHS clinicians and support staff develop the skills they need and the NHS requires in the decades ahead**

Providing palliative and end of life care to larger numbers of people, especially in community settings, requires the development of new skills. If all are to receive palliative care from specialist teams, a massive increase in training of specialist nurses and physicians will be needed immediately.

Generalists will likely need to continue playing a major role in providing palliative and end of life care, especially in community settings, with support from specialist teams for patients with more complex needs<sup>22</sup>.

Specialist palliative care services still predominantly treat patients with cancer, and this is likely to increase given the high prevalence of pain and other symptoms involved in advanced cancer. However, the unprecedented increase in deaths from dementia mean that a change in focus towards both specialist and generalist support for people with dementia will also be required.

Workers in different parts of our health and care system will need to engage in more systematic joint working to meet the complex needs of individual patients in a personalised way. Lessons can be learned from recent experience during the pandemic on how this could be done over the next 15 years. Palliative care teams in all settings made rapid innovations during the Covid-19 pandemic in order to educate, upskill and support wider health and social care professionals across the sector to deal with widespread pressure across healthcare services. These adaptations enabled provision of care to people with Covid-19, as well as people with other life-limiting conditions<sup>23</sup>.

Primary healthcare professionals, in partnership with specialist palliative care teams, managed both increased volume and increased complexity of palliative and end of life care need in the community. Hospice and specialist palliative care teams shifted resources into the community, supporting people in their homes and in care homes, and providing education and support for other health professionals. Adaptations included streaming, extending and increasing outreach of services and using technology to facilitate communication<sup>24</sup>.

Barriers continue to exist for workers seeking to work flexibly across different settings, such as inconsistent requirements in areas such as safeguarding. Recent changes to the GP training contract have also made it difficult for GPs to develop a specialism in palliative and end of life care.

Every health and social care worker is likely to be involved in caring for people experiencing dying, death or bereavement at some point in their career, but palliative and end of life care training is not currently a compulsory part of either initial training or continuing professional development for most workers<sup>25</sup>.

***Recommendation:*** A requirement for palliative and end of life care training as a compulsory part of initial training and continuing professional development for all health and social care workers, not just those in regulated professions, for example through inclusion on the General Practitioner and Nursing curriculums.

#### **Government commitment 4. Supporting moves towards prevention and support, we will go faster for community-based staff.**

The workforce employed by charitable hospices is just one part of the health and care workforce that is necessary for ensuring everyone who needs it can access the palliative and end of life care they need at the end of life.

---

<sup>22</sup> Quill, T, Abernethy, A (2013) [Generalist plus specialist palliative care – creating a more sustainable model.](#)

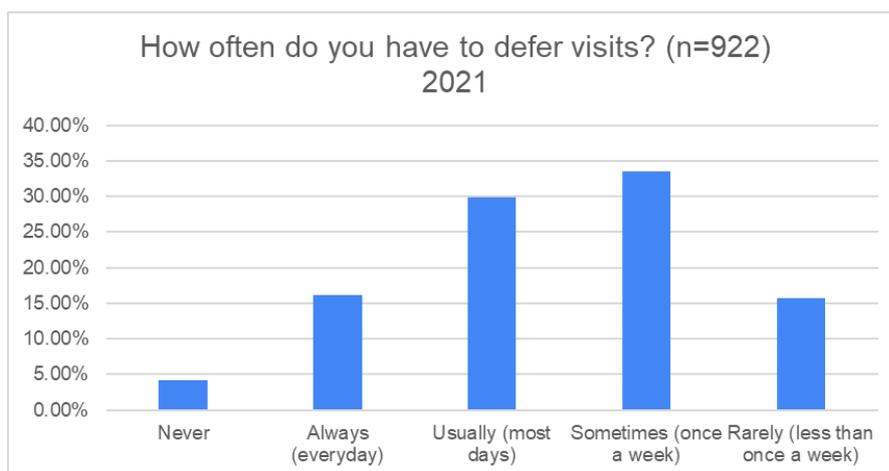
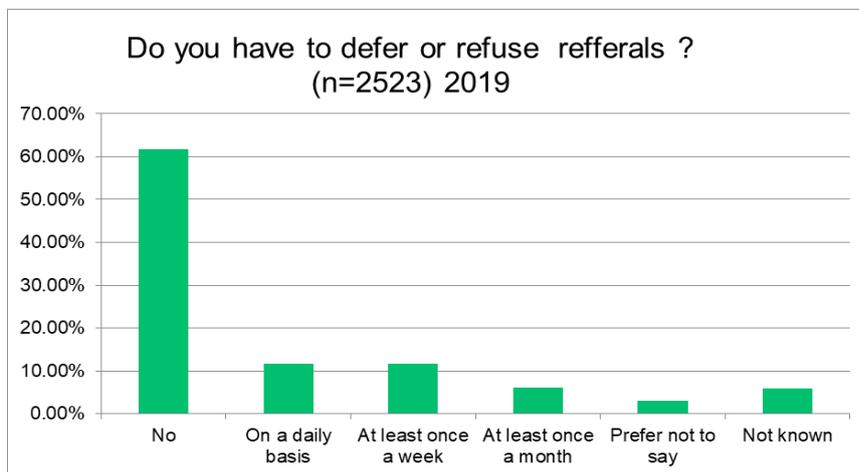
<sup>23</sup> Marie Curie (2021) [Better End of Life 2021 report](#) (p13)

<sup>24</sup> Marie Curie (2021) [Better End of Life 2021 report](#) (p37)

The primary care workforce plays a vitally important role in providing generalist end of life care to people who are dying in community settings such as care homes and private homes. Yet this workforce is also experiencing significant challenges:

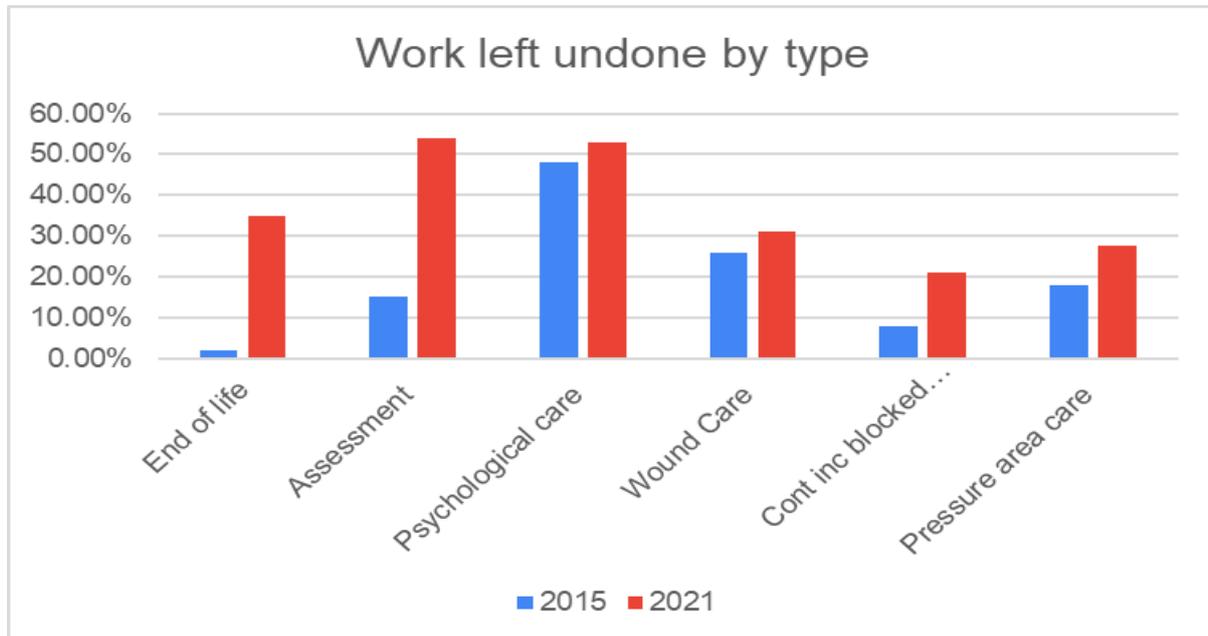
- There were 5.2% (1,516) fewer full-time equivalent GPs in Dec 2021 than in September 2015.
- On average each GP is looking after 9.7% (165) more patients than they were in Sept 2015.
- 34% (13,500) of GPs say they are unlikely to be working in general practice in 5 years
- GPs delivered 10.9% (1,460,569) more consultations and 14.2% (2.2 million) clinical administrative activities in Nov 2021 than Nov 2019
- 60% of GPs say that their mental health has deteriorated in the last year and 34% say they can't cope with their job at least once a week

Recent [research by the Queen's Nursing Institute](#) reveals the extent of the challenges confronting district nurses, another vital component of the workforce caring for people at the end of life in community settings. Research undertaken in 2019 & 2021 demonstrates that there is not enough available workforce capacity to cope with the demand for work and home visits are regularly cancelled or deferred.



Queen's Nursing Institute & International Community Nursing Observatory data demonstrates that delay and de-prioritisation of end of life care by district nursing teams has increased to around 35% despite the significant increase in the numbers of deaths at home. This causes moral distress for

District Nurses and is cited by them as one of their reasons for leaving or retiring early from the profession.



Gaps in the social care workforce are also already significant and are widening with increased demand for services during the pandemic. As demand for palliative and end of life care services has increased, the budget for social care has fallen significantly in real terms. Spending per person on adult social care services fell in real terms by around 12% between 2010/11 and 2018/19<sup>26</sup>.

The social care workforce is also under pressure. In 2019/20, the estimated staff turnover rate in the adult social care sector was 30.4%, equivalent to approximately 430,000 leavers over the year. It is estimated that 7.3% of the roles in adult social care were vacant, equal to approximately 112,000 vacancies at any one time. Around a quarter of the workforce (24%) and almost half (42%) of the domiciliary care workforce were on zero-hours contracts<sup>27</sup>.

**Recommendation:** Ensure a pro-active approach to supporting health and wellbeing for all palliative and end of life care workers in every setting.

**Policy Area: Wellbeing at work**

**Government commitment 5: Introduce new services for NHS employees to give them the support they need, including quicker access to mental health and musculoskeletal services.**

Research carried out by the Association for Palliative Medicine found that over 75% of the palliative care workforce were aged 40 or over. The ‘mean intended age of retirement’ for palliative care consultants is 61.2 years, and data indicates that over the next 10 years approximately 207 consultants in palliative medicine, representing 33% of the workforce, are likely to retire and exit the

<sup>26</sup> Health Foundation (2020) evidence to DHSC Select Committee inquiry into Social care: funding and workforce [SCF0044](#)

<sup>27</sup> Skills for Care, Workforce Intelligence (2020), [The state of the adult social care sector and workforce in England](#) p10

workforce<sup>28</sup>.

Alongside those already due to leave the profession, there are physical and mental health impacts associated with caring for people with a terminal illness. The physical demands of caring such as lifting and moving people with terminal illnesses and helping with washing and dressing can be taxing and cause injury as well as long term health conditions<sup>29</sup>.

The workforce delivering PEOLC in community settings also faces significant challenges due to unsuitable environments for care. The All-Party Group for Terminal Illness found that experiencing housing and fuel poverty has profound impacts on a person's experience at the end of life, meaning that they are less likely to be able to die at home even if it is their wish – or if they do so, this experience is needlessly stressful, painful or undignified<sup>30</sup>. Lack of space in smaller properties can present difficulties for those providing care at the end of life, for example a small amount room around a bed is needed to safely provide care at the end of life. Unsuitable environments can be hugely challenging for care-givers.

Marie Curie, alongside academics at the Universities of East Anglia, De Montfort and the ImpACT research group, co-created a career development framework to support practitioners.<sup>31</sup> Currently in its third phase, the framework centres around giving members of the work force clarity of purpose, an understanding of how their role contributes to the future of Marie Curie, and the delivery of services. This enables our organisation to:

- Lead the professional agenda in the field
- Evidence high quality standards of care
- Develop a career pathway for recruitment of the workforce
- Improve staff retention

This utilises the Skills for Health framework, a nationally recognised and independent framework which maps out key skills and competencies of practitioners, taking into consideration diversity of the workforce across all four nations. This comprises of 9 levels beginning at an entry level requiring basic general knowledge, ranging up to the most advanced with responsibility for development or delivery of service at the highest level of an organisation.

Marie Curie is the leader in end of life experience in the UK. We work hard to provide a better life for people living with a terminal illness and their families. We offer expert care across the UK in people's own homes and in our nine hospices. Last year, we supported more than 50,000 people across the UK at the end of their lives.

Our free information and support services give expert care, guidance and support to families so they can have something that really matters to them – time to create special moments together.

We are the largest charitable funder of palliative and end of life care research in the UK and

<sup>28</sup> Association for Palliative Medicine (2019) [Report and overview of the palliative medicine workforce in the United Kingdom](#) 2.3.5 p7

<sup>29</sup> Marie Curie and Carers NI (2019) '[Lost retirement: The impact on older people of caring for someone with terminal illness](#)'

<sup>30</sup> All-Party Parliamentary Group for Terminal Illness (2021) [No Place Like Home?](#) P7

<sup>31</sup> Marie Curie, Carrie Jackson, Director of ImpACT Research Group, and Associate Professor at the University of East Anglia, Dr Lynn Furber, Director of Healthcare Communication Matters and former Associate Professor Cancer, Palliative and End of Life Care at De Montfort University, Professor Kim Manley CBE, Co-Director of the ImpACT Research Group

campaign inside and outside Parliament for the policy changes needed to deliver the best possible end of life experience for all.

**May 2022**