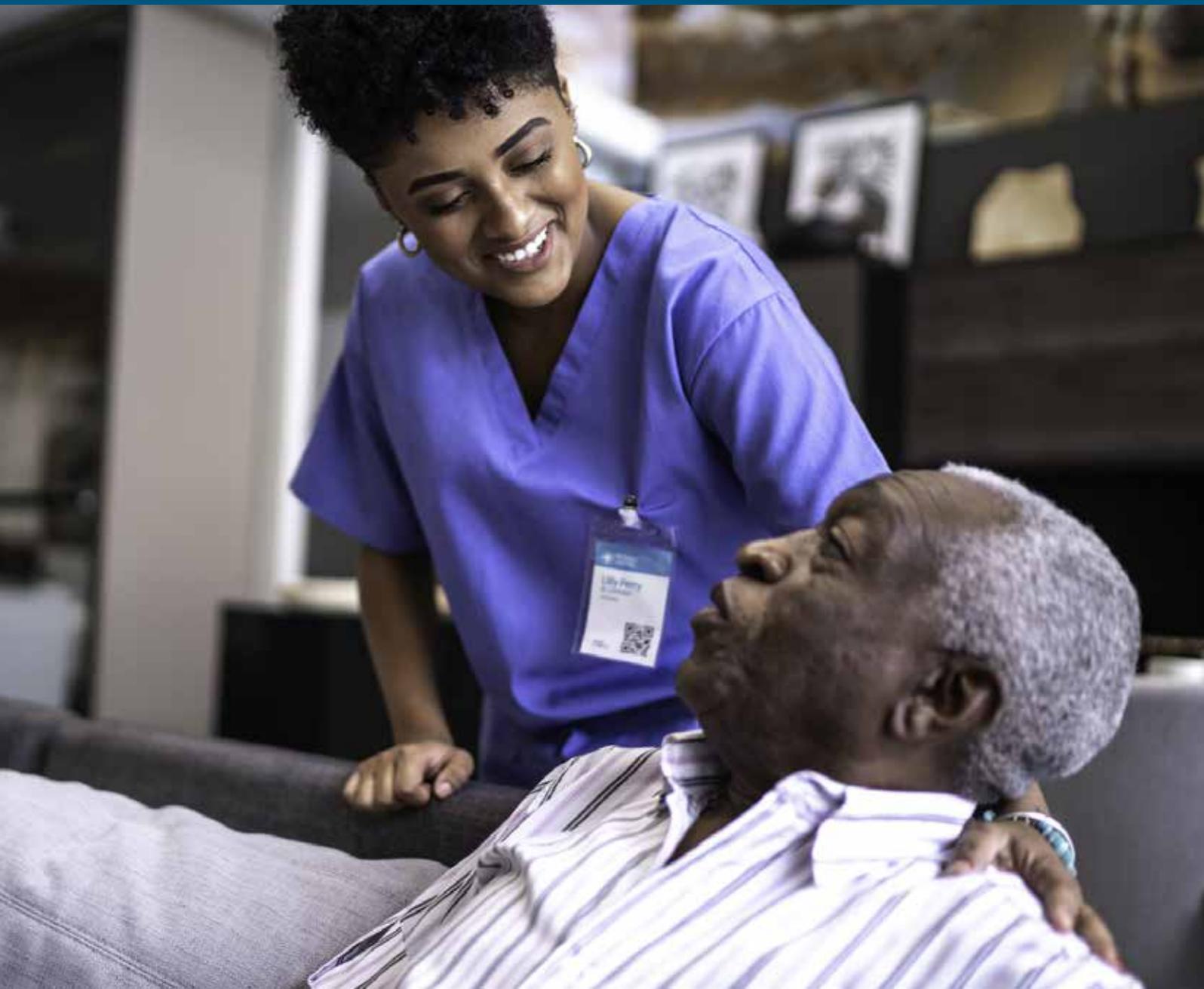


# Cross Party Group on Hospice and Palliative Care

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**Inquiry:** Experiences of palliative and end of life care in the community during the COVID-19 pandemic

January 2023



# About the Cross Party Group on Hospice and Palliative Care

The purpose of the Cross Party Group is to maintain and develop understanding and interest by Members of the Senedd on issues affecting people who need hospice and palliative care, in the furtherance of improving palliative and end of life care for all in Wales.

## Cross Party Group Chair

Mark Isherwood MS, Welsh Conservatives, North Wales

## Current Cross Party Group MS membership

Mabon ap Gwynfor MS, Plaid Cymru, Dwyfor Meirionnydd

Rhun ap Iorwerth MS, Plaid Cymru, Ynys Môn

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# Chair's foreword

It is clear from the contributions to our inquiry that the Covid 19 pandemic turned the world of palliative care on its head, dramatically disrupting the lives of individuals at end of life, their loved ones and the health and social care workers supporting them. I would like to express my thanks and gratitude to the family members, carers, nurses, doctors and many others who generously shared their often heart-breaking, but also uplifting and insightful accounts of caring for some of our most vulnerable citizens through the most testing of times.

Our inquiry sought to give people and organisations at the very sharp end of the pandemic a voice and a platform. We wanted to learn from their experiences of end of life care at home and in care homes so we are better prepared for any future disaster and better placed to meet the ongoing impacts of Covid and the cost of living crisis.

We believe this is more important than ever before, considering demand for palliative care in the community is forecast to nearly double by 2040 and the pandemic has given us a glimpse into how our health and social care system will cope under similar pressures in the not so distant future. With that in mind, I am pleased to share some of the overarching findings from our inquiry:

- **Hospice and palliative care played a critical role in the pandemic response** and was supported by a wave of community engagement and action. However, the massive increases in demand for care in the community revealed weaknesses in pre-pandemic planning.
- **Many people faced difficulties accessing end of life care at home and in care homes**, increasing existing inequalities in palliative care and leading to some devastating experiences, including complex bereavement.
- **Health and social care workers went above and beyond to support patients and their families at end of life**, facilitating a revolution in collaboration, innovation and creative working across primary, secondary and social care.

The Cross Party Group is keen to work together with partners to learn from these experiences and take forward the following key recommendations:

- **Learn from the pandemic and build on good practice** by ensuring palliative care is at the heart of plans for potential future pandemics; developing an electronic patient record with advance and future care preferences; nurturing innovation; and making sure the experiences of people and service providers in Wales are fully included in the UK Covid-19 Inquiry.
- **Pivot capacity into the community** by prioritising the development of palliative care capacity in the community and upscaling existing good practice; ensuring the new quality statement for palliative and end of life care is supported by a detailed implementation plan and its values are hardwired into the development of a new National Care Service.
- **Make palliative and end of life care everybody's business** by supporting greater death literacy within communities; investing in hospices as experiential learning sites; addressing inequalities; and ensuring that workforce strategies prioritise the wellbeing, staffing, education and training needs of those working across the full spectrum of palliative and end of life care.



Mark Isherwood MS, Chair  
Cross Party Group on Hospice and Palliative Care

# Recommendations and key findings

This report summarises over 50 written and oral responses to the Cross Party Group (CPG) inquiry into experiences of palliative and end of life care (PEoLC) in people's homes and care homes during the pandemic. The majority of respondents gave evidence based on their own individual personal and professional lived experience as family members, unpaid carers, social workers, nurses and doctors. The aim of this report is to understand, share and learn from their experiences in order to improve PEoLC for everybody in Wales.

## Learn from the pandemic and build on good practice

As the UK Covid-19 Inquiry gets underway, it is essential that people with lived experience, service providers and decision makers in Wales have the opportunity to come together to share their stories and learn from their experiences. The CPG heard compelling accounts of how the pandemic irrevocably changed individuals' lives and disrupted palliative care services across the country. It also heard about the incredible bravery, resilience and ingenuity of health and social care workers in Wales who faced overwhelming challenges and hardships supporting people at end of life.

**32%** 

Deaths in private homes in Wales were 32% higher than the previous five-year average. This is a trend which has largely continued throughout 2021 and 2022.<sup>(1)</sup>

*“ In Wales, specialist palliative care was recognised as paramount to the Covid-19 pandemic response. Crucial to future sustainability and the ability to deliver; will be a recognition of the positive effect of specialist palliative care as part of a value-based healthcare system. ”*

*End of Life Care Implementation Group, Review of Specialist Palliative Care Services<sup>1</sup>*

Key findings from the inquiry include:

- Visiting restrictions in care homes and other settings caused untold pain and distress, leaving many patients and their families isolated at end of life leading to cases of complex bereavement.
- Many people had devastating experiences of caring for loved ones at home and struggled to access adequate palliative care support.
- People at end of life faced difficult and tragic transitions between home, hospital and care home.
- Pandemic responses sparked a revolution in collaboration, creative working and use of communication technology across health and social care services delivering palliative care.
- Care home staff and those working with them were at times concerned with hospital discharge into homes and the use of do not attempt cardiopulmonary resuscitation (DNACPR) decisions.

- There were widespread shortages of staff, personal protective equipment (PPE) and end of life medication impacting on the delivery of vital palliative care.

### Recommendation 1

Welsh Government should ensure PEOLC is at the heart of plans for potential future pandemics and work with families and professionals to review how future visiting regulations could be enacted in a more compassionate and consistent way for those with a palliative care need.

### Recommendation 2

The findings and recommendations of the UK Covid-19 Inquiry must be informed by the lived experiences of people in Wales and recognise the impact the pandemic has had on the nation's healthcare systems, specifically for people at end of life.

### Recommendation 3

The National Programme Board for PEOLC should develop an innovation programme aimed at better capturing evidence and data that consistently records outcomes, facilitates learning and identifies good practice that can be embedded in national policy and local strategy.<sup>2</sup>

### Recommendation 4

Welsh Government should, as a matter of urgency, develop an electronic patient record with Advance and Future Care preferences and decisions.<sup>3</sup>

## Pivot capacity into the community

Demand for palliative care in the community is forecast to nearly double by 2040<sup>4</sup> and the pandemic has given us a glimpse into how our health and social care system will cope under similar pressures in the not so distant future. Even now, data from the Office for National Statistics demonstrates the number of excess deaths at home in England and Wales continues to be very high. The CPG heard how those working in hospice and palliative care shifted services into homes and care homes at the start of the pandemic whilst improving collaborative working across health and social care. Welsh Government played a key role enabling this by providing financial support to Welsh hospices throughout Covid.<sup>5</sup>

**19% ↑**

Deaths in care homes in Wales were 19% higher in 2020 compared to the five-year average, with Covid as the registered cause of death in many cases.<sup>[iii]</sup>

It is essential that this pivot of capacity, knowledge and skills into community settings is developed and built upon. The CPG welcome the commitment in the new Quality Statement for PEOLC that 'people's priorities for place of care, such as care closer to home (including care homes) ... will be reflected in workforce planning and in investment'<sup>6</sup>, but would like to see more detail as to how this is implemented at the local level.

*“ For care to be delivered closer to home effectively, there must be a significant rebalancing of resources (human and financial) across the system to ensure that more can be delivered by all the agencies working in the community. ”*

*National Clinical Framework, Wales<sup>7</sup>*

Key findings from the inquiry include:

- The pandemic saw a massive increase in demand for PEOLC in the community, with deaths at home increasing by over 30% and continuing at this level today, while deaths in care homes and hospitals have returned closer to pre-Covid levels after peaking at the start of the pandemic.
- Palliative care was prioritised and redirected into communities to meet increases in demand.
- Hospice and palliative care services that were more community orientated and integrated before Covid were better placed to meet the challenges of the pandemic.
- Despite the incredible efforts of those in health and social care, people still experienced a lack of PEOLC support in their homes and relied heavily on family and friends at end of life.
- At times care homes faced challenges accessing PEOLC and often felt less valued than health care.

### **Recommendation 5**

The End of Life Care Funding Review should prioritise the development of palliative care capacity in the community, with the aim of making care at home and in care homes equal in prioritisation to inpatient care, starting with improving out-of-hours support and ensuring people have a single point of access to co-ordinated care.

### **Recommendation 6**

The National Programme Board for PEOLC, supported by Welsh Government, should develop a detailed implementation plan for the new Quality Statement for PEOLC that ensures people's priorities for place of care are reflected in workforce planning and investment at the local level.

### **Recommendation 7**

Welsh Government should ensure that PEOLC in the community is hardwired into the development of the new National Care Service and National Framework for Social Care and involve people with personal and professional lived experience in this process.

### **Recommendation 8**

Welsh Government and health boards should prioritise support for the development and roll out of the CARiAD package (Lay Carer Administration of As-Needed Subcutaneous Medication)<sup>8</sup> and Specialist Palliative Care Paramedic scheme in local areas across Wales.<sup>9</sup>

## Make palliative and end of life care everybody's business

The CPG heard how the pandemic accelerated a breakdown in traditional silo working and fostered the development of creative workaround solutions across primary, secondary and social care, making PEOLC “everybody's business”. It also resulted in greater community involvement and understanding of end of life care and showed the power and potential of nurturing compassionate communities. Despite these developments, inequalities in access to PEOLC appear to have been exacerbated by the pandemic, alongside having a detrimental impact on workforce health and wellbeing.



The long-term projections to sustain current trends in preference for end of life care in the community estimate that community palliative care and care home capacity will need to double by 2040.<sup>[iii]</sup>

Key findings from the inquiry include:

- There were dramatic improvements in shared learning and partnership working across primary, secondary and social care through multi-disciplinary teams and co-location of services.
- Paring back of in-person support and the rapid shift to telephone or virtual consultations revealed the importance of face-to-face contact with patients and families.
- The pandemic revealed the power and potential of involving communities in support of palliative care and resulted in improved societal understanding and awareness of death and dying.
- Innovation and collaboration ensured continued support for children, young people and their families throughout the pandemic, despite huge workforce challenges and reduced services.
- Existing inequalities in access to PEOLC were accentuated by the pandemic, particularly for ethnic minority groups, isolated older communities, unpaid carers, and people with a cognitive impairment.
- The pandemic and ongoing pressures in health and social care have had a detrimental impact on workforce health and wellbeing, affecting provision of palliative care.

### **Recommendation 9**

Health Education and Improvement Wales (HEIW) and Social Care Wales should review and update the 10-year workforce strategy<sup>10</sup> to ensure that the wellbeing, future staffing requirements and education and training needs of all those working across PEOLC are included in line with projected future health population needs.

### **Recommendation 10**

Welsh Government should support greater death literacy within communities in Wales, encouraging higher levels of advance planning for end of life, alongside improving support for bereaved people, in line with recommendations from the UK Commission on Bereavement.<sup>11</sup>

### **Recommendation 11**

Health boards should invest in hospices as experiential learning sites for professionals with an interest in improving their skills and developing a seamless approach to PEOLC across health and social care.

### **Recommendation 12**

Welsh Government should review progress addressing inequalities in access to PEOLC against previous CPG inquiry recommendations.<sup>12</sup>



# Background

## Our inquiry

1. The Cross Party Group on Hospice and Palliative Care took evidence for its inquiry between October 2021 and May 2022. We received 22 written and video submissions and ran a number of oral evidence sessions involving contributions from 28 practitioners, clinicians, family members and carers of people with a palliative care need.
2. Over half of respondents to the inquiry (30) gave evidence based on their own individual personal and professional lived experience, while a further 20 responded in their capacity as organisations and representative bodies. Responses came from a broad range of sectors including independent hospices, health boards, care homes and a variety of organisations representing ethnic minority, carer and clinical interests.
3. We would like to thank all those who have taken the time to contribute to this inquiry by giving evidence. Lists of those who gave oral and written evidence are included in Annexes A and B.

## Context

4. Prior to Covid, more than 33,000 people died each year in Wales, including around 200 children,<sup>13</sup> however, this figure has increased to over 36,000 a year since the pandemic.<sup>14</sup> Pre-Covid estimates of palliative care need indicate that 74% of people who die in Wales would benefit from palliative care, but numbers are likely to be significantly higher since the pandemic. On average hospices in Wales care for over 12,000 adults and 700 children each year.<sup>15</sup> They provide care free of charge to improve the quality of life and wellbeing of adults, children and young people who have a terminal illness or a long-term condition that cannot be cured, also known as life-limiting.<sup>16</sup>
5. Palliative care is defined by the National Institute for Health and Care Excellence (NICE) as “the active holistic care of patients with advanced progressive illness”<sup>17</sup> and is delivered by a multi-disciplinary team, which can encompass colleagues in primary, secondary and tertiary care. End of life care is a specific aspect of palliative care for people considered to be in the last year of life.
6. In 2021 Welsh Government made commitments to ‘focus on end of life care’ and ‘review patient pathway planning and hospice funding’.<sup>18</sup> In line with these commitments it is developing a National Programme for PEO LC, including a high-level document outlining its policy intentions (called a Quality Statement), funding reviews of both hospice<sup>19</sup> and wider palliative care, and creating a National Programme Board to oversee this work.

## Why the Cross Party Group looked at this issue

7. As well as highlighting the value and importance of palliative and end of life care amongst the public and decision makers, Covid has changed the landscape of palliative care. The pandemic saw a massive increase in the number of people dying at home and in care homes, with non-COVID-19 deaths in private homes increasing by 30% above the five-year average and deaths from all causes in care homes rising by 21% over the same period in 2020.<sup>20</sup> This resulted in huge stresses and strains being placed on hospice and palliative care services and a significant pivot of capacity, knowledge and skills into communities.
8. During this time, hospices played a significant role in facilitating rapid discharge from hospital to home, care home or hospice at end of life. The pandemic also shone a light on the fragility of their charitable funding model, with financial support from Welsh Government being critical to their survival throughout the pandemic, enabling them to support ever increasing numbers of people in the community.<sup>21</sup>
9. Understanding these changes is vitally important in planning and delivering future palliative care services in Wales. This is especially true considering overall deaths in the community are projected to increase to pandemic levels by 2040, while hospital deaths are expected to decline by more than 50% in the same period.<sup>22</sup> The overarching aim of this inquiry has been to understand, share and learn from people's experiences in order to improve PEOLC for everybody in Wales.

## Terms of reference

10. The inquiry focused its work on the following key questions:
  - How did changes in health and care services during the pandemic affect the delivery of PEOLC for children and adults at home and in care homes?
  - What were the experiences of people receiving end of life care, their families and loved ones at home and in care homes as a result of changes to services?
  - Was there inequality in access to care for people from certain groups dying at home and in care homes during the pandemic?
  - What positive ways of working and innovative approaches to delivering PEOLC at home and in care homes have been developed during the pandemic?
  - What impact has the pandemic had on the health and wellbeing of frontline health and care workers, families and unpaid carers who deliver end of life care in the community and how can they be best supported going forward?

## Scope of this report

11. The key findings and recommendations in this report are largely based on the evidence the inquiry received and grounded in people's personal and professional experiences during the pandemic. The inquiry report does not pertain to represent a full or complete picture of end of life care in Wales during this period, but does draw on wider data and research to put people's lived experiences in context.

# 1. Changes in delivery of community palliative care

12. Evidence submitted to the CPG painted a picture of a health and social care service turned on its head, its systems in flux and fundamentally re-shaped in a short period of time. Hospice and palliative care teams were at the very centre of this, having to contend first hand with an unknown and deadly virus driving massive increases and changes in demand for end of life care.

*“ I don't think any of us could have anticipated what happened. It turned the world of palliative care upside down. Everything that we've known, for the last 30-40 years just changed completely in terms of how the referrals were coming in, how people were dying, people were dying far more quickly than they used to. ”*

*Carys Stevens, Palliative Care CNS/Team Leader,  
Hywel Dda University Health Board, oral evidence in a personal capacity*

*“ Working through the Covid Pandemic was like standing on the shore with a battered Peppa Pig umbrella, waiting for the Tsunami to hit. Then it was like being on a rollercoaster with no seatbelt or safety harness, for 2 years! ”*

*Laura Hugman, Clinical Team Manager, Paul Sartori Hospice at Home, oral evidence*

13. Many carers, nurses and doctors described high levels of fear, confusion and uncertainty in the early days of the pandemic. Information overload regarding infection prevention and control measures and rapid changes to services presented serious challenges, combined with a desperate scramble to access personal protective equipment (PPE) during the early weeks and months of the first wave. They also described significant differences in how health boards, hospices, care homes, GPs, District Nurses and others in health and social care responded to Covid. A common theme in this inquiry is how the pandemic affected many different people and many different services in many different ways.

## Massive increase in demand for end of life care at home and in care homes

14. Evidence from Marie Curie and Hospice UK shows the extent to which the pandemic changed the landscape of community palliative care. In the first year deaths in private homes in Wales were 32% higher than the previous five-year average. This is a trend which has largely continued throughout 2021 and 2022, including between the waves of Covid when deaths in other settings dropped significantly. It is also a trend which is mirrored across the UK, with the vast majority of deaths at home being from conditions other than Covid.<sup>23</sup>
15. Deaths in care homes in Wales were 19% higher in 2020 compared to the five-year average, with Covid as the registered cause of death in many cases. Most of these deaths occurred at the start of the pandemic and numbers have since returned closer to pre-pandemic levels, in line with wider figures across the UK.<sup>24</sup> However, the long-term projections to sustain current trends in preference for end of life care in the community estimate that community palliative care and care home capacity will need to double by 2040.<sup>25</sup> In this sense the pandemic provided a glimpse of the pressures community palliative care services, and in particular care homes, may be under in years to come and the importance of planning now to meet that need.
16. Evidence from health boards and hospices attributes the massive increase in demand for end of life care at home to a variety of factors, including hospitals and clinicians avoiding admissions for non-Covid and non-emergency patients; individuals and their families wishing to avoid acute hospitals for fear of contracting Covid and dying alone; and access to hospice beds being significantly reduced due to infection prevention control measures and decreased staffing levels. The overall increase in demand also led to an increase in the complexity of care people needed at home.

“ Changes were brought about by the hospice to limit the transmission of Covid-19; these included closing the day therapy service and limiting visitors to the in-patient ward. As a consequence, more people were choosing to be cared for at home at the end of their lives to make it possible to receive visitors. ”

*Glenys Sullivan, Matron, St David's Hospice, North Wales, oral evidence*

“ The increased need for palliative and end of life care at home was in part because many people were reluctant to be admitted to in-patient units for fear of not being able to see their families due to restricted visiting regulations. This led at times to more complex care being provided at home than is usual. ”

*Betsi Cadwaladr University Health Board, written evidence*

17. The huge increase in deaths in care homes was driven by the overwhelming waves of Covid infections that tragically swept through so many homes across Wales in 2020, pushing already overstretched social and palliative care services to the limit. The CPG heard how carers and specialist palliative workers tried to meet ever increasing demand for end of life support in care homes while contending with visiting restrictions and infection prevention control measures designed to keep Covid out and people safe.
18. This was often a difficult balance, with both care home staff and specialist palliative care teams expressing frustration when residents' access to end of life care was sometimes limited due to interpretation of visiting restrictions, wider healthcare staffing pressures and the shift to remote consultations.<sup>26</sup>

*“ Face-to-face care and support for patients at home and in care homes by community services such as District Nursing and specialist palliative care services continued. However, this was impacted, particularly in care homes, by providers' anxieties about reducing footfall in those settings so the care was more limited to those at the very end of life... Some families and particularly care homes felt that infection, prevention and control restrictions guidance and a significant shift to remote consultations by other health professionals e.g. GPs, oncology, left them managing things without as much support as they might have wanted. ”*

*Cardiff and Vale University Health Board, written evidence*

19. However, the CPG heard many inspiring accounts of carers and specialist palliative care teams working tirelessly together in extremely difficult circumstances to ensure as many care home residents as possible had access to care and support at end of life (see Chapter 3).

## Prioritisation of hospice and palliative care services in the community

20. At the same time as hospitals, hospices and care homes were having to regulate and reduce contact with the public, particularly in in-patient settings, many palliative care services were rapidly re-orientating themselves to support more people in their homes and in care homes. The scale, speed and coordination of this change was remarkable, not only in terms of meeting people's immediate and critical end of life care needs in the midst of the Covid crisis, but also in fundamentally rethinking and redesigning how palliative care in the community is delivered.

*“ At the start of the pandemic, the decision was made to close our Specialist Palliative Care in-patient unit. This was in response to staffing pressures and also recognising the escalating need for specialist palliative care support in the community. The closure of the specialist palliative care in-patient unit in many ways enhanced our presence in the community settings, especially care homes. ”*

*Dr Helen Fielding and Dr Rebecca Croft, Specialist Palliative Care consultants in Carmarthenshire, Hywel Dda University Health Board, written evidence in a personal capacity*

*“ Hospices and palliative care teams therefore shifted resources into the community, as well as educating, upskilling and supporting other healthcare professionals. ”*

*Marie Curie Wales/Cymru, written evidence*

*“ Overnight we had to change our service to meet the demands of the lockdown and the infection risks associated with the pandemic. ”*

*St David's Hospice Care Newport, written evidence*

21. Health boards describe prioritising palliative and end of life care as an essential service, continuing to visit patients in their own homes and providing targeted support for care homes in crisis. This involved a sea change in working practices, characterised by enhanced cooperation between palliative care services and community, primary care, care homes, pharmacy services and secondary care. In one health board this involved NHS employed nurses being contracted to work in local authority or privately owned care homes to fill nursing shortages during the first wave of Covid.<sup>27</sup>
22. Hospices also responded to the pandemic by diversifying their services and delivering more support in patients' homes and in care homes, rather than on hospice premises. One hospice at home service supported several care homes by providing skilled registered nurses and health care support workers to keep the care homes open at the height of the pandemic.<sup>28</sup> Another children's hospice created a comprehensive virtual support service providing symptom control clinics, welfare calls, virtual play and a variety of other support to families who were isolating to protect their vulnerable children.<sup>29</sup>
23. Evidence from Hospice UK shows that in 2020/21, more care was provided in the community and through hospice at home, and less care in hospice buildings, such as day services.<sup>30</sup> In many cases, these changes built on developments in service provision that were already taking place before the pandemic, with the majority of hospice care for adults in Wales already being provided in the community in 2019.<sup>31</sup>

24. Evidence provided by those working in specialist palliative care and the Royal College of General Practitioners also points towards pre-pandemic community orientated services being more resilient during the crisis. A study undertaken by Aneurin Bevan University Health Board found that care planning was more effective in care homes where the local GP had an established relationship with the care home and had completed regular visits prior to Covid.<sup>32</sup> Palliative care teams also highlighted the benefits of delivering training and building relationships in care homes before the pandemic.

*“ Before Covid we invested a lot of time delivering training to the care home sector. We did a lot around advance and future care planning, important conversations and what matters. I think they were a little bit forearmed for the pandemic. There was that level of knowledge in there before the pandemic hit us, so thankfully they knew who we were and what we did and how to access us which I think served us well. ”*

*Carys Stevens, Palliative Care CNS/Team Leader, Hywel Dda University Health Board, oral evidence in a personal capacity*

25. Despite the huge efforts of so many in health and social care, a combination of massive increases in community demand, visiting restrictions and Covid driven staffing shortages significantly affected the delivery of palliative and end of life care to many people across Wales. These factors also led to many staff working under immense emotional and physical strain dealing with often overwhelming, complex and distressing clinical workloads.

*“ COVID-19 greatly impacted the workforce across the full range of health and social services, due to staff being infected or exposed to the virus. Reduced staffing levels at times made it challenging to deliver packages of care, as well as timely access to visits and prescribing, particularly in rural areas. ”*

*Betsi Cadwaladr University Health Board, written evidence*

*“ At the height of the pandemic and during each successive wave, Covid patients in the community who were put onto an end of life pathway were dying very rapidly. District Nursing and palliative care staff found the emotional impact of having to get to know and support a family and a patient only for them to die within 24-48 hours and then to be replaced immediately by another patient, emotionally and psychologically draining. ”*

*Cardiff and Vale University Health Board, written evidence*

## Paring back of in-person support and rapid shift to remote contact

26. The CPG received evidence of various health care providers reducing in-person contact with palliative care patients and shifting to remote consultations and video messaging. In practice this meant they were not providing the same service patients were used to in the same format. For example, the inquiry heard reports of GP practices not visiting patients at home or in care homes and shifting the majority of contact to virtual consultations. There were also reports of in-person access to other services, like oncology and continence, also being significantly limited and more likely to happen remotely.<sup>33</sup>

*“ During COVID-19 contact between staff, patients and families was dramatically reduced, however discussions regarding care planning were able to take place via email. ”*

*Royal College of General Practitioners, written evidence*

*“ There were restrictions in GPs visiting and some difficulties in patients gaining access to their surgeries, but this situation is now improving. ”*

*Dr Jo Hayes, Medical Director, Marie Curie Hospice Cardiff and Vale, written evidence in personal capacity*

27. The paring back of in-person services and rapid shift to telephone or virtual consultations appears to have varied significantly between providers, with many going to great efforts to meet patients face-to-face. Respondents to the inquiry also discussed the advantages and disadvantages of remote working, with most emphasising the importance of ensuring patients and families have the option for in-person interaction with clinicians in the interests of their health and wellbeing.

“ I saw a different narrative play out to the one recounted in the wider UK media. Whilst there were often mentions of GPs, DNs and other HCPs not going into care homes, I saw many who did (safely), where there was a real need... There was a big shift towards remote consultations and video messaging, for instance for my clinic patients. This had advantages (patients and relatives able to access me from the comfort of their own home) and disadvantages (limited ability to examine, proximity being an important factor in breaking bad news situations)... Personally I saw several patients/relatives who wanted to make contact with me face-to-face in the hospital car park, where they were able to speak to me from their car. This is not something I ever expected to be required to do, but people were desperate for help and contact. ”

*Professor Mark Taubert, Consultant/Clinical Director Palliative Medicine, Velindre University NHS Trust, written evidence in personal capacity*

28. A consequence of certain services reducing in-person support was added pressure on workers delivering palliative care who continued visiting patients at home and in care homes. For example, staff in community care described GP consultations being done via phone or videoconference with the nurse by the bedside, while hospice at home teams told us about having to break bad news and explain complex diagnoses to patients and families.

“ The shift in oncology practice at the start of the pandemic (decisions not to continue anticancer therapies and move to virtual interaction with patients) resulted in added pressure on hospice at home teams who were often having to explain to patients and their immediate families diagnosis and reasons around decision making instead of discussing disease trajectory and future care planning on first assessment. This sometimes included breaking bad news or delivering results of a scan. ”

*Dr Margred Capel, Consultant in Palliative Medicine, City Hospice, written evidence in personal capacity*

## Supporting children, young people and their families through the pandemic

29. The CPG were told how the pandemic magnified the growing disparity between need and available services for the estimated 3,200 babies, children and young people in Wales living with a life-limiting condition. As Covid worsened, many families faced increased anxiety and fear, deciding to cancel their health care packages in order to stay at home and protect their vulnerable children. The closure of schools and limited or no access to respite left many families isolated and exhausted as the pandemic progressed.<sup>34</sup>
30. Before the pandemic struck, the workforce providing end of life care for children at home – usually the children’s community nursing team – was small. There is no district nursing service for children as there is for adults. This posed significant challenges for families during the pandemic, in terms of the capacity of the service to provide the care they may want, need or expect, and for the services themselves in terms of the impact on the workforce when a child is approaching end of life.
31. Despite these challenges, and with some disruption to services, hospice and palliative care teams continued to support children and their families at home, in hospices and in hospitals. To make this possible hospice and children’s community nursing teams focused on collaborating and adapting to meet the needs of children and their families.

*“ We endeavoured to ensure that the pandemic didn’t affect our delivery of care to families, especially at end of life, although initially we closed to routine respite from march 2020- July 2020, we were still available for children who may have required end of life care either at the hospice or at home. ”*

*Tŷ Gobaith, Hope House Children’s Hospices, oral evidence*

32. Tŷ Gobaith created a virtual hospice providing crisis and end of life care, symptom control clinics, physiotherapy support, welfare support, virtual play, and a counselling service to families who were isolating. Ty Hafan Children’s Hospice collaborated with Hywel Dda University Health Board pooling paediatric nursing capacity through innovative honorary contracts to support two children approaching end of life at the same time in the same area.

“ Care was available for the children for five out of seven nights through pooling the workforce, which involved arranging honorary contracts for Ty Hafan nurses with the Health Board (for the first time), drawing on the Hywel Dda COINS (Children’s Outreach Inreach Nursing Service) bank and through agency staff. While there was a significant amount of care for the families, this wasn’t 24 hours, which was felt necessary by one family. ”

*Rebecca McDonald, Paediatric Palliative Care Nurse,  
Hywel Dda University Health Board, oral evidence*

“ The experience we had was positive and made death not scary like most people would imagine. Even during the tough Covid restrictions you put human compassion first. ”

*Extract from a letter by Micaela, mum of a little boy Cai who was supported  
by Ty Hafan before he died in February 2021*



## 2. Experiences of deaths at home

33. The dramatic changes in the delivery of palliative care services during the pandemic had a huge impact on the experiences of people at end of life at home, including their families, loved ones, and the carers and clinicians supporting them. Understanding these experiences is central to the inquiry's aims of making sure people's voices are heard and exploring what lessons can be learned for the future.

### Lack of support and increased reliance on family and friends at end of life

34. The inquiry heard moving accounts from families who couldn't always access support for their loved ones at home during the pandemic. People described feeling abandoned and struggling to access the care, medication and equipment needed. Specific issues included provision of coordinated care and a key point of contact, access to out-of-hours support and pain relief/medication, and timely referrals to palliative care.

*“ I was shocked at the lack of support you get when you've got someone at home. Shocked. He came home to us. I bought a bed. They gave me some bits of kit, then hell for the next five weeks. ”*

*Sara Morgan, who cared for her father at home before he was admitted and died in a care home, oral evidence*

*“ We were given a few leaflets and booklets but there was no one source of information on what to do or what to expect... We had to resort to calling paramedics after failing to get a response from District Nurses, Palliative Care, or Out of Hours. In fact, the Out of Hours number was saying the answer phone message facility was full and when it did finally ring it had been ringing for 40 minutes and was still ringing when the Paramedics arrived. ”*

*Ceridwen Hughes, who cared for her mother who died at home, written evidence*

35. Evidence from Marie Curie put these individual experiences into context, showing that three out of four home deaths during the pandemic did not get the care they needed. The UK wide survey, which included respondents from Wales, found that those who died at home during the pandemic didn't get all the help they needed with pain management (64%), personal care (61%) and out-of-hours support (65%).<sup>35</sup>

36. A major contributory factor was national medication and staff shortages, with healthcare professionals in Wales more likely to experience shortages relative to other areas of the UK: more than 40% reported experiencing medication shortages, while more than 60% reported staff shortages.<sup>36</sup>
37. However, evidence to the inquiry also highlighted how local hospice at home and community palliative care teams went above and beyond to continue meeting their communities' needs, in most cases significantly increasing support for people at home.<sup>37</sup> The CPG note the importance of documenting these local experiences and recognising how the pandemic affected many different people and many different services in many different ways.
38. Despite these efforts, the dearth of support many experienced during the pandemic resulted in palliative care patients relying more on their immediate families and friends to support them with personal care, but often without the requisite knowledge, skills and specialist support to do so properly. This situation was compounded by an increase in demand for more complex end of life care at home.<sup>38</sup>

*“ There was a decrease in practical ‘hands on’ support for patients and their families. This resulted in patients who received palliative and end of life care at home, relying on their immediate family or neighbours/friends to support them with personal care tasks. This was not necessarily the ideal or preferred option. ”*

*Cardiff and Vale University Health Board, written evidence*

39. The CPG heard how the pandemic shone a light on the difficulties people face accessing appropriate PEoLC support at home, but that crucially, many of these problems were present in the system prior to the pandemic.<sup>39</sup> It was reminded that if pre-pandemic trends continue, by 2040 the number of people dying in their own homes will increase by over 80%<sup>40</sup> compared to the over 30% increase witnessed since the start of the pandemic.

## Devastating experiences and difficult transitions between settings

40. The lack of support for people at home resulted in some families having to endure devastating experiences, witnessing loved ones in pain without access to the right medication and support at the end of their lives. As a result, there was increased reliance on more acute services in order to access support and pain relief. The inquiry heard of cases where families felt they couldn't cope and loved ones had to be admitted to hospital, sometimes against their final wishes, in some cases to never see their families again.

“ My Mum had previously said she didn’t want to go to hospital because of the COVID 19 pandemic. When the ambulance came she looked at me with a frown as she wasn’t happy to be leaving for the hospital. I had no idea that that was the last time I was going to be able to properly care for my Mum at home and looking back now I think I would have done things differently had I know...She was already dying when she was at home but I didn’t know that, she knew she was dying and wanted to die at home with her family but I wasn’t understanding it. ”

*Annika Nation-Reid, who cared for her mother at home before she died in hospital, oral evidence*

“ It’s the most horrific thing I’ve ever experienced, you just feel totally helpless... Something is wrong with the system, that when you pick up the phone you haven’t got someone at the end of the line you can actually speak to. ”

*Alison Baynton-Power, who cared for her mother who died at home, oral evidence via video*

“ In supporting one service user living at home with dementia at end stages, there were considerable difficulties getting any physical health checks done despite several attempts. This led to the need for ambulance services to be called on several occasions as the family felt that the person was deteriorating rapidly due to an infection. If this person had been assessed at an earlier point, this would have avoided this experience for the person and the family which stayed with them following their loss as they held on to the anger and the viable complaint that they had. ”

*Katy Evans, Registered Social Worker, written evidence in personal capacity*

41. Both families and palliative professionals describe these experiences having long-term impacts, including complex bereavement<sup>41</sup> for those who lost loved ones and moral distress or injury for carers, nurses and doctors who provided end of life care in very difficult circumstances.<sup>42</sup>
42. These pressures, combined with visiting restrictions and infection prevention and control measures, also resulted in disrupted transitions between home, hospital, care home and hospice settings, especially during the height of the pandemic. The CPG heard evidence of people’s preferred place of death not being achieved and in some cases patients getting stuck in the system.

*“ The College has received anecdotal accounts of terminally ill patients being admitted to hospital with no contact with families until they either died or were discharged. We have also received reports of patients waiting to be discharged from hospital to spend their final days being cared for at home, but being unable to make this transition due to COVID-19 delays. ”*

*Royal College of General Practitioners, written evidence*

*“ Visiting restrictions impacted discharge planning from acute hospitals whereby some families who were not permitted to visit prior to discharge were subsequently unprepared for how ill their loved one was at the time of discharge. On occasion, this led to readmission of patients into hospital. ”*

*Betsi Cadwaladr University Health Board, written evidence*

## Importance of face-to-face contact with patients and families

43. Many in palliative care emphasised the value and importance of continuing to provide in-person support to people at home. One hospice described patients and families feeling more isolated as many services were either suspended or moved to virtual platforms. This included their day hospice service shutting which meant weekly respite could not happen and therefore carer burden increased as they also missed family visiting at home.<sup>43</sup>

*“ Many patients reported distress at not seeing clinicians face-to-face. Many patients were given results of scans etc. over the telephone. Some reported distress at being told their disease had progressed over the telephone which they found very difficult to cope with. ”*

*St David's Hospice Care Newport, written evidence*

*“ Patients and families articulated their appreciation that the palliative care service continued to visit them (face-to-face) and support them when they described feeling “abandoned” by other healthcare providers. ”*

*Dr Margred Capel, Consultant in Palliative Medicine, City Hospice,  
written evidence in personal capacity*

44. One hospice at home service reported that the vast majority of their patients and families strongly declined offers of alternatives to face-to-face on follow up appointments, saying, that particularly for end of life care, they felt they should be seen face-to-face by professionals.<sup>44</sup> However, evidence to the inquiry also highlighted how remote clinical assessments and telephone support for patients had benefits, like improving accessibility and patient choice, particularly at the height of the pandemic, at the same time as recognising that it brings challenges, particularly for sensitive conversations.<sup>45</sup>

## Disproportionate impact on ethnic minorities, isolated communities, and unpaid carers at home

45. The inquiry asked if there had been inequality in access to care for people from certain groups during the pandemic. In the context of deaths at home, there was limited evidence available to say there was inequality in the palliative care response. However, the end of life experiences of individuals and health providers indicate that certain groups may have been disproportionately impacted by service pressures and Covid policies introduced during the pandemic, in some cases limiting their access and options for care.
46. Marie Curie's response highlights that while wider inequalities in relation to ethnicity and socioeconomic group were well described during the pandemic, relatively little is known about how ethnicity and deprivation influenced care for dying or bereaved people. Since then, they have published research showing that the increase in deaths at home in Wales that occurred during the pandemic was accompanied by a widening of socioeconomic inequality, with the least well off being the least likely to die at home and the most likely to die in hospital.<sup>46</sup>
47. The pandemic is widely recognised as having a disproportionate impact on many ethnic minority communities, with people of colour experiencing a significantly higher death toll due to Covid.<sup>47</sup> Evidence to the inquiry and wider research<sup>48</sup> highlights the particular challenges facing these communities who experienced disruption to cultural norms of caring for loved ones at home and fulfilling home going or rites of passage essential for family bereavement.<sup>49</sup>

*“ I come from Nigeria originally, and in our culture you don't put your elderly into care, you have to keep them with you in your house and look after them...for many of our communities the biggest thing is that sense of isolation, that they don't have immediate family living in Wales. ”*

*Uzo Iwobi, Chief Executive, Race Council Cymru, oral evidence*

48. The CPG was told how travel restrictions and Covid driven pressures on services may have adversely impacted ethnic minorities and older, more isolated rural communities' access to palliative and end of life care in parts of Wales. Respondents described the 'stay local' and 'five-mile rule' imposed as part of Covid restrictions disproportionately impacting people who do not live near to their friends and family, making it difficult for them to make memories with the dying person or to provide support for a carer at home.

*“ There was restricted travel, and people who lived away were not allowed to visit and towards end of life there were a lot of families who could not come and support their loved ones. At one point you were limited to 5 miles and that wouldn't get you anywhere in rural Wales. ”*

*Sonia Hay, General Manager Community Care Pembrokeshire, Hywel Dda University Health Board, oral evidence in personal capacity*

*“ I think more about the disadvantages of some elderly people, often living in more isolated rural areas, who may have been a little independent pair not wanting to ask for help. How can we ever measure how we didn't deliver to those individuals? ”*

*Jina Hawkes, General Manager Community Primary Care, Hywel Dda University Health Board, oral evidence in personal capacity*

*“ Reduced staffing levels at times made it challenging to deliver packages of care, as well as timely access to visits and prescribing, particularly in rural areas. ”*

*Betsi Cadwaladr University Health Board, written evidence*

49. Unpaid carers were also significantly impacted by the pandemic and describe having to provide more care due to service reductions and disruptions. Before the pandemic it was estimated that there were 487,000 unpaid carers in Wales providing care to family members or friends who required support due to age, illness, disability or because of a mental health condition. At the height of the pandemic, in summer 2020, the number of unpaid carers in Wales was estimated to have increased to 683,000.<sup>50</sup>

*“ Carers who said the person nearing end of life faced barriers in accessing care attributed this to understaffed services unable to provide the required care and in other cases the barrier was due to the fact that they couldn't receive end of life care at home as they would have wished. ”*

*Carers Wales, written evidence*

50. Lack of support at home and limited face-to-face contact with service providers were key challenges identified by unpaid carers. The CPG was also told about practical equipment (including beds, perching stools, commodes and grab rails) taking too long to access, contributing to difficulties for patients living independently and their carers.<sup>51</sup>

## Positive experiences and increased public awareness of end of life at home

51. Despite the majority of evidence submitted to the inquiry understandably focusing on the challenges presented by the pandemic, the CPG also heard positive experiences and perspectives of end of life at home during this difficult period. Many of the positives relate to improved collaboration and innovation delivering palliative services in the community (see Chapter 4), but respondents also described wider societal benefits, such as improved understanding and awareness of death, dying and how end of life at home can be a positive experience for individuals and their families.<sup>52</sup>

*“ For some who were working from home, or who were on furlough, the greater flexibility this offered them meant they felt able to support their loved one to die at home when previously this would not have been a consideration. ”*

*Cardiff and Vale University Health Board, written evidence*

*“ It raised awareness of dying at home as an option to patients and families who might not have considered this before and those who had a good experience may be more likely to choose this for other relatives or for themselves. As numbers of deaths rise due to the ageing population with numbers of hospital and hospice beds not planned to increase, dying at home or in a care home is likely to be the only choice available to many so society becoming more familiar with home deaths is encouraging. ”*

*Dr Jo Hayes, Medical Director, Marie Curie Hospice Cardiff and Vale, written evidence in personal capacity*

52. For clinicians the pandemic also encouraged a more proactive focus on talking about death and dying, ceilings of care, resuscitation and advance care planning with families who may not have had those conversations otherwise. Respondents expressed a hope that this more open approach to talking about PEoLC continues going forward and that Welsh Government, the NHS and community partners nurture and support this.<sup>53</sup>



### 3. Experiences of end of life in care homes

53. Family members and those who cared for residents in care homes at end of life told the CPG of the pain and distress they experienced trying to access and provide care for loved ones and patients during the pandemic. Their accounts were fundamentally shaped by the overwhelming waves of Covid infection that tragically swept through so many care homes across Wales in 2020, pushing already overstretched social and palliative and care services to the limit.
54. Care Forum Wales highlighted that care homes are not institutions, but extended families, where the residents and carers form relationships. However, with the advent of the pandemic this quickly changed and many homes became more like hospital settings; an experience that was traumatic for both residents and staff.

*“ When you see your whole home falling apart before your eyes it’s really traumatic...It was dangerous. It was like a warzone. It was that bad at times. One of our care home members lost 21 residents in two weeks. ”*

*Melanie Minty, Care Forum Wales, oral evidence*

#### Visiting restrictions caused untold pain and distress to residents and their families

55. Some of the most upsetting pieces of evidence the inquiry heard were people’s heartbreaking accounts of care home residents being isolated from family and loved ones towards the end of their lives, and in some cases dying without their nearest and dearest by their sides. Respondents also described similar situations in hospitals and hospices subject to visiting restrictions.

*“ His chest wasn’t right...He’d been there two weeks and then we had the call to say that he had Covid. Five people in the home tested positive. Ten days later he’d gone...I couldn’t speak to him, I couldn’t facetime him – there was no signal. A shocking way to go, on his own...I rang the home for records. They rang back and said they held his hand. ”*

*Sara Morgan, who cared for her father at home before he was admitted and died in a care home, oral evidence*

“ I had a patient with dementia admitted for a fall, and she was medically fit for discharge but couldn't be discharged, she didn't understand what was going on and was isolated in a single room when she contracted Covid. She held my hand and looked me in the eye and told me she wanted to go home and I couldn't facilitate that...I'd never imagined myself saying that families couldn't visit their relatives and that they may have to die alone, I'd never imagined that. ”

*Emma Priest, Advanced Nurse Practitioner, Hospice of the Valleys, oral evidence*

56. For those who did get to spend final moments with loved ones, they often had to wait until the resident was diagnosed to be actively dying. At this stage precious time was lost and families often expressed distress at the difficulties they had encountered in achieving access to their loved ones prior to the last days of life.<sup>54</sup>

“ I wasn't able to care for my loved one as I would have wanted to. I wasn't allowed to visit, touch or sit by my loved one until 3 days before they passed. ”

*Unpaid carer's lived experience, Carer Wales written evidence*

“ During the pandemic, homes were able to only offer 15-minute visits for the families of someone at end of life. This caused great difficulties both for those families and for staff. ”

*Debbie South, Care Home Worker, Caron Group, oral evidence*

57. The limitations on visiting rights were exacerbated by staffing shortages and turnover in many care homes, which disrupted social activity and the close relationships that often develop between carers and residents over time. The inquiry was told of families even struggling to make contact with loved ones over the phone, due to new staff not knowing the residents in the home or simply not having time to answer the phone.<sup>55</sup>
58. Infection prevention and control measures within homes added to this disruption, often requiring residents to isolate in their rooms for long periods of time. As a consequence, many faced social isolation, often resulting in a significant decline in their mental and physical wellbeing. The use of protective masks made what little contact carers and residents had more difficult. This was particularly devastating for those with a communication difficulty or cognitive impairment who were disproportionately affected.<sup>56</sup>

*“ My mother was in a care home with Dementia and COPD and not getting to see her was horrendous. She must have thought we had abandoned her. Being left alone to isolate from COVID made her fall several times as she was being left on her own so much. She ended up with a bleed on her brain, after that she couldn't walk again properly, she kept falling backwards. ”*

*Sharon Green, whose Mother was in a care home during the pandemic and whose Aunt died of Covid after being discharged from hospital to a care home, written evidence*

*“ PPE provided a level of reassurance and protection but really scared our patients, particularly the elderly and frail and those with Dementia, struggling to make sense of day to day life. ”*

*Laura Hugman, Clinical Team Manager, Paul Sartori Hospice at Home, oral evidence*

59. While accepting the exceptional circumstances visiting restrictions were implemented in, some family members and health and social care workers retrospectively questioned the moral legitimacy of stopping people seeing the people they love, especially at the end of their lives. They also highlighted the hidden impact on many dementia residents who might now be able to see their families but may no longer know who they are.<sup>57</sup>

*“ He was emotionally starved for the last two years of his life, as probably so many other people were in care homes because their special people weren't there. I think it's inhuman, I understand why it was all done, but it's just morally wrong to stop people seeing the people they love, because it causes untold emotional damage, not only to the residents in the care homes, but the people on the other side. ”*

*Mary Mitchell, whose husband Mike died in a care home during the pandemic, oral evidence*

*“ People should have had the right to see their family and we stopped them, didn't we? We looked after some of our most elderly and vulnerable people in society when time is often short and we limited the options they had to see their family. On a personal level, I'm not so sure their human rights were maintained, they didn't have that option, they didn't have that choice. ”*

*Kim Jones, Deputy Head of Clinical Services at Hospice of the Valleys, oral evidence*

## Many care homes faced challenges accessing specialist palliative care

60. Visiting restrictions also negatively impacted access to palliative and end of life care in care homes, with some in specialist palliative care describing difficulties getting to patients due to care home interpretation of Covid guidance.<sup>58</sup> In some case this resulted in referrals to palliative care services from care homes decreasing during the pandemic.<sup>59</sup>
61. Those working in palliative care also acknowledged the challenges facing care homes keeping up-to-date with constantly changing national guidance and recognised they were doing the best they could to keep residents safe. The extreme staffing pressures and turnover in many homes also made coherent decision making in a fast moving crisis very difficult.

*“ Sometimes there was a lack of support within the care home. Quite often the management would be off sick themselves so sometimes you would have care workers on minimum wage taking all this responsibility and having to make end of life decisions over the phone when GPs weren't coming in. ”*

*Melanie Minty, Care Forum Wales, oral evidence*

*“ Once the home caught Covid you were being scrutinized, there were lots of people calling you up asking where you've been, what you've been doing, it was as if you'd have to go to prison for catching Covid, it was an awful experience for everybody. ”*

*Lisa Griffiths, Head of Services & Responsible Individual, Pen-Y-Bont Care Home*

62. Care home staff also reported challenges getting the support they needed from wider healthcare providers. This was partly due to Covid regulations and staffing pressures, but also the paring back of in-person support and rapid shift to remote consultations.<sup>60</sup> The Royal College of General Practitioners told the inquiry that regular palliative care sessions between GPs and care homes, which would have taken place in person prior to the pandemic, were impacted by both staff availability and the inability to hold face-to-face meetings.<sup>61</sup>

“ Carers from a home reported that in the first weeks of the pandemic, they were looking after a resident (who did not have any family) who was approaching end of life. When the resident then contracted Covid, they were advised by the GP to “shut the door and only have contact with the resident when fully necessary.” The GP did not visit the resident. To the carers credit, they did not leave this person alone to die, putting themselves at some personal risk with inadequate PPE (at the time) to provide comfort and care to the person. ”

*Katy Evans, Registered Social Worker, written evidence*

63. These challenges had a detrimental impact on residents’ experiences at end of life and left many care home and visiting healthcare staff feeling unable to properly support them. They also limited access to more specialist interventions in homes that often prevent escalations in care. For example, one respondent told the inquiry that some dementia nursing homes could not get support from older person’s mental health teams, leading to increased admissions to mental health wards.<sup>62</sup>
64. In the early days of the pandemic these issues were compounded by difficulties sourcing end of life medications and PPE,<sup>63</sup> alongside conflicting guidance and advice on how to deal with Covid patients in homes.

“ We had difficulties sourcing end of life medications (diamorphine/ midazolam/ hyoscine). Sometimes death happened before medications were available. Staff were fearful and felt helpless to support patients. Patients with pyrexia would receive paracetamol suppositories for elevated temperature, but staff were advised not to administer them due to the nature of the unknown virus. We were advised not to use fans due to the risks of spreading the virus. The unknown was extremely challenging. ”

*Nicola Kearney, Clinical Nurse Specialist Palliative Care, Hospice of the Valleys, oral evidence*

## Care homes felt less valued and faced challenges with advance care planning

65. The CPG heard troubling accounts of some care homes being leaned on to take patients who had or were suspected to have Covid, as well as confusion over the best place of care for them. Care home staff said such situations placed them under enormous pressure and created real concerns for residents and their families. Such experiences made them feel the care home sector and its residents had been forgotten and were seen as less valuable in the wider Government message to ‘protect the NHS’.<sup>64</sup>

“ On Wednesday 25th March a resident became poorly, a nurse called out of hours and the resident was taken to hospital which was a forty-five minute trip each way. As soon as he arrived, the home was told he wouldn't be admitted as he had Covid symptoms and was at end of life. So, he was sent back to the home two hours after leaving... The resident eventually passed away on the Friday... Care homes were taking patients untested; which is where the incidents occurred. Some homes were reportedly threatened with being reported to Care Inspectorate Wales if they did not take them. ”

Mary Wimbury, Chief Executive, Care Forum Wales, oral evidence

66. These individual and localised experiences are not reflected in national cohort analysis carried out by Public Health Wales and Swansea University Medical School into risk factors for outbreaks of Covid in care homes following hospital discharge. This study found that large homes were at considerably greater risk of outbreaks throughout the epidemic, and after adjusting for care home size, a discharge from hospital was not associated with a significant increase in risk. The report also highlighted other sources of outbreaks, including the risks to and from staff and the overlap with other community transmission. However, it did recognise that further analyses should investigate the risk where discharges were confirmed or probable cases of Covid, and also consider additional evidence on likely chains of transmission.<sup>65</sup>
67. Considering these conflicting accounts of hospital discharge into care homes and its consequences, the CPG believe further investigation on a case by case basis is needed at health board level, ensuring that the lived experiences of families and health and social care workers are fully considered.
68. Others working across health and social care told the CPG of possible instances where so called blanket or inappropriate 'do not attempt cardiopulmonary resuscitation' (DNACPR) decisions were put in place within care homes, deeming certain residents not fit for resuscitation or hospital admission.<sup>66</sup> In one instance, this allegedly happened in a dementia care setting, where many residents were potentially lacking mental capacity, and without either best interests discussion with families/significant other, or consultation with a lasting power of attorney for health and welfare.<sup>67</sup>
69. These accounts echo wider experiences from families and carers in England who told a Care Quality Commission (CQC) review of blanket DNACPR decisions for certain groups of residents in care homes. While the review found limited evidence of blanket decisions for whole categories of patients, it did identify inconsistencies in the use of DNACPR decisions in care homes, often associated with Covid related staffing/service pressures and visiting restrictions preventing proper involvement of families in decisions. It also recognised that some inappropriate DNACPR decisions could have gone unnoticed, and provided evidence of a blanket decision being applied to everyone over 80 with dementia in one care setting.<sup>68</sup>
70. The inquiry also heard positive examples where care homes and GPs held advance care planning conversations, including discussions around DNACPR decisions with residents and their families before and at the start of the pandemic, ensuring people's wishes were known and staff informed.<sup>69</sup>

“ Our GP talked to me and Mike at the start of the pandemic about a DNR and he was brilliant and talked it through with us and they had everything on hand towards the end of Mike’s life. ”

*Mary Mitchell, whose husband Mike died in a care home during the pandemic, oral evidence*

“ A Paramedic and Hospital Pack’ was developed. Should a paramedic be called, or an appropriate admission be required a summary of the individual’s choices and wishes, and essential documents such as the ACFP/DNACPR would be available to the receiving teams... Use of this pack has prevented many inappropriate admissions at the point of paramedic access, or if an appropriate admission was required the pack was returned from the hospital teams with additional information added. Admitting wards have also reported back that the pack has provided essential information and helped make the hospital admission less traumatic for the individual, particularly those living with dementia. ”

*Swansea Council care homes, written evidence*

71. Despite this local good practice, the CPG was also told how Advance Decisions to Refuse Treatment, DNACPR decisions and details of Lasting Power of Attorney (LPA) for Health & Welfare, are not accessible via an electronic patient record system at present. This means a patient may have stated that they under no circumstances would want artificial feeding tubes, or CPR for instance, but their decision may not be recordable in systems that are readily accessible to paramedics, out of hours GPs, 111 or 999 call-handlers, and hospital doctors in Wales. This meant that health services in Wales, compared to other areas of the UK, were less able to respect people’s wishes through the increased pressures of the pandemic, compared to those areas of the UK that had a system in place, like greater London.<sup>70</sup>

## Carers and specialist palliative care workers went to incredible lengths to support residents and each other

72. Despite the huge crisis that engulfed so many care homes early in the pandemic, carers and palliative care workers went to incredible lengths and made huge personal sacrifices to care for residents, especially at end of life. The inquiry heard accounts of carers spending weeks away from their families and living in care homes to help protect and support residents. There were examples of carers physically comforting and supporting people with Covid at end of life, despite inadequate PPE. In some cases, carers themselves lost their lives to Covid after infections swept through a home.

“ The biggest thing for me was that my sister in law, who worked for me at the time in the home, contracted Covid and unfortunately passed away, so on top of all that I had to try and keep the morale up with the staff, giving them as much support as possible and be there every single day, having to face the loss of our residents as well as a staff member. ”

*Lisa Griffiths, Head of Services & Responsible Individual, Pen-Y-Bont Care Home*

“ As well as supporting patients in the care homes, an evolving part of our role was being present to support the wellbeing of the carers who were facing an unprecedented challenge. Their care and compassion was inspiring. In addition, their individual and collective sacrifices in supporting their residents should never be forgotten. ”

*Dr Helen Fielding and Dr Rebecca Croft, Specialist Palliative Care consultants in Carmarthenshire, Hywel Dda University Health Board, written evidence in a personal capacity*

73. Hospice and palliative care workers went to huge efforts to support carers and residents, organising across primary, secondary and social care to ensure as many residents as possible had the support and medication they needed at end of life.<sup>71</sup> In many cases this led to new and improved ways of working, breaking down institutional silos and enabling the full spectrum of palliative care to pivot more towards the community (see Chapter 4).



## 4. Innovation delivering palliative care in the community

74. The pandemic saw a wave of collaboration, innovation and community action across the full spectrum of palliative care.<sup>72</sup> The inquiry heard many examples of established ways of working changing overnight and a shift towards palliative and end of life care becoming everybody's business across the health and social care system. In the shadow of two very difficult years, respondents spoke with pride about what they had achieved and the positive legacy it left.

### Revolution in collaboration and creative working across health and social care

75. One of the most notable changes was the rapid increase in collaboration and communication across health and social care aimed at better supporting people at end of life in their own homes and care homes. There was a widely held feeling, especially amongst those working in health boards, that "palliative care had become everybody's business" and that this approach has continued today.<sup>73</sup>

*“ The pandemic accelerated a breakdown in traditional silo working and fostered the development of creative workaround solutions to challenges presented. Close partnerships between palliative care services, community, primary care, care homes, pharmacy services and secondary care supported innovation and communication. ”*

*Betsi Cadwaladr University Health Board, written evidence*

*“ If there's any good that came out of it, it made us all work far more closely together, from the care homes, district nurses, GPs and SPC. It's broken down quite a few barriers actually. We have a daily touch point meeting we all started and I can't imagine life without it now because we all know where patients are that are imminently dying and we know where they can go and can't go. I'm hoping that whole system approach will continue. ”*

*Carys Stevens, Palliative Care CNS/Team Leader,  
Hywel Dda University Health Board, oral evidence in a personal capacity*

76. However, closer partnership working and more coordinated service delivery was not a universal experience across Wales. Some families highlighted the struggles they faced accessing coordinated care for loved ones at home (see chapter 2), while some third sector organisations expressed frustration that health boards continue silo working and not recognising and adequately resourcing the work they do in communities.
77. Where collaboration and innovation did thrive, creative working and use of virtual communications were key to enabling this whole system approach. Examples include the use of virtual multidisciplinary meetings to coordinate patient care,<sup>74</sup> co-location of specialist palliative care cover with urgent primary care and out of hours services,<sup>75</sup> and increased partnership working and shared learning with care homes.<sup>76</sup>

*“ Prior to the pandemic we had struggled to have regular multidisciplinary meetings with GPs and district nurses but now that everyone is so used to using virtual meeting platforms this is much easier and I feel the improved partnership working has been of great benefit to patients. ”*

*Dr Jo Hayes, Medical Director, Marie Curie Hospice Cardiff and Vale, written evidence in personal capacity*

78. The pandemic also saw the expansion and redeployment of roles across health and social care to ensure continued palliative care support for people. This included greater recognition of the role of Advanced Nurse Practitioners who were able to assess, diagnose and prescribe for District Nursing Teams and liaise with GPs. At the height of the pandemic hospices redeployed palliative care Clinical Nurse Specialists from their community hospice teams to be stationed in care homes in need.<sup>77</sup> The CPG also heard evidence of innovative contracts enabling the redeployment of nurses into care homes which faced staff shortages and to provide paediatric nursing capacity for children at end of life at home where services were overstretched.<sup>78</sup>

*“ Another positive development during the COVID pandemic was the development of a Service Level Agreement (SLA) which allowed NHS employed nurses to work in Local Authority or privately owned care homes to fill nursing shortages if required. This SLA remains in place. Previously NHS employed nurses were required to register with an agency before they could be employed by a care home if there were gaps in staffing. ”*

*Dr Helen Fielding and Dr Rebecca Croft, Specialist Palliative Care consultants in Carmarthenshire, Hywel Dda University Health Board, written evidence in a personal capacity*

*Multi-disciplinary staff from the day therapy service were redeployed to care for people in their own homes in a hospice at home service model. The team consisted of Health Care Workers, Advance Nurse Practitioners and Clinical Nurse Specialists. For people with an Advance Care Plan that identified home as their preferred place of care and death, around 80% of people achieved that preference.*

*Glenys Sullivan, Matron, St David's Hospice, North Wales, oral evidence*

79. The pandemic also gave rise to innovative pilots, such as the CARiAD scheme involving unpaid carers administering as-needed subcutaneous medication for breakthrough symptoms that would normally require a healthcare professional to travel to the home to administer.<sup>79</sup> The training and development of Specialist Palliative Care Paramedics has also potentially enhanced the offer of palliative care in the community, enabling paramedics to provide expeditious face-to-face assessments, symptom management and vital reassurance to patients and their families.<sup>80</sup>

## Enhanced use of technology and improved medicine distribution

80. As highlighted above, the use of video technology and virtual meeting platforms supported multidisciplinary and partnership working, which in turn benefited patient care. Widespread adoption of remote clinical assessments and telephone support for patients also had benefits, for example improved accessibility and patient choice, but also brought challenges, particularly for sensitive conversations.

*The rapid roll out and use of virtual consultations platforms (including Attend Anywhere and Accrux) and remote meetings was positive. However, this was sometimes limited by patients' IT limitations or literacy which did impact on the effectiveness. Patients and families articulated that especially at the end of life, they valued and wanted face-to-face contact with professionals.*

*Cardiff and Vale University Health Board, written evidence*

81. The CPG heard a strong body of evidence highlighting the importance of ensuring people still have the option for in-person conversations and assessments, particularly at end of life.<sup>81</sup> The group were also shown examples of hospices blending virtual and face-to-face support for patients and families as part of a programme of developing their virtual services post Covid.<sup>82</sup>
82. The development of more efficient and resilient models of end of life care medicine use and distribution were also key innovations in the delivery of palliative care in the community. These included emergency measures enabling the reuse of medicines in care homes at the height of the pandemic and the armed forces helping to distribute just in time emergency medicines to people in their homes.

“ The pandemic proved to be a catalyst for Pharmacy to focus on business continuity around access for medicines in palliative care. This included national advice to care homes on reuse of medicines in the event of shortages, the national End of Life COVID-19 Medicines Service to supply Just in Time Emergency Medicine Packs (JEMP) if needed and the development of the Community Pharmacy End of Life Care Medicines Hubs and enhanced service which has been successful and is on-going. ”

*Betsi Cadwaladr University Health Board, written evidence*

“ The work with paramedics was inspiring, and also with army personnel. It meant it was possible to get controlled drugs to a dying patient’s home within an hour, to help symptoms of breathlessness. ”

*Professor Mark Taubert, Consultant/Clinical Director Palliative Medicine, Velindre University NHS Trust, written evidence in personal capacity*

83. Another innovation was the decision for all ambulances in Wales to carry end of life care medication. This involved collaboration between multiple parties and appropriate training for all paramedics across the country. The programme continues today, enabling patients in the community to access medication in a timely manner where it isn’t readily available locally.<sup>83</sup>

## The power and potential to involve communities in palliative care

84. The community response to Covid has been widely documented in Wales<sup>84</sup> and was very evident in this inquiry. Hospices described how local people and businesses quickly organised to support them in the early days of the pandemic and the key role community members played supporting one another through the most difficult times.

“ We were overwhelmed with offers of PPE people had for other purposes, e.g. vets, beauticians. It was never hundreds, it was a few packets here and there from many sources. Mechanics donated car seat covers, hundreds of scrubs were sewn together from bedding donated to our retail stores by our volunteer army. Visors were made at the local college. We were quickly able to offer every team member a PPE box, with everything they needed to feel a bit safer. ”

*Laura Hugman, Clinical Team Manager, Paul Sartori Hospice at Home, oral evidence*

*“ Once permitted on the ward, volunteers were able to help in connecting patients with their family through digital means. Hospitals have now built up a library of approved digital equipment which can be used to support palliative care in the future. ”*

*Fiona Liddell, Helpforce Wales Manager/ Marie Curie Helper model, WCVVA*

85. The pandemic highlighted the importance of connected and collaborative communities and the key role they can play developing community led initiatives that reduce loneliness and isolation, improve health and wellbeing, and support families and carers affected by death, dying and bereavement.<sup>85</sup> These local support networks were all the more important considering that at the height of the pandemic, an additional 196,000 people in Wales became unpaid carers, many of whom cared for people towards the end of their lives.<sup>86</sup>
86. Hospices themselves are community-led organisations and the CPG heard numerous accounts of how they increased community support and coordinated with GPs, district nurses, social care workers and others to support patients and families. This is unsurprising considering the majority of hospice care in Wales is delivered in the community, including in people’s homes and care homes.<sup>87</sup> However, the pandemic response is an example of the key role hospices can play connecting communities with the whole spectrum of end of life care services, including statutory and voluntary sectors, specialist and generalist, adults and paediatrics.
87. The pandemic has also led to higher public and community awareness of certain aspects of death and dying, which could result in greater general understanding of the need to make advance plans for end of life. In evidence submitted to the inquiry by Marie Curie, survey respondents offered reflections about how the pandemic had, in their view, encouraged more willingness to talk about death, as well as positive opportunities to introduce discussions in new environments, such as the workplace.<sup>88</sup> This may present an important opportunity for Welsh Government, NHS and community partners to capture this shift in public attitudes, to promote greater death literacy, and encourage higher levels of advance planning for the end of life within the Welsh population.



## 5. Impact on health and wellbeing of workforce, families and carers

88. Covid has had a profound impact on the wellbeing of people supporting those at end of life, with the greatest burden being carried by those providing prolonged, direct and intimate patient care.<sup>89</sup> The CPG heard about the extreme challenges and pressures facing unpaid carers, social care workers, nurses and doctors, especially in the early days of the pandemic, when confusion reigned and there were widespread shortages of PPE, medication and staff. It also heard moving accounts of those who lost loved ones and their disrupted and often complex journey navigating grief in the midst of a pandemic.

### Lack of preparedness and access to PPE

89. Lack of PPE and shortages of end of life medication, especially in the early days of the pandemic, were common issues reported by health and social care workers providing palliative care in the community. In many cases palliative and social care workers were reliant on donations of makeshift PPE items such as visors, scrubs and masks from the local community and described feeling fearful for their safety.<sup>90</sup>

*“ We were fearful for our staff, because when we first found out that Covid was coming we didn't know we were going to see patients dying in corridors and staff dying, it was just so frightening really. We had to keep calm and make a plan, we had to do that. ”*

*Jina Hawkes, General Manager Community Primary Care, Hywel Dda University Health Board, oral evidence*

*“ Due to the concerns around his potential Covid symptoms they sought to quickly access PPE – but none was immediately available. After five hours of chasing, they accessed some flimsy masks and there was a real concern about staff, other residents and families. ”*

*Mary Wimbury, Chief Executive, Care Forum Wales, oral evidence*

90. Evidence from Marie Curie put these individual experiences in context, citing a study where almost half of healthcare respondents in Wales reported shortages of PPE and insufficient training in its use, affecting their ability to provide care to patients. The same study found respondents from Wales were more likely to experience medication shortages compared to other parts of the UK, with more than 40% describing scarcities in end of life meds.<sup>91</sup>

*“ On a visit one evening to the care home we were presented with over 20 COVID-19 positive patients who were being cared for in what had been the communal dining room. Many of these patients were unwell and several were actively dying (decisions had already been made regarding escalation of treatment). In an effort to provide some dignity and privacy to the most seriously unwell, staff had hung shower curtains from the ceiling using coat hangers to try and create individual bays. There was limited PPE available and it was a struggle to access EOLC medication for some residents where this had not already been put in place. ”*

*Dr Helen Fielding and Dr Rebecca Croft, Specialist Palliative Care consultants in Carmarthenshire, Hywel Dda University Health Board, written evidence in a personal capacity*

91. The Welsh Parliament Health, Social Care and Sport Committee identified lack of appropriate PPE across health and social care as one of the biggest issues during the early part of the outbreak. Evidence to the inquiry heard how staff in care homes struggled to access appropriate PPE, especially at the start of the pandemic.<sup>92</sup>

*“ Some homes had difficulty sourcing PPE initially, and staff were advised to reuse face masks by placing a paper towel underneath their mask due to limited supply. ”*

*Nicola Kearney, Clinical Nurse Specialist Palliative Care, Hospice of the Valleys, oral evidence*

92. Hospices faced similar challenges early on, however, as the pandemic progressed, the Health, Social Care and Sport Committee heard how more hospices became part of their health board's weekly supply planning process. Despite this, hospices highlighted that most were also still reliant on purchasing PPE through private suppliers (where supplies were available) and on the generous donations from their communities.<sup>93</sup>
93. At the start of the pandemic, respondents also described challenges keeping up-to-speed, communicating and keeping version control with fast changing guidance from Welsh Government.<sup>94</sup> For example, some specialist palliative care teams and care homes had very different interpretations of guidance on visiting restrictions, which at times affected access to palliative care patients in care homes.<sup>95</sup> Others in healthcare described initial problems trying to negotiate a path where primary and secondary care could work collaboratively together in community settings.<sup>96</sup>

*“ As a senior manager I felt everyone was looking to me for answers, I had nursed for 40 years and never experienced such an event.... And I didn't have the answers, I looked to Public Health Wales on a daily basis for the answers, but still the uncertainty continued. ”*

*Jane McGrath, Clinical Service Manager, St Kentigern Hospice, written evidence*

94. In Wales and across the UK, the initial shortages, uncertainty and confusion reveal a general lack of strategic planning and pandemic preparedness in palliative and end of life care which undoubtedly affected services' ability to respond and impacted on workforce health and wellbeing.<sup>97</sup> Despite these challenges, staff from across health and social care displayed incredible bravery, transforming services in a remarkably short period to best meet the massive increase in complexity and demand for end of life care.

## Detrimental impact on workforce health and wellbeing

95. The CPG heard how unpaid carers, social care workers, nurses, doctors and many others working across palliative care faced both physical and mental exhaustion resulting from their experiences during the pandemic. The word burnout was repeatedly used to describe how they felt, particularly in the context of frontline workers.<sup>98</sup>
96. Considering the scale and speed of deaths witnessed during the pandemic, the knowledge, experience and skills of those in palliative care was heavily relied upon.<sup>99</sup> The CPG heard how many felt unprepared and overwhelmed, having to contend first hand with an unknown and deadly virus driving massive increases and changes in demand for end of life care.

*“ People were very quick to say you're a palliative nurse, you deal with dying all the time, but this was nothing like I'd ever prepared for or seen before. ”*

*Emma Priest, Advanced Nurse Practitioner, Hospice of the Valleys, oral evidence*

*“ Many frontline workers are struggling with exhaustion and burnout after a very challenging two years. ”*

*Marie Curie, written evidence*

97. The long-term impact of these experiences on workforce health and wellbeing cannot be underestimated. The inquiry heard how frontline workers are more likely to present with post-traumatic stress disorder (PTSD), while anxiety and depressive symptoms are more common in the wider health and social care workforce.<sup>100</sup> There were also accounts of moral distress and moral injury<sup>101</sup> resulting from experiences during the pandemic, but also as a result of the ongoing institutional and resource constraints and pressures being felt across health and social care.<sup>102</sup>

*“ Some staff are now experiencing compassion fatigue and exhaustion. Some staff also report experiencing ‘moral injury’ when they felt compromised and unable to provide the level of care they felt was needed, for example, managing the impact of restricted visiting for patients and families towards the end of life. ”*

*Betsi Cadwaladr University Health Board, written evidence*

*“ There is a lasting legacy from Covid, people are effectively suffering from PTSD, they are physically and mentally exhausted, we’re seeing increasing numbers of people asking to change their hours and go part-time, while a lot are choosing to leave the sector. ”*

*Melanie Minty, Care Forum Wales, oral evidence*

98. The CPG also heard how the massive strains placed on those working in palliative and social care, alongside the wider societal impacts of the pandemic, led to significant stresses in people’s personal and family lives, including cases of domestic violence, guilt and anxiety at not being able to care for loved ones, and struggles taking care of children and home schooling.<sup>103</sup> There were also reports of part-time social care staff who increased their hours to support the workforce being penalised through Universal Credit and not being able to afford to buy food.<sup>104</sup>

99. For many, these stresses and strains continue today as palliative and end of life care services come under increasing pressure due to more sickness amongst staff and the acuity of patients coming through the door being more complex.<sup>105</sup> These challenges are now being compounded by the wide ranging impacts of the cost of living crisis. Some respondents told the CPG they were more worried now than they’ve ever been.

*“ Staff are really tired dealing with their own issues and we have more people who are unwell coming through the system and I think I’m more concerned now than I’ve ever been about how we’re going to cope. I can’t see that it’s going to improve anytime in my working life. ”*

*Carys Stevens, Palliative Care CNS/Team Leader,  
Hywel Dda University Health Board, oral evidence in a personal capacity*

100. In response to these concerns people highlighted the need to renew energy and focus on the health and wellbeing of the workforce, including improving access to local clinical supervision and reflection models. They also emphasised the need to prioritise workforce planning, develop recruitment and retention strategies, increase focus on innovation and sharing good practice as well as the prioritisation of education and training and support for staff.<sup>106</sup> Most importantly, respondents said that people need to feel valued and the efforts and sacrifices they have made and continue to make are properly recognised.

*“ Substantial and sustained support is required to ensure that palliative care has the workforce it needs into the future, including workforce planning, prioritisation of education and training, and remuneration. ”*

*Marie Curie, written evidence*

*“ The pandemic will have a lasting impact on the way that all staff will work moving forward. Ensuring innovative and sustainable delivery of palliative and end of life care remains a priority, in addition to supporting the well-being of staff. ”*

*Betsi Cadwaladr University Health Board, written evidence*

*“ The lessons to take forward are staff are bruised by Covid, tolerance, capacity and energy levels are low. There is a reluctance to talk about it but a need for recognition about what we’ve done... If people do not feel valued and appreciated they will leave. They need to know you care. ”*

*Laura Hugman, Clinical Team Manager, Paul Sartori Hospice at Home, oral evidence*

## Isolation at end of life and complicated bereavement

101. The CPG heard heart breaking stories of family members being isolated from one another at end of life. Such experiences inevitably had long lasting emotional effects and impacted the bereavement process, often creating complicated grief<sup>107</sup> for people who were not able to say goodbye to their loved ones in a way which they would during normal times.<sup>108</sup>

*“ I didn't get to properly care for my Mum at the end of her life and I will never be able to live that down. I just feel robbed. After she had died, the hospital refused me the right to give her a wash and permitted two male nurses to do so. In our West Indian culture this is unacceptable and humiliating. I felt robbed of what would have been my last opportunity to serve my Mum. For the last two years I've consistently had nightmares that my mother is not resting in peace. People tell you you need to get over it, but if you don't get to do the last rites, to do a Caribbean funeral, a homegoing and a nine night, which is a celebration of their life, then you're left in limbo. ”*

*Annika Nation-Reid, who cared for her mother at home before she died in hospital, oral evidence*

102. Isolation at end of life had a particular impact on the bereavement experiences of people from ethnic minority communities during lockdown, with many families unable to fulfill cultural and religious rites of passage that often involve the gathering of many families in the bereaved family's home over an extended period of time.<sup>109</sup>

*“ The impact of not being able to visit care homes was repeatedly a theme in bereavement sessions, the enormity of the individuals' sense of not coming to terms with this cannot be overemphasised. The inability to have a funeral and carry out the various religious and cultural traditions was very evident. In one particular session a relative explained, following the death of a loved one, that in their culture family would visit for three days after the death and celebrate and talk about the loved one. This could not happen and they felt they would never come to terms with that loss. ”*

*St David's Hospice Care Newport, written evidence*

103. In some cases these experiences were made worse by changes to the death certification process, where the introduction of electronic submissions meant family members did not have opportunities to ask their GP questions and resolve queries regarding the death of a loved one.<sup>110</sup> Verification of death in care homes was also subject to significant delays,<sup>111</sup> impacting on families waiting to make funeral arrangements.<sup>112</sup>

104. As highlighted earlier in this report, some people with personal and lived experience were uneasy about the use of visiting restrictions and thought that people should have been able to see their family and loved ones properly towards the end of their lives.<sup>113</sup> This perspective was reiterated by some respondents who emphasised the importance of ensuring that any future regulations of this sort are enacted in a more compassionate way with a view to the impact on the bereaved as well as those at end of life.<sup>114</sup>

*“ There will be a long-term effect on people not being able to be there for their loved ones at end of life and that’s going to cause major problems in years to come. ”*

*Carys Stevens, Palliative Care CNS/Team Leader,  
Hywel Dda University Health Board, oral evidence in a personal capacity*

105. Bereaved relatives highlighted the importance of aftercare for carers and loved ones. They described how the pandemic has been an isolating experience for all, but especially for people who have been bereaved. Key to supporting them means ensuring good palliative care extends to care for the bereaved person and this should be available to people where the person has died in their own home, regardless of whether there is specialist palliative care involvement or not.<sup>115</sup>



# Annex A: Oral evidence presented to the Cross Party Group

Rebecca McDonald, Paediatric Palliative Care Nurse, Hywel Dda University Health Board

Glenys Sullivan, Matron, St David's Hospice Llandudno

Tracy Jones, Head of Community Services and Partnerships Tŷ Hafan

Nicola Kearney, Clinical Nurse Specialist Palliative Care, Hospice of the Valleys

Rachel Mills, Care Home Worker, Hospice of the Valleys

Mary Wimbury, Chief Executive, Care Forum Wales

Kim Ombler, Care Home Worker, Glan Rhos Nursing Home

Debbie South, Care Home Worker, Caron Group

Cai's Story, lived experience, letter from Micaela, mum of Cai, read by Tracy Jones

William's Story, lived experience, read by Angharad Davies

Angharad Davies, Head of Care, Tŷ Gobaith Hope House Children's Hospices

Laura Hugman, Clinical Team Manager, Paul Sartori Hospice at Home

Lowri Griffiths, Head of Policy and Public Affairs, Marie Curie

Kim Jones, Clinical Team Manager, Hospice of the Valleys

Emma Priest, Advanced Nurse Practitioner, Hospice of the Valleys

Melanie Minty, Policy Adviser, Care Forum Wales

Lisa Griffiths, Head of Services & Responsible Individual, Pen-Y-Bont Care Home

Lynne Williams, Covid-19 Families Wales, lived experience

Professor Jonathan Bisson, Cardiff University and Director of Canopi mental health support service for NHS and social care staff

## Annex B: Written submissions, interviews and videos received

Ceridwen Hughes, Same but Different, lived experience

Alison Baynton-Power, lived experience

Jacqui Crowley, lived experience

Sharon Green, lived experience

Sara Morgan, lived experience

City Hospice Cardiff

Dr Jo Hayes, Medical Director, Marie Curie Hospice Cardiff and the Vale

Professor Mark Taubert, Clinical Director Palliative Medicine, Velindre University NHS Trust

Royal College of General Practitioners

St David's Hospice Care Newport

Jane Mcgrath, Matron, St Kentigern Hospice

Katy Evans, Registered Social Worker

Tŷ Gobaith, Hope House Children's Hospices

Swansea Council

Carers Wales

Dr Helen Fielding, Specialist Palliative Care Consultant, Hywel Dda University Health Board

Dr Rebecca Croft, Specialist Palliative Care Consultant, Hywel Dda University Health Board

Cardiff and Vale University Health Board

Fiona Liddell, Helpforce Wales Manager, WCVA

Betsi Cadwaladr University Health Board

Marie Curie

Hospice UK

Mary Mitchell, volunteer with TIDE, lived experience

Race Council Cymru

Annika Nation-Reid, lived experience

Jina Hawkes, General Manager Community Primary Care, Hywel Dda University Health Board

Carys Stevens, Palliative Care CNS/Team Leader, Hywel Dda University Health Board

Sonia Hay, General Manager Community Care, Hywel Dda University Health Board

Alison Bishop, Hywel Dda University Health Board

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