



Health, social care and sport committee consultation: impact of the Covid-19 outbreak, and its management on health and social care in Wales

A Hospice UK and Hospices Cymru response

19 May 2020

About Hospice UK

1.1 Hospice UK is the national charity for hospice care. We champion and support the work of more than 200 member organisations, which provide hospice and palliative care across the UK, so that they can deliver the highest quality of care to people with terminal or life-limiting conditions, and support their families.

About Hospices Cymru

2.1 Hospices Cymru is the collective voice of Hospice UK members in Wales. This includes the ten adult hospices and the two children's hospices in Wales. The group seeks to advance hospice care and enable better palliative and end of life care for more people in Wales.

Summary and recommendations

- Hospices have seen a move to **greater support delivered in the community or in people's homes and care homes** during this period, including to support rapid discharge from hospital at end of life for non-Covid-19 deaths. The Welsh Government should continue to monitor places of death and invest to ensure everyone gets access to good end of life care, no matter what setting, including by **facilitating specialist hospice advisory services to support professionals and care for people in all settings**.
- All frontline end of life care services, including hospices, should have **guaranteed and consistent supply of Personal Protective Equipment from their health boards** as we move to the next stage of the pandemic response.
- Hospices welcome the funding support made available to them from the Welsh Government during April-June 2020 to help meet the cost of their core clinical services. There is concern, however, about the ability to fund these core services beyond June 2020 and the funding of the broader hospice offering during a time of halted fundraising. As such, Hospice UK recommends that **funding support is made available to hospices in Wales beyond June 2020 and until hospices are able to fundraise sufficiently to maintain their services, including their core clinical services**.
- The outstanding £5.7m/quarter received by Welsh Government in Barnett consequential from support to hospices in England should be used to strengthen the hospice and wider palliative and end of life care sector's response to Covid-19.

- The full extent of need for bereavement care may not be realised during the emergency response period. The Welsh Government must **fund hospice bereavement care beyond June 2020 if hospices are to meet this need** and continue to recognise the importance of this service beyond the Covid-19 period.

Hospice care during the Covid-19 pandemic

- 4.1 Palliative and end of life care is listed as an ‘essential’ service that must be maintained by NHS Wales under current guidance during Covid-19.ⁱ
- 4.2 Hospices work in partnership with the NHS and the wider health and care sector to deliver palliative and end of life care within their communities where there is no equivalent NHS provision. As such, hospices are key to delivering what would be considered a statutory service, despite being charitable bodies. Children’s hospices in particular deliver services, such as respite care, that meet both social and health care needs.

Adapting services

- 4.3 In comparison with previous recent years, the latest estimates of the ‘excess’ death rate in Wales during the pandemic is 42 per cent, indicating that hospices are likely to be caring for additional people in comparison with previous years.ⁱⁱ Whilst many of these ‘excess’ deaths will be for people not cared for directly by hospices, such as in care homes and hospitals, hospices may be contributing to their care through specialist advice and training or through supporting bereaved families.
- 4.4 Hospice services have adapted to continue to meet the existing and increased palliative and end of life care needs within their communities. Following suit with other health and care services, hospices across Wales have pared back many of their person and family facing services to reduce transmission of Covid-19 amongst patients and staff. As a general trend, this has meant a move towards supporting people with acute symptom control and end of life care needs, as opposed to the wider, longer-term, holistic care that hospices ordinarily deliver. For example, the suspension of family days, day hospice services and respite care to ensure the sustainability of inpatient units and hospice at home services. Despite this trend, many clinics and services have managed to adapt to be delivered online or by phone, such as some occupational therapy and physiotherapy clinics or bereavement counselling sessions.
- 4.5 As a general trend Hospice at Home services and Hospice Community Nursing services have seen an increase in referrals during the Covid-19 emergency response period. This is because people who are already known to the hospice are proactively reviewing their Advance Care Plans and care preferences and noting their wishes to be cared for at home and to avoid admission to hospital, where this is possible. Hospice at home services also report increased caseloads to support people being discharged swiftly from hospital to receive end of life care in their own home; this is usually for people not previously known to the service so is in addition to the hospice existing caseload.
- 4.6 In line with the trend for more people to be cared for in their own homes, hospice inpatient units report seeing lower numbers of people during this period. This is thought to be because people are concerned about Covid-19 transmission in inpatient settings and about the restrictions on visiting, which means people are less able to be surrounded by the whole family at the end of life. Despite a ‘quieter’ period for inpatient units (as a general trend), hospice inpatient units in several areas of Wales have seen Covid-19 outbreaks. This has adversely affected the hospice through temporary closure of the hospice building for deep cleaning and staff absence for those who have contracted the virus or who are self-isolating.

4.7 Hospice activity data for the period will be available shortly, as monitoring requirements are completed. The Welsh Government will need to monitor population need for end of life care across all settings to enable planning and coordination of palliative and end of life care services to meet this need.

Hospice advisory and out-reach services

4.8 Hospices continue to offer advisory services to other health and care professionals, promoting an integrated approach to delivering expert end of life care to people in all settings. This includes maintaining their 24/7 specialist advice line to professionals and extensive support to care homes, General Practitioners and district and community nursing services and is applicable for all 'expected' deaths and Covid-19 related deaths.

4.9 Hospices tell us that their advisory services to care homes have been drawn upon extensively during the course of the pandemic, which is to be expected given that 23% of all Covid-19 related deaths to date are for care home residents.ⁱⁱⁱ In normal times, hospices manage care home case loads either by providing hands on care or advising care home staff and primary care colleagues on the appropriate palliative and end of life care needs of each person. During the Covid-19 pandemic hospices have continued to support people living in care homes who were already known as having palliative care needs as well as those who have required end of life care as a result of Covid-19 symptoms (including those people who were identified as being at the end of life prior to the pandemic and those who were not). City Hospice have told us that *“From the start we have been proactive with the staff and we have offered clinical supervision to our nursing homes. Initially care homes all did this lockdown and tried to stop us from visiting and supporting but then very quickly realised they needed the support. The nursing home I cover had 17 patient deaths in two weeks, not all covid but who knows as testing not done. Many of the staff at that home had covid.”*

Changes for the better

4.10 Hospices for the most part have reported being well-supported by their health boards and as being a valued and core part of the local health and care sector, including by being included for the first time in emergency planning. Nightingale House Hospice report positive partnership working with Betsi Cadwaladr UHB including hosting joint fit testing for PPE for hospice and health board staff, using the hospice facilities.

Barriers to effective working

4.11 Reliance on fundraised income in normal times means that planned innovation and expansion of services that could support the Covid-19 effort have in some cases been put on hold. For example, the planned expansion of St David's Hospice to a satellite site in Holyhead – which would have provided the first palliative and end of life care beds on Ynys Môn – has been postponed until alternative funding can be secured.

Personal Protective Equipment (PPE) in hospices

5.1 Hospices in Wales have been included in their local health board supply of PPE and, following some issues early on in late March, most hospices are now part of their health board's weekly supply planning process. This is in contrast to hospices in England that were only included in NHS England PPE supply chains from early May.

5.2 Hospices in Wales have told Hospice UK that supply of PPE has largely been adequate in challenging circumstances and are pleased that health boards and supply chains in the main have been responsive and helpful in ensuring what is needed reaches the frontline. Hospice UK is also grateful for the lines of communication from Public Health Wales and Welsh Government that enables us to flag where challenges with PPE may exist.

- 5.3 Whilst PPE supply from some health boards has been sufficient to meet need, such as in Aneurin Bevan UHB, most hospices are still reliant on purchasing PPE through private suppliers (where supply is available) and on the generous donations of PPE from their communities. For example, Paul Sartori Hospice at Home in Pembrokeshire noted, in addition to receiving supplies from their health board and purchasing through local suppliers, the role of volunteers in ensuring they are able to protect their staff and the people they care for:
- “We have 36 volunteers making scrub gowns, hats, wash bags and mask bands. Scrub material has been donated, patterns cut and we have also sourced material from our shop stock using sheets, duvet covers etc. which has been wash, dried, distributed to volunteers safely, collected, washed and dried again before being distributed to the nursing team.”*
- 5.4 However the very nature of core clinical services delivered by hospices, both in house and within the community, mean that hospices must continue to be regarded as a key partner for supply of PPE equipment. The safety, wellbeing and confidence of patients, families, workforce and volunteers depends on reliable and flexible deliveries of PPE. It will enable hospice services to continue to change and adapt to best respond to the needs of local communities, supporting the next stage of Wales’ framework for recovery. For example hospices have flagged that increasingly they will return to delivering Aerosol Generating Procedures (AGP), which will require a consistent supply of appropriate masks that have been properly fitted.
- 5.5 Hospice UK is also aware that approaches to supply of PPE can vary from one Health Board to another. In some places PPE drops are more infrequent, less certain and sometimes result in hospices needing to complete their requirements through other, potentially unreliable, sources. We would like to see a more uniform and established approach that results in all hospices receiving what they need.
- 5.6 While we recognise the ongoing national challenge in providing PPE across the health and social care system, we hope that as steps to recovery are taken by Welsh Government measures will be included that provide greater security and confidence to end of life care providers. Currently many hospices must take a week by week approach to PPE, which is then reflected in service planning. Some are avoiding requesting beyond immediate need to avoid depriving others in the system, Guarantees that they will be able to receive the required volume of PPE in a timely fashion will enable hospices to plan further ahead and increase their capacity to support the recovery framework.

Funding of hospice care during the Covid-19 pandemic

Hospice funding prior to covid-19

- 5.1 In normal circumstances, hospices in Wales receive the equivalent of a total of £8.4million annually from statutory sources such as the NHS, the End of Life Care Board and local health boards. This is in comparison with £28million of fundraised income per annum.^{iv}
- 5.2 Since 2009 core clinical roles in adults’ hospice care in Wales have been funded by health boards using the Welsh Funding Formula. In total, the Welsh Government funded 26 per cent of the expenditure incurred by adults’ hospices. This figure is based on an average taken across the ten adults’ hospices; there is significant variation between the levels of statutory funding received by each hospice, ranging from no funding at all to up to 49 per cent from statutory sources.^v The remaining 74 per cent (average) of funding for hospice expenditure is raised through fundraising and income generating activities such as events, charity retail and campaigns.

5.3 There is no equivalent funding formula for children's hospices in Wales. The two children's hospices operating in Wales are funded through a mixture of funding from the End of Life Care Board for all-Wales services, service level agreements with health boards and commissioned services with local authorities and health boards. As a UK trend, children's hospices receive significantly less funding as a proportion of their total expenditure than adults' hospices.^{vi} In Wales this is as low as 6 per cent for one children's hospice.^{vii}

Emergency funding during covid-19

5.4 As part of the Covid-19 emergency response, the Welsh Government has committed up to £6.3million per quarter to support hospices to continue delivering their vital services.^{viii} This funding covers the period from April to June 2020. This funding has been welcomed by the sector.

5.5 The support offered by the Welsh Government to Welsh hospices was triggered following Hospice UK's negotiations with the UK Government, which resulted in a package of support for hospices across the UK where up to £200million per quarter has been made available by the UK Government to hospices in England. This funding for hospices in England will continue beyond quarter 1 of 2020 on a monthly rolling basis, dependent on evidence of need from the hospice sector. The UK Government's funding for hospices in England triggered Barnett consequential to the other UK nations.

5.6 HM Treasury have confirmed that £12million in consequential funding will be allocated to the Welsh Government's Covid-19 budget in response to the £200million allocated to support hospices in England.^{ix} Of this £12m, £6.3m has so far been allocated to support hospices, with the remaining £5.7m still unallocated as part of the Welsh Government's Covid-19 emergency response fund.

Why the funding is needed

5.7 Hospices have been doubly impacted by the Covid-19 pandemic; an increase in the need for their services has coincided with the almost complete cessation of the fundraising activities that sustain their services.

5.8 The Welsh Government acknowledges that ensuring 'continuity' of hospice care during this period of emergency is a key part of the health and care sector's response to the pandemic. The funding is provided in recognition that hospices 'are a critical part of the NHS family, providing essential care ... and helping prevent avoidable admission to hospital'.^x

What is being funded

5.9 Welsh Government, in the Deputy Chief Medical Officer's letter to hospices allocating their funding, notes that funding is provided:

'specifically to reimburse hospices for their loss of charitable income, to protect core clinical services and to strengthen hospice bereavement support.'^{xi}

This indicates three separate purposes for the funding:

1. As a replacement for the income anticipated through fundraising in normal times
2. To maintain core clinical services during the emergency period
3. To bolster hospice bereavement services in anticipation of increased and more complex need

5.10 Funding allocations have been made only with respect to the latter two criteria: maintaining core clinical services and supporting hospice bereavement services. The majority of the funding (£1.816m) for the month of April was allocated to core service provision with the remaining funding (£284k) allocated to bereavement care. For the month of April the full possible funding of approximately £2.1m was allocated.

- 5.11 Funding has not been provided to support hospices cope with the loss of fundraised income that would ordinarily support the full breadth of holistic care offered by hospices, nor to support administrative and running costs.
- 5.12 13 adults' hospices and both the children's hospices serving Wales have been allocated funding. Of the 13 adults' hospices, ten are independent charitable hospices and the remaining three are NHS hospices with a charitable branch offering services considered to be in addition to core clinical services.
- 5.13 Funding allocations for core clinical services were calculated based on the annual costs (per hospice) of providing charitable activities, less the monthly payments to hospices from health boards as part of their service level agreements. Calculations were based on the most recent audited accounts.

Core clinical services

- 5.14 The Welsh Government define 'core clinical services' in line with the historic allocation of funding for hospices using the Welsh Funding Formula. This refers to the delivery of palliative and end of life care in hospice inpatient, community nursing and hospice at home services, overseen by specialist clinical staff.
- 5.15 This does not include care provided by Allied Health Professionals, bereavement care, social work, support for carers or any of the broader, holistic care associated with hospice care.
- 5.16 Eligibility for receiving funding to maintain core clinical services is dependent on having a service level agreement with a local health board to deliver this service under normal circumstances.

Bereavement care

- 5.17 Hospice bereavement services are not ordinarily funded from statutory sources; these services would usually be funded through grants and trusts and from the hospice's fundraising activities.
- 5.18 The funding of hospice bereavement care as part of the Welsh Government's Covid-19 support for hospices is therefore a significant recognition of the importance of this service, both during the pandemic and into the future as we see the emergence of more complex grief surfacing.
- 5.19 Hospice UK and Hospices Cymru welcome this step forward. The full scale of the bereavement care needed by people in response to Covid-19 is likely to be ongoing over the coming 6-18 months and beyond. Hospice bereavement services must be supported beyond the current funding if they are to begin to meet this future need.
- 5.20 The inclusion of bereavement care in this funding should be a first step towards recognising the role of this service as 'core' to hospice care in the post-covid landscape.

Monitoring

- 5.21 A rigorous monitoring template has been shared by Welsh Government which requires hospices to report on daily hospice (inpatient and community, including care homes) capacity and patient outcomes; monthly figures with regards patients testing positive for Covid-19; and information about the hospice's fundraising activity and reserves.
- 5.22 Hospices receiving funding to support their bereavement service are required to submit a plan to be approved by the End of Life Care Board and to share monthly activity data on bereavement services, including the number of people seen and the programme of care they have received.

Comparisons with other UK nations – and why this matters

- 5.23 The Scottish Government and the Northern Ireland Executive have agreed to pass on the full Barnett consequential funding stemming from the UK Government's support to hospices in England to hospices in their respective country. At present, the Welsh Government has

allocated 53 per cent of the consequential funding to hospices in Wales. It is not yet clear how the remaining allocation will be distributed or whether the Welsh palliative and end of life care sector will similarly be invested in through this funding.

- 5.24 The Welsh Government's funding allocation to each hospice is set out at 5.13. It sets out to ensure sufficient funding for the hospice's core clinical services without directly compensating for loss of income to the wider business. This funding formula was devised by a sub-group of the End of Life Care Board.
- 5.24.1 The UK Government have funded hospices in England based on a model devised by Hospice UK that anticipates the likely loss of fundraised income during this period, taking into account the relative effect of the pandemic on charity retail, events and donations. Using this allocation the UK Government has purchased the equivalent of 80 per cent of hospice capacity in England.
- 5.24.2 The Scottish Government is working in partnership with hospices to devise a fair and transparent means of allocating funding. This is yet to be agreed.
- 5.24.3 The Northern Ireland Executive also worked in partnership with the hospice sector to agree the appropriate level of funding for each hospice.
- 5.25 With £5.7m of the possible £12m as yet unallocated to hospice care in Wales, hospices are concerned at the underinvestment in the sector in comparison with other UK nations, particularly in relation to the inability to adapt and be agile in their response to Covid-19 due to restrictions on funding only core clinical services.
- 5.26 We recognise that hospices are a part of the wider health and care landscape delivering end of life care during this emergency period. Expertise from hospices should continue to be drawn upon and disseminated to the wider sector as part of our response to the pandemic. For this reason, we advocate for part of the £5.7m to be allocated to the End of Life Care Board to be used to invest in end of life care where this acute need or where Covid-19 is known to have had a greater effect, such as in care homes, BAME communities or for people living in more deprived areas.

Grief and bereavement

Hospice bereavement care during Covid-19

- 5.1 Psychological and emotional support is a crucial part of the holistic care that hospices provide. This includes supporting the patient, their family and their carers to prepare for an approaching death, as well as care for the bereaved. Three quarters of hospices in Wales provide bereavement care to 2,300 people each year.^{xii}
- 5.2 During the course of the Covid-19 outbreak, over 1,000 people have died in Wales having tested positive for the virus.^{xiii} We know that, as a result, hospices in Wales have seen an acute rise in demand for bereavement services. For example, at City Hospice, senior members of the clinical team are now offering bereavement support over the phone, in addition to the counselling provided by bereavement counsellors, to meet this rise in demand.^{xiv}
- 5.3 Across the UK, we have seen hospices devise innovative solutions to continue offering bereavement support that enable social distancing measures. For example, Children's Hospices Across Scotland (CHAS) have launched a virtual children's hospice to provide children with life-limiting conditions and their families with bereavement and other forms of support during this crisis.^{xv} Similarly, St Helena Hospice in Essex have partnered with a home care provider to provide psychological support to patients and families in the comfort of their own homes via the creation of a virtual ward.^{xvi}

Visiting loved ones at the end of life

- 5.4 Whilst Welsh Government guidance state that visiting someone at the end of life should be supported where possible,^{xvii} hospices have had to implement restrictions on visitors to protect their vulnerable patients, the staff that care for them, and reduce the risk of the virus spreading. These are essential measures but will invariably increase the number of people needing bereavement support and the complexity of their grief.
- 5.5 Hospices are reporting that more patients are choosing to be cared for by hospice at home services due to these visitation restrictions in clinical settings. For example, Severn Hospice has told us that:
- “The patients that we would normally admit for symptom control are in many cases choosing not to be admitted to our wards and so we have bolstered our community services so that we can support these patients with greater complexity of need at home.”*
- 5.6 This is a trend we have seen across the UK, for example, St Leonard’s Hospice in York and Wirral Hospice have both seen a 50 per cent increase in hospice at home referrals, including end of life care for COVID-19 patients. Meeting this increased, changing demand requires service redesign and resource. For example, Dr Kershaw’s Hospice in Oldham have redeployed all their nursing staff and medical resources to be community facing, with view to treble the number of patients who can be cared for in their own homes at end of life.

Funerals

- 5.7 At an already challenging time, significant changes to the ways in which funerals must be conducted place further restrictions on the bereaved.
- 5.8 The overarching advice from Welsh Government is that people must only attend the funeral of their closest family and friends, and only if they have been invited, are not symptomatic or considered vulnerable to the virus, and attendance would not involve extensive travel.^{xviii} In addition, everyone attending a funeral – whether at a crematorium, place of worship, or cemetery – must take reasonable measures to stay 2 metres away from people they do not live with or care for.^{xix}
- 5.9 We know that having to adapt such meaningful, important ceremonies will impact the bereaved, and that hospices will play a central role in supporting their local communities in coming to terms with these changes both over the course of this pandemic and after it subsides.

For further information

6. Please contact Policy and Advocacy Manager (Wales), Hospice UK.

ⁱ <https://gov.wales/sites/default/files/publications/2020-05/maintaining-essential-health-services-during-the-covid-19-pandemic-summary-of-services-deemed-essential.pdf>

ⁱⁱ Financial Times ‘Excess UK deaths in Covid-19 pandemic top 50,000’, 12 May 2020

ⁱⁱⁱ <https://gov.wales/notifications-deaths-residents-related-covid-19-adult-care-homes-1-march-8-may-2020-html>

^{iv} Hospice UK (2018). ‘Hospice care in Wales 2018’.

^v Hospice UK (2019) ‘Hospice Accounts 2019’

^{vi} Hospice UK (2019) ‘Hospice Accounts 2019’

^{vii} Ty Hafan (2019) ‘Roundtable: Children’s hospice funding in Wales’.

^{viii} <https://gov.wales/minister-announces-ps63-million-hospices-wales-during-covid-19-outbreak>

^{ix} <https://www.parliament.uk/business/publications/written-questions-answers-statements/written-question/Commons/2020-04-27/40626/>

^x <https://gov.wales/minister-announces-ps63-million-hospices-wales-during-covid-19-outbreak>

^{xi} Letter from Prof Chris Jones, Deputy Chief Medical Officer to hospices eligible for Welsh Government support, 22 April 2020.

^{xii} Hospice UK, *Hospice care in Wales 2018*

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- xiii Public Health Wales, *Rapid COVID-19 surveillance*, <https://public.tableau.com/profile/public.health.wales.health.protection#!/vizhome/RapidCOVID-19virology-Public/Headlinesummary>
- xiv <https://www.cityhospice.org.uk/coronavirus-news-advice/coronavirus-pandemic-coping-with-grief-and-loss/>
- xv <https://www.chas.org.uk/news-articles/chas-launches-the-uks-first-virtual-childrens-hospice>
- xvi <https://www.sthena.org.uk/news-publications/news/hospice-partners-with-home-care-provider-to-support-end-of-life-patients-in-virtual-ward>
- xvii <https://gov.wales/hospital-visiting-during-coronavirus-outbreak-guidance>
- xviii Welsh Government, *Guidance to local authorities on the impact of the Health Protection (Coronavirus Restrictions) (Wales) Regulations 2020 on funerals*, <https://gov.wales/sites/default/files/publications/2020-04/covid-19-guidance-on-funerals.pdf>
- xix Welsh Government, *Health Protection (Coronavirus Restrictions) (Wales) Regulation 2020*