

### Funding and access to hospice care in Wales

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# Funding and access to hospice care in Wales

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### **Executive Summary**

#### Palliative and end of life care in Wales

The growing number of elderly people resident in Wales, coupled with challenges within social care regarding recruitment and retainment of staff are placing increased supply and demand pressures on palliative care resources (Skills for Care, 2019; Welsh Government, 2017). Palliative care referrals increased significantly due to comorbidities associated with COVID-19, and there have been calls for further investment by Welsh Government to address palliative care workforce issues (Bryer et al., 2022; Fenton et al., 2022; Rawlinson et al., 2021). There are various models of palliative care used in Wales, including hospice at home, hospice in-patient care and a combination of approaches (Luta et al., 2021; Mann et al., 2019).

In Wales, the End of Life Implementation Board (Welsh Government, 2017, 2021) has been set up to provide a national, one Wales approach to end of life care, providing leadership and peer support. The End of Life Implementation Board acts as a forum to drive forward change and oversee the efforts of Health Boards to deliver the Welsh Government vision of improving end of life care in Wales (Welsh Government, 2017).

#### Purpose of this report

This report provides a high-level analysis of reported income of hospices in Wales, together with illustrative case studies of providing hospice care for eight patients in North Wales. This report highlights the important role hospices have in providing care and reducing pressures on hospital resources in Wales.

#### Access to end of life care funding across Wales

Hospices in Wales have historically received public funding from a range of sources. Some hospices have clear commissioning arrangements or Service-Level Agreements with Health Boards that contribute to core services such as inpatient beds or hospice at home services, while others do not. Since 2008, there has been a level of funding provided to hospices across Wales through Welsh Government following the Sugar review (Sugar et al., 2008). This meant that some hospices were then in receipt of funding from both Local Health Boards and the Welsh Government, which made up their total funding. In 2016, The Welsh Government transferred responsibility for all funding to Health Boards under a ring-fenced arrangement.

#### Our objectives

- To review the level of statutory funding for each adult hospice in Wales for the year 2019 (pre-COVID-19 pandemic), using publicly available accounts data from Companies House.
- 2) To calculate and forecast the number of hospice beds required in Wales in accordance with the Specialist Palliative Care Funding Formula for Wales (Finlay, 2009).
- 3) To compare and contrast the costs of end of life care for hospice service users through illustrative case studies obtained from work with Hosbis Dewi Sant and hospital end of life care costs in Wales.

#### **Findings**

There is variation in statutory funding between hospices across Wales. Statutory funding as a proportion of hospice care expenditure across Wales in 2019 ranged from 10% to 71%. Statutory funding as a proportion of hospice care expenditure in North Wales ranged from 15% to 19%, while in South Wales and Powys, the proportions ranged from 10% to 71%. The average statutory funding proportion across Wales was 30%. This highlighted a strong dependence on charitable donations to supplement the statutory income in those hospices not directly managed and financed by the NHS. Hospices in Wales can reduce pressures on public expenditure through their integrated financing models, as opposed to hospital-based end of life care fully funded by public funds through Local Health Boards.

Using the Specialist Palliative Care Funding Formula for Wales in conjunction with the latest Welsh population estimates, we calculated a current shortfall of 114 hospice beds in Wales (Finlay, 2009; Welsh Government, 2022b). Applying the formula indicates a current need for a total of 211 hospice beds in Wales. As of 2018, there were only 97 inpatient adult hospice beds in Wales (Hospice UK, 2018). This number does not account for children and young person hospice beds.

The cost of end of life care delivered by hospices and hospitals in Wales are presented through illustrative case studies for eight patients who received care in Hosbis Dewi Sant. The cost for a hospice patient staying for fourteen days ranged from £5,131 to £6,332, with a mean cost of £5,708 per patient. The cheapest hospital-based option in Betsi Cadwaladr University Health Board (BCUHB) for the same period was £6,860. Significant public expenditure savings can be achieved through increased utilisation of hospice-based care when considering the average statutory contribution to hospices is just 30%. With hospices contributing the other 70% of the cost of care through raising their own funds, ultimately reducing public expenditure through the co-funding model.

#### Recommendations

- Hospice funding should be reviewed in Wales, to better align funding allocations across Health Boards to reflect population density, urban and rural settings and any other services available.
- Based on efficiency and equity arguments, increase funding to provide the best support for complex case individuals with Palliative care needs.
- To explore patterns in patient preferences for end of life care and to configure services accordingly.
- End of life care needs to be well represented at Health Board level across all Health Boards in Wales. This would reflect better connectedness between acute care, social care and the third sector in Wales.
- Hospice staff are well placed to contribute to teaching future medical and nursing staff and students to support a better environment in hospitals at the end of life.

#### Future research

 Future research should investigate the quality of tailored end of life care in hospice services throughout the whole of Wales with an emphasis on cost-

- benefit to the wider society, including opportunity cost factors such as the impact on productivity of family carers in the wider economy.
- Collection of detailed costs for hospice and hospital-based end of life care would allow future economic analyses, including demand forecasting and the modelling of service provision.

## **Key messages**

- Hospices in Wales provide complex end of life care beyond that provided by the NHS.
- As hospices are only partly publicly funded, they provide a cost saving approach to palliative and end of life care, as opposed to NHS care which is fully publicly funded.
- There is an estimated shortfall of 114 adult hospice beds in Wales.
- The average statutory contribution to hospice care in Wales is just 30%.

### Introduction

#### Hospice care

Hospice care aims to improve the quality of life and wellbeing of adults, young people and children who have terminal illnesses (Dreamscape and Hospice UK, 2023; National Association for Hospice at Home, 2023; The Kings Fund, 2018). Hospice care places a high value on dignity, respect, and the wishes of the person at the end of their life. It aims to look after their medical, emotional, social, practical, psychological, and spiritual needs and considers the needs of the family and carers (National Health Service (NHS), 2022). Hospices are places where terminally ill people can be cared for in calm, patient-centred environments at the end of their life (Youngwerth & Minton, 2023). Hospice at home services aim to enable patients with advanced illness to be cared for at home, and to die at home if that is their preference (Barker et al., 2017; Wheatley & Baker, 2007). Hospice care may be provided to prevent admission to or to facilitate discharge from hospital inpatient care (National Association for Hospice at Home, 2023). Hospices also provide respite care, which can be defined as taking over the care normally provided by informal family carers to provide relief for the carer (Shaw et al., 2009).

A systematic review including 34 studies from across the UK and Ireland found that patients and carers valued context-specific hospice service components, which individually and collectively contribute to improvements in quality of life (Hughes et al., 2019). Patients and carers valued the availability of services. There were disparities identified in the availability of services (commonly associated with geographical variations). Having local services was especially important for those lacking social support at home. The Hughes et al (2019) systematic review highlighted gaps in service provision in meeting the social needs of carers (Hughes et al., 2019).

There is little available published literature on hospice costs. One study identified that hospital costs are the largest cost element of end of life care. The cost for the last 90 days of care presented in 2014 was £4,580 (adjusted to July 2023 prices, this figure would be £5,998). Most of this cost was driven by emergency treatment in the final week of life as patient conditions deteriorate (Mitchell et al., 2020).

The post-pandemic cost of living crisis has led to hospices operating in an increasingly difficult environment. Hospices are anticipated to face additional costs of £115 million in 2023. With rising energy and staff costs being the two largest factors. Hospice energy bills are set to increase by £29 million over the next year. Furthermore, 86% of hospices in the UK will have come to the end of a fixed price energy deal by the end of the year, with new deals likely to be increasing significantly in cost given current global events (Dreamscape and Hospice UK, 2023).

There is a need to consider the future of hospice funding as the cost of living crisis is placing increased pressure on donors, of which hospice funding is largely reliant (Dreamscape and Hospice UK, 2023). Clinical Commissioning Groups (CCG's) in England and Local Health Boards in Wales should work with hospices to develop funding schemes to protect funding structures for the future.

Staff development is a further issue for palliative care services as experienced staff are leaving the profession, and newer staff are reporting being too exhausted to undertake training out of hours. The lack of experienced staff leads to a deficit in peer support and a decrease in quality of care (Fenton et al., 2022).

#### Hospices in Wales

In 2022, the Welsh Government released a statement on palliative and end of life care:

"Good palliative care can make a huge difference to the quality of life for people and those who care for them, helping them to live as well as possible and to die with dignity. Anyone requiring palliative and end of life care in Wales should have access to the best possible care" (Welsh Government, 2022a) (p. 4).

Hospices have historically been a part of the Welsh healthcare system since 1979 (St David's Hospice, 2022). Hospices in Wales adhere to the National Gold Standards Framework for care, which includes advanced care planning, a process that supports individuals at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical or end of life care (The National Gold Standards Framework (GSF) Centre in End of Life Care, 2022).

In Wales, there is an End of Life Implementation Board (Welsh Government, 2017, 2021) that has been set up to provide a national, one Wales approach to end of life care, providing leadership and peer support. The End of Life Implementation Board is a forum to drive forward change and oversee the efforts of health boards to deliver the vision of Welsh Government for improving end of life care in Wales (Welsh Government, 2017).

Around 33,000 people die each year in Wales (Hospice UK, 2018). It is likely that 23,000 people (0.75% of the overall population of Wales) will have palliative care needs at any one time (Welsh Government, 2017). Projections indicate that the need for palliative care will rise over the coming years (Welsh Government, 2022a). With a growing ageing population in Wales, more people are living with multi-morbidities and frailty (Welsh Government, 2017). This means people may not necessarily follow a typical or predictable trajectory towards death and will tend to have more complex needs requiring specialist palliative care, contributing to a projected 25% increase in palliative care need by 2040 (Hospice UK, 2021).

There is a disparity between where people say they would like to die and where they die. In 2017, 60% of people in Wales died in hospital, 21% at home, 13% in care homes, and 6% in hospices (3%), psychiatric units and elsewhere (Ziwary et al., 2017). This is not aligned with where the population say they would like to die. Home was the preferred place of death (63%), followed by hospice (28%), hospital (8%) and care home (1%) (Marie Curie Cancer Care, 2013).

#### Hospice funding in Wales

Hospices have historically received public funding through different means, with some hospices having clear commissioning arrangements or Service Level

Agreements with Health Boards to contribute to core services such as inpatient beds or hospice at home. Since the Sugar review, Welsh Government has provided some hospice funding (Sugar et al., 2008). This meant that hospices were in receipt of funding from both Local Health Boards and Welsh Government, which made up their total funding. In 2016, Welsh Government transferred responsibility for all funding to Health Boards under a ring-fenced arrangement. In 2018, £5 million was awarded to hospices in Wales via statutory funding. This was £31 million less than the combined 2018 Welsh hospice revenue of £36 million (Hospice UK, 2018). In 2021, additional Welsh Government monies were awarded to Hospices on a recurring basis following the Phase 1 review of palliative and end of life care services (Welsh Government, 2021).

Hospice funding models differ in Wales, with some being fully (100%) funded and directly managed by the NHS and others funded through a combination of statutory funding and charitable donations. The statutory funding stream consists of two key components: firstly, direct funding from the Welsh Government and secondly, Service Level Agreements with local Health Boards.

There are seven Local Health Boards across Wales. BCUHB covers the whole of North Wales. The other health boards are the Aneurin Bevan University Health Board (ABUHB); Cardiff & Vale University Health Board (CVUHB); Cwm Taf Morgannwg University Health Board (CTMUHB); Hywel Dda University Health Board (HDUHB); Swansea Bay University Health Board (SBUHB), and Powys Teaching Health Board.

#### How does Welsh funding compare with that of other UK nations?

The cost of end of life care in the final year of life in England was around £3.9 billion in 2015 (Public Health England, 2017). This cost covered both NHS specialist and non-specialist services and social care. Most of the money was spent on NHS services, followed by voluntary services (including hospices) and social care services provided by local authorities. Most (but not all) hospices in England receive a proportion of their overall funding from statutory sources, including clinical commissioning groups, local authorities, and NHS England. A 2015 survey of adult and children hospices found that clinical commissioning groups contributed, on average, 30% of the total cost of care of adult hospices and 10% of the cost of care of children's hospices (Hospice UK and Together for Short Lives, 2015). Clinical commissioning group funding makes contributions ranging from less than 1% to more than 50% of total hospice care costs (Hospice UK and Together for Short Lives, 2015).

In Scotland, 50% of the running costs of the hospice service are funded by the grant for independent hospices (The Scottish Government, 2012). This allows the hospice independence in determining how they plan and develop their services while providing a core level of stability. This grant is subject to a year-on-year uplift, meaning there are fluctuations in the average percentage awarded.

In Northern Ireland in 2019/20, 32% of hospice care through Northern Ireland Hospice was funded by statutory funding (Northern Ireland Hospice, 2020).

#### A focus on hospice care in North Wales

The geography of Wales is such that there is a large variation in population density between North and South Wales. Within both North and South regions, there are urban and rural areas, with the centre of the country being more sparsely populated. South Wales is more densely populated than North and Mid Wales, with concentrations around the capital city Cardiff and the South Wales Valleys. The whole North Wales population is served by BCUHB, the biggest in Wales. See Figure 1 for a Map of the hospices in Wales.

There are three main adult hospices in North Wales providing in-patient beds, all partly funded by BCUHB:

- Nightingale House Hospice, Wrexham
- St Kentigern, St Asaph, Denbighshire
- Hosbis Dewi Sant/St David's Hospice, Llandudno, Conwy (Plus, satellite hospice in Holyhead, Anglesey)

#### A comparison with the rest of Wales

There are eight adult hospices providing in-patient beds or hospice at home services or other hospice services across the rest of Wales and West England partly funded by their respective health boards (StatsWales, 2022).

- Bracken Trust, Llandrindod Wells, Powys (Powys Teaching Health Board)
- City Hospice, Cardiff (CVUHB)
- Marie Curie Hospice, Cardiff (CVUHB)
- Hospice of the Valleys (ABUHB)
- St David's Hospice Care, Newport (ABUHB)
- Paul Sartori Foundation, Haverfordwest (HDUHB)
- Shalom House, St David's, Pembrokeshire (HDUHB)
- Severn Hospice, Shrewsbury (NHS England)



Figure 1 Locations of all hospices and palliative care services in Wales. Key: Blue locations show palliative care services within a hospital; Yellow locations show adult in-patient hospices; Purple locations show children and young people's hospices. Source: NHS Wales Executive (NHS Wales Executive, 2024).

# Objectives of this report

- 1) To review the level of statutory funding for each adult hospice in Wales using publicly available accounts data from Companies House.
- 2) To calculate and forecast the number of hospice beds required in Wales in accordance with the Specialist Palliative Care Funding Formula for Wales (Finlay, 2009).
- To compare the costs of adult end of life care for hospice service users through illustrative case studies compared with the cost of hospital bed days.

# Methodological approach

This report focuses on the costs of adult hospice care in North Wales through our illustrative case studies of eight in-patients at Hosbis Dewi Sant, Llandudno. These are compared with the costs of an equivalent in-patient stay in a BCUHB hospital.

#### Statutory funding method

The amount of funding each hospice in Wales received in 2019 was extracted from publicly available annual accounts from the Charity Commission Register in September 2022 (Charity commission for England and Wales, 2022). The financial year ending 2019 was chosen as the comparator year as it was the last financial year before the impact of the COVID-19 pandemic. The annual accounts for each adult hospice with in-patient beds in Wales were searched to identify statutory funding arrangements. Charitable expenditure was chosen as the comparator for hospice outgoings as it directly relates to expenditure on care provision. This data was then collated into an Excel spreadsheet to compute the calculations and generate the figures and tables presented in this report.

#### Formula for number of end of life care beds

A funding formula for specialist palliative care services in Wales was implemented in 2009 (Finlay, 2009) following the Sugar Report (Sugar et al., 2008). One aspect of this formula was the requirement of one hospice bed per 15,000 population. The latest population estimates for Wales were obtained, and the formula was applied to calculate the number of hospice beds there should be in Wales. To forecast the future demand for beds in Wales, the formula was applied to Welsh population forecasts for mid-2030 and mid-2045 (Welsh Government, 2022b).

#### Illustrative cost comparison through case studies

Illustrative, anonymised hospice patient data was provided by Hosbis Dewi Sant, and the costing calculations were conducted by the authors using unit costs from the Personal Social Services Research Unit (Personal Social Services Research Unit (PSSRU), 2022). These are standardised costs which allow for comparison and inform choices regarding health and social care provision in the UK. These costs were selected over hospice specific costs to allow for national comparison. It should be noted that hospice specific costs may vary from the ones presented in this analysis. In a 2017 analysis, Public Health England assumed a mean stay in an adult hospice of 14 days (Public Health England, 2017). St David's Hospice state a typical stay at their adult hospice is two weeks across complex symptom management, end of life and respite care (St David's Hospice, 2023). Therefore, the illustrative case studies presented cover a range of 14 days.

#### Results

#### Variation in statutory funding of hospices across Wales

For the year 2019, we found significant variation in the level of statutory funding of hospices via Health Boards across Wales. In North Wales, this ranged from 15% to 19%; in the rest of Wales and bordering areas of England (including Shalom House) this ranged from 10% to 71% and from 10% to 45% (not including Shalom House). There was a mean statutory funding proportion across Wales of 30%. Shalom House

may be seen as an outlier as it has significantly lower income and expenditure when compared to the other hospices in Wales. Figure 2 shows the proportion of hospice charitable expenditure funded by statutory funding agreements. Figure 3 presents the total statutory funding received by hospices in Wales in 2019. Tables A1 and A2 in Appendix 2 present the numerical data.

Some of the financial year 2018/19 accounts were filed in March 2019 and others in December 2019. There was variation in the reporting of statutory funding sources from Local Health Board and Welsh Government agreements within the annual accounts. Some accounts offered detailed breakdowns of the statutory funding channels, while others simply stated the total statutory funding. For this reason, a detailed breakdown of statutory funding from Welsh Government and Local Health Board arrangements was not possible. The total amount of statutory funding is used instead, along with the proportion. This total makes up of charitable expenditure by each hospice.

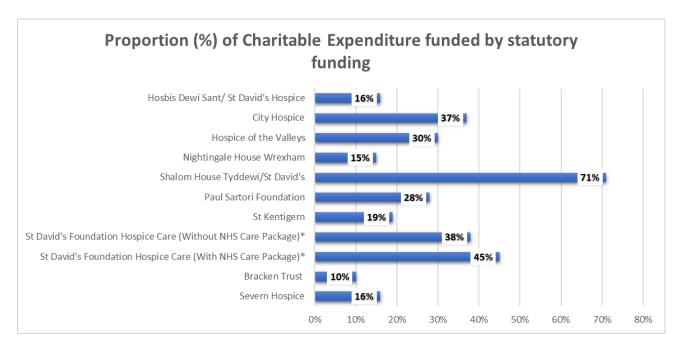


Figure 2 Proportion of Hospice Funding provided by statutory funding arrangements in 2019.

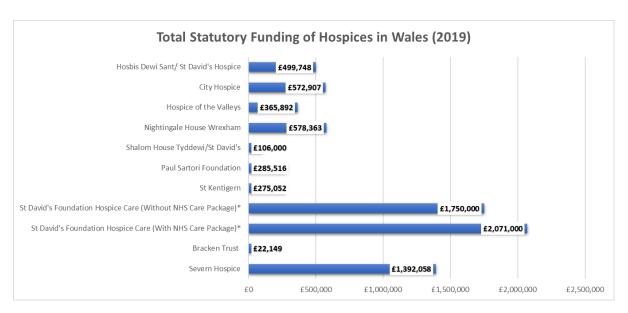


Figure 3 Total statutory funding of hospices in Wales using data from 2019.

#### Forecasting the future need for hospice beds across Wales

The 2022 Welsh Government population estimates place the Welsh population at 3,169,586 (Welsh Government, 2022a). Twenty-three thousand people (making up 0.75% of the Welsh population) will have palliative care needs at any one time (Welsh Government, 2017).

A funding formula for specialist palliative care services in Wales was implemented in 2009 (Finlay, 2009) following the Sugar Report (Sugar et al., 2008). One aspect of this formula was the requirement of one hospice bed per 15,000 population. Using the 2022 population estimate in conjunction with the formula bed requirement, there should be 211 hospice beds available across Wales. As of 2018, there were 97 inpatient hospice beds for adults across Wales (Hospice UK, 2018). There is currently an estimated shortfall of 114 adult hospice beds. This number does not include the need for child or young person hospice beds.

The funding formula for specialist palliative care was used in conjunction with the latest Welsh population projections to forecast future bed requirements. By 2030, the population of Wales is projected to increase by 2.6% to 3.25 million. We forecast a need of 217 end of life care beds across Wales. By 2045, the population is projected to increase to 3.30 million. We forecast a need of 220 end of life care beds across Wales. The growing number of people living into older age will rise and subsequently place greater pressure on the health and social care sectors. This under-provision is historical and was noted in 2008 (Sugar et al., 2008).

These forecast calculations assume current attitudes to dying at home, in hospital or in hospice (if available) remain the same and that current medical techniques remain the same.

### An illustrative cost analysis using eight patient examples from North Wales

The following eight case studies are of individuals who accessed hospice care in North Wales. Services received and costs of those services for 14 days (the mean length of inpatient stay in a hospice) are presented as examples from these typical and atypical service users.

#### Patient 1

Patient 1 is a 72-year-old female with bowel cancer who was resident at a North Wales hospice in 2022 after being admitted from an acute ward as symptoms were too complex for step-down. The treatments this patient received while at the hospice and their respective unit costs are presented in the table below (see Table 1).

Table 1 Costs of hospice care for Patient 1 over a fourteen day stay

#	Aspect of service	Number of units	Total cost	Costs over 14 days
1.	Daily Medical review Nursing needs require extra Bank Health Care Support Worker (HCSW) to support turning 24 hrs. Clinical support worker (Band 3) (Personal Social Services Research Unit (PSSRU), 2022)	£41.00 per hour X 24	£984	£13,776 for 24 hour care.  Each nurse looks after 4 patients. Therefore, the cost per patient is: £3,444 (for 24 hr care for 14 days).
2.	Complementary therapist (aromatherapy, Reiki, massage)	£45 per hour* X 4 (max)	£180	£180
3.	Pre bereavement support from counsellor Scientific Professional Staff – Counsellor (Personal Social Services Research Unit (PSSRU), 2022)	£65 per hour X 1h	£65	£65
4.	Daily senior medical review Consultant medical (Personal Social Services Research Unit (PSSRU), 2022)	£123 per hour X 7h over 14 days	£861	£861
5.	Daily physiotherapy passive movements  Community physiotherapist (Band 7) (Personal Social Services Research Unit (PSSRU), 2022)	£63 per hour X 8h over 14 days	£504	£504
6.	Social worker (adult services) (Personal Social Services Research Unit (PSSRU), 2022)	£46 per hour X 4h per week	£184 per week	£368
7.	Bariatric bed hire from a private company (£65 per day) 14 days = £910	£65 per day X14 days	£65	£910
	Total			£6,332

<sup>\*</sup>Aromatherapy session cost £45 Source: https://hollysholistics.co.uk/price-guide/

Patient study 2 is a 51-year-old male with lung cancer who was resident at a North Wales hospice in 2022 after being admitted from an acute ward as symptoms were too complex for step-down. The treatments this patient received while at the hospice and their respective unit costs are presented in the table below (see Table 2).

Table 2 Costs of hospice care for Patient 2 over a fourteen day stay

#	Aspect of service	Number of units	Total cost	Costs over 14 days
1.	Nursing Care	(See patient 1)	(See patient 1)	£3,444
2.	Complementary therapist (aromatherapy, Reiki, massage)	£45 per hour* X 4 (max)	£180	£180
3.	Daily senior medical review  Consultant medical (Personal Social Services Research Unit (PSSRU), 2022)	£123 per hour X 7h over 14 days	£861	£861
4.		£52 X 14 hours	£728	£728
5.	Daily physiotherapy passive movements  Community physiotherapist (Band 7) (Personal Social Services Research Unit (PSSRU), 2022)	£63 per hour X 8h over 14 days	£504	£504
	TOTAL			£5,717

<sup>\*</sup>Aromatherapy session cost £45 Source: <a href="https://hollysholistics.co.uk/price-guide/">https://hollysholistics.co.uk/price-guide/</a>

Patient 3 is a 96-year-old male with transverse colon cancer who was resident at a North Wales hospice in 2022 after being admitted from home for respite care. The treatments this patient received while at the hospice and their respective unit costs are presented in the table below (see Table 3). This patient will be considered a candidate for hospice at home in the future.

Table 3 Costs of hospice care for Patient 3 over a fourteen day stay

#	Aspect of service	Number of units	Total cost	Costs over 14 days
1.	Nursing care	(See patient 1)	(See patient 1)	3,444
2.	Daily senior medical review  Consultant medical (Personal Social Services Research Unit (PSSRU), 2022)	£123 per hour X 7h over 14 days	£861	£861
3.	Daily physiotherapy passive movements  Community physiotherapist (Band 7) (Personal Social Services Research Unit (PSSRU), 2022)	£63 per hour X 8h over 14 days	£504	£504
4.	Social worker (adult services) (Personal Social Services Research Unit (PSSRU), 2022)	£46 per hour X 7h	£322	£322
	Total			£5,131

Patient 4 is a 58-year-old female with multiple sclerosis (MS) who was a resident at a North Wales hospice in 2022 after being admitted from a general acute medical ward bed. The treatments this patient received while at the hospice and their respective unit costs are presented in the table below (see Table 4).

Table 4 Costs of hospice care for Patient 4 over a fourteen day stay

#	Aspect of service	Number of units	Total cost	Costs over 14 days
1.	Nursing Care	(See patient 1)	(See patient 1)	£3,444
2.	Daily senior medical review  Consultant medical (Personal Social Services Research Unit (PSSRU), 2022)	£123 per hour X 7h over 14 days	£861	£861
3.	Registrar (Personal Social Services Research Unit (PSSRU), 2022)	£52 X 14 hours	£728	£728
4.	Community physiotherapist (Band 7)(Personal Social Services Research Unit (PSSRU), 2022)	£63 per hour X 8h over 14 days hours	£504	£504
5.	Social worker (adult services) (Personal Social Services Research Unit (PSSRU), 2022)	£46 per hour X 4h	£184	£184
	Total			£5,721

Patient 5 is an 85-year-old male with end-stage Chronic Obstructive Pulmonary Disease (COPD) who was a resident at a North Wales hospice in 2022 after being admitted from a general acute medical ward bed. The treatments this patient received while at the hospice and their respective unit costs are presented in the table below (see Table 5).

Table 5 Costs of hospice care for Patient 5 over a fourteen day stay

#	Aspect of service	Number of units	Total cost	Costs over 14 days
1.	Oxygen in situ at 2L/min	£36.91 1 unit	£36.91	£36.91
2.	Nursed fully in bed  Nurse (hospital) (Band 6) (Personal Social Services Research Unit (PSSRU), 2022)	(See patient 1)	(See patient 1)	£3,444
3.	Complementary therapist (aromatherapy, Reiki, massage)	£45 per hour* X 4 (max)	£180	£180
4.	Daily senior medical review  Consultant medical (Personal Social Services Research Unit (PSSRU), 2022)	£123 per hour X 7h over 14 days	£861	£861
5.	Registrar (Personal Social Services Research Unit (PSSRU), 2022)	£52 X 14 hours	£728	£728
6.	Community physiotherapist (Band 7) (Personal Social Services Research Unit (PSSRU), 2022)	£63 per hour X 8h over 14 days hours	£504	£504
7.	Social worker (adult services) (Personal Social Services Research Unit (PSSRU), 2022)	£46 per hour X 4h	£184	£184
	Total			£5,938

<sup>\*</sup>Aromatherapy session cost £45 Source: <a href="https://hollysholistics.co.uk/price-guide/">https://hollysholistics.co.uk/price-guide/</a>

Patient 6 is a 72 year old male with Metastatic Merkel Cell Carcinoma who was resident at a North Wales hospice in 2022 after being admitted from a general acute medical ward bed. The treatments this patient received while at the hospice and their respective unit costs are presented in the table below (see Table 6).

Table 6 Costs of hospice care for Patient 6 over a fourteen day stay

#	Aspect of service	Number of units	Total cost	Costs over 14 days
1.	Nursing Care	(See patient 1)	(See patient 1)	£3,444
2.	Daily senior medical review  Consultant medical (Personal Social Services Research Unit (PSSRU), 2022)	£123 per hour X 7h over 14 days	£861	£861
3.	Registrar (Personal Social Services Research Unit (PSSRU), 2022)	£52 X 14 hours	£728	£728
4.	Community physiotherapist (Band 7) (Personal Social Services Research Unit (PSSRU), 2022)	£63 per hour X 8h over 14 days hours	£504	£504
5.	Social worker (adult services) (Personal Social Services Research Unit (PSSRU), 2022)	£46 per hour X 4h	£184	£184
	Total			£5,721

Patient 7 is a 58-year-old female with Metastatic Colon Cancer who was resident at a North Wales hospice in 2022. The treatments this patient received while at the hospice and their respective unit costs are presented in the table below (see Table 7). This patient was due to go home after a medical review (22 days after being admitted).

Table 7 Costs of hospice care for Patient 7 over a fourteen day stay

#	Aspect of service	Number of units	Total cost	Costs over 14 days
1.	Nursing Care	(See patient 1)	(See patient 1)	£3,444
2.	Pre bereavement support from counsellor Scientific Professional Staff – Counsellor (Personal Social Services Research Unit (PSSRU), 2022)	£65 per hour X 1h	£65	£65
3.	Daily senior medical review  Consultant medical (Personal Social Services Research Unit (PSSRU), 2022)	£123 per hour X 7h over 14 days	£861	£861
4.	Registrar (Personal Social Services Research Unit (PSSRU), 2022)	£52 X 14 hours	£728	£728
5.	Daily physiotherapy passive movements  Community physiotherapist (Band 7) (Personal Social Services Research Unit (PSSRU), 2022)	£63 per hour X 8h over 14 days hours	£504	£504
6.	Social worker (adult services) (Personal Social Services Research Unit (PSSRU), 2022)	£46 per hour X 4h	£184	£184
	Total			£5,136

Patient 8 is a 69-year-old female with Metastatic Sigmoid Cancer who was a resident at a North Wales hospice in 2022. The treatments this patient received while at the hospice and their respective unit costs are presented in the table below (see Table 8).

Table 8 Costs of hospice care for Patient 8 over a fourteen day stay

#	Aspect of service	Number of units	Total cost	Costs over 14 days
1.	Nursing Care	(See patient 1)	(See patient 1)	£3,444
2.	Complementary therapist (aromatherapy, Reiki, massage)	£45 per hour* X 4 (max)	£180	£180
3.	Pre bereavement support from counsellor  Scientific Professional Staff – Counsellor (Personal Social Services Research Unit (PSSRU), 2022)	£65 per hour X 1h	£65	£65
4.	Daily senior medical review  Consultant medical (Personal Social Services Research Unit (PSSRU), 2022)	£123 per hour X 7h over 14 days	£861	£861
5.	Registrar (Personal Social Services Research Unit (PSSRU), 2022)	£52 X 14 hours	£728	£728
6.	Daily physiotherapy passive movements  Community physiotherapist (Band 7) (Personal Social Services Research Unit (PSSRU), 2022)	£63 per hour X 8h over 14 days	£504	£504
7.	Social worker (adult services) (Personal Social Services Research Unit (PSSRU), 2022)	£46 per hour X 4h	£184	£184
	Total			£5,966

<sup>\*</sup>Aromatherapy session cost £45 Source: <a href="https://hollysholistics.co.uk/price-guide/">https://hollysholistics.co.uk/price-guide/</a>

Table 9 Total costs to hospice over fourteen day patient stay

Illustrative patient examples	Costs to hospice
Patient 1	£6,332
(Bowel cancer)	
Patient 2	£5,717
(Lung cancer)	
Patient 3	£5,131
(Colon Cancer)	
Patient 4	£5,721
(MS)	
Patient 5	£5,938
(COPD)	
Patient 6	£5,721
(Merkell Cell Carcinoma)	
Patient 7	£5,136
(Colon cancer)	
Patient 8	£5,966
(Sigmoid cancer)	
Mean cost per patient	£5,708

#### Summary of case studies

In this report, eight North Wales hospice patients and their associated costs are presented. The mean cost of a fourteen-night stay was £5,708. The costs in our illustrative examples ranged from £5,131 and £6,332 per patient stay. These costs do not include overheads.

Comparative costs of a hospital bed day in Betsi Cadwaladr University Health Board Table 10 shows the average cost per bed day across different bed types within BCUHB. These costs include nursing, medical and pharmacy diagnostic costs. This range of bed costs are presented as BCUHB does not have any dedicated palliative care beds (Information Governance Office BCUHB, 2022).

Table 10 Costs per bed day in Betsi Cadwaladr University Health Board, 2022

Bed costs	£ per bed day	Source
General acute medical ward bed in a BCUHB hospital (2022)	£602	Freedom of Information, (Information Governance Office BCUHB, 2022).
General community hospital bed (2022)	£490	Freedom of Information, (Information Governance Office BCUHB, 2022).
Specialist palliative care bed (2022)	£767	Freedom of Information, (Information Governance Office BCUHB, 2022).

For the fourteen day stay considered in the case studies, the costs for a bed within a BCUHB hospital would range from £6,860 (General community hospital bed), £8,428 (General acute medical ward bed in BCUHB hospital) to £10,738 (Specialist palliative care bed). Each of these options would cost more than the most expensive of the illustrative case studies.

Beyond the differences in total costs associated with inpatient stays, further cost savings can be evidenced in hospice care through consideration of the proportion of expenditure borne by the public purse in each instance. If care is delivered by the NHS through a health board as in our example, then 100% of the cost of care is funded by the health board, financed by public funds. Our analysis showed hospices in Wales received a mean level of statutory income of 30% in 2019. For Hosbis Dewi Sant/St David's Hospice, this proportion was 16%. Indicating 16% of care costs in 2019 were funded by the public purse, with the other 84% being funded by the hospice themselves. Applying the 16% statutory funding figure to the mean cost of care in the illustrative case studies, the cost to the public purse is only £913 (16% of £5,708). The remaining costs are borne by the hospice themselves, saving £5,947 of public funds when compared against the cheapest hospital-based option (general community hospital bed).

If the statutory funding allocations in Hosbis Dewi Sant/St David's Hospice were aligned with the Welsh average of 30%, hospice-based care would still constitute average savings to the public purse of £5,148 (a 30% funding level would contribute £1,712 to the mean cost of care in our example).

Potentially, more statutory funded hospice beds could provide care at a lower cost and offer a more dignified and tailored level of end of life care (Dreamscape and Hospice UK, 2023)

It should be noted that these cost comparisons do not constitute a direct comparison as considerations of estate and overhead costs were not identifiable in this instance.

### Discussion

Bringing the level of statutory funding allocated to hospices in Wales into greater alignment can allow investment in hospices to increase capacity across the country, aiding in alleviating hospital resources at the end of life and reducing cost burden on public funds. Providing a consistent level of statutory funding to hospices in Wales will help mitigate financial risks faced by hospices in the current economic climate.

Hospices face the challenge of arguing for statutory funding within an NHS that is faced with unprecedented demands and linked to an overstretched social care system. Depending on fundraising, hospices have seen changing patterns of donations. At a UK level, income from major/corporate donors has declined by 14% due to COVID-19 suppressing corporate confidence (Dreamscape and Hospice UK, 2023). There was an 18% increase in small donations, but it is likely that this will not be sustained due to the current cost of living crisis. The COVID-19 pandemic reinforced how important end of life care can be for everyone. Since 2020, 72% of all donations made to hospices were for less than £30, and these accounted for 11% of donor income. While only 1% of donations are greater than £5,000, these make up 39% of hospice income in the UK. Hospice UK estimates that hospices are likely to face additional costs of £115 million throughout 2023 (Dreamscape and Hospice UK, 2023). With rising energy and staff costs being the two largest factors. Energy bills are set to increase by £29 million over the next year. 86% of hospices in the UK will

have come to the end of a fixed price deal by the end of the year, with new deals likely to be increasing significantly given current global events. The commitment to pay a living wage to hospice staff, in conjunction with the ongoing NHS pay disputes, would place a further £120 million in additional costs to hospices in the UK should the negotiations lead to a pay increase for NHS staff (Hospice UK, 2023).

There is a need for consideration of the future funding of hospices as the cost-of-living crisis places increased pressure on donors, on whom Hospice funding is largely reliant (Dreamscape and Hospice UK, 2023). The onus is now on the UK Government, CCGs in England, and Local Health Boards in Wales to work with hospices on developing sustainable funding schemes to protect palliative and end of life care across the UK. Hospices can provide potential cost-savings to the NHS, whilst also providing the opportunity for people to have planned deaths in comfortable surroundings.

### Strengths and weaknesses of the report

#### Strengths of the report

This report is the first to present the statutory funding received by adult hospices in Wales. It is intended to open debate about the future funding of hospice care in Wales.

The use of the patient case studies and the presentation of the costs of hospice care received illustrates the potential added value of bespoke end of life care offered to patients over hospital care.

#### Weaknesses of the report

Although presenting for the first time the statutory funding received by adult hospices in Wales, the comparator year chosen was 2019 to compare hospice funding in a 'business as usual' setting. The COVID-19 pandemic placed extraordinary pressures on staff and resources, and it is unclear whether the same issues impacted adult hospices in Wales differently or in the same way.

# How to design and deliver palliative care services for Wales

### The changing landscape for hospice care

Since 2017, there has been a move away from palliative care in secondary medical care settings into the home or community settings throughout the UK (Public Health England, 2017). There is a growing body of research suggesting that people would prefer to die in a hospice or in their own home than in a hospital (Barker et al., 2017; Ziwary et al., 2017).

#### Staffing issues

Staff development is an issue for palliative care services as experienced staff are leaving their professional roles, and newer staff are too exhausted to take part in out of hours training opportunities. The lack of experienced staff leads to a deficit in peer support and a decrease in quality of care (Fenton et al., 2022). Palliative healthcare

professional roles are often funded by service providers such as Macmillan and Marie Curie (Marie Curie, 2021). The commitment to pay a living wage to hospice staff, in conjunction with the ongoing NHS pay disputes, places an additional £120 million in costs to hospices in the UK should the negotiations lead to a pay increase for NHS staff (Hospice UK, 2023).

#### Palliative care models in hospice and hospital

Clinical models vary between hospices, with some having full medical teams and others having a nurse-led approach. There is a need for functioning multidisciplinary teams when providing end of life care, especially when complex care needs are considered. End-of-life care teams currently tend to consist of a combination of nurses and other medical professionals, including occupational therapists, physiotherapists, complementary therapists, doctors, and pharmacists. There are staffing issues, including problems with recruitment and retention (Skills for Care, 2019).

#### The role of hospices in training NHS staff in end of life care

People die right across hospitals on many types of wards. There is an opportunity for hospice staff, given they have sufficient capacity, to share their experience in training nursing and medical staff early on in their career.

Currently, end of life care training is not mandatory. The COVID-19 inquiry and other audits mean that end of life care will be part of conversations and future education for everyone involved, from porters to consultants.

### Comparisons

During the literature search for this report, no other reports introduced figures of funding for individual hospices within Wales or provided a detailed breakdown of end of life care costs, which made this report unique in both regards.

Hospice UK offer useful publications on their website, covering hospices across the UK. The latest Hospice UK report focusing on Wales was published in 2021 (Hospice UK, 2021). Welsh Government publishes reports on hospice/palliative care through The End of Life Implementation Board and the Palliative and End of Life Care Delivery Plan. The latest update to the Palliative and End of Life Care Delivery Plan was released in October 2022.

#### Report summary

This report highlights a variation in the way hospices are funded across Wales, specifically the proportion of charitable spend funded by statutory NHS sources. Hospices in South Wales tend to receive more statutory funding than hospices in North Wales as a proportion of their care expenditure. Statutory funding proportions for North Wales ranged from 15% to 19%, whilst in South Wales and Powys, the proportions ranged from 10% to 45%. On average, statutory funding accounted for 30% of hospice charitable spend across Wales.

Currently, there is a shortfall of 114 adult hospice beds across Wales when using the existing funding formula for specialist palliative care services in Wales in 2009 (Finlay, 2009). We highlight potential access issues that are concerning based on this current level of provision. Variations in both the number of beds and proportion

of hospice charitable spend funded from statutory sources inevitably lead to variation in access to hospice care, particularly impacting people in mid Wales, South West Wales and South Gwynedd (the more rural areas of Wales). Population forecasts predict a growing shortfall of adult hospice bed provision. Wales will need 217 hospice beds by 2030. By 2045, Wales will need 220 adult end of life care beds. These figures will change if there is a substantial shift in place of death, i.e., emphasis on hospice at home, enabling more people to die at home. The population of Wales is not expected to grow rapidly, but the number of people living into older age will rise and subsequently place greater pressure on the health and social care sectors.

The mean cost of a fourteen-night stay was £5,708. The costs in our illustrative examples ranged from £5,131 and £6,332 per patient stay over fourteen days. These costs did not include overheads. This does not account for overhead/site costs. When compared to the costs of hospital beds in BCUHB, the hospice studies are consistently lower cost while offering more complete additional therapies.

This analysis evidences the cost-savings that can be achieved through greater utilisation of hospice services, where there is significantly less reliance on public expenditure than hospital-based care.

#### Policy implications and recommendations

- Hospice funding should be reviewed in Wales, to better align funding allocations across Health Boards to reflect population density, urban and rural setting, and any other services available.
- Based on efficiency and equity arguments, increase funding to provide the best support for complex case individuals with life-limiting/terminal conditions on a cost-per-case basis.
- To explore patterns in patient preferences for end of life care and to configure services accordingly.
- End of life care needs to be well represented at Health Board level across all Health Boards in Wales. This would reflect better connectedness between acute care, social care and the third sector in Wales.
- Hospice staff are well placed to contribute to teaching future medical and nursing staff and students to support a better environment in hospitals at the end of life.

#### Future research

- Future research should investigate the quality of tailored end of life care in hospice services throughout the whole of Wales with an emphasis on costbenefit to the wider society, including opportunity cost factors such as the impact on productivity of family carers in the wider economy.
- Collection of detailed costs for hospice care would allow future economic analyses including demand forecasting and the modelling of service provision.

#### Conclusion

This report identified that there is great variation in the funding that hospices throughout Wales receive from Welsh Government. Additionally, the cost of a fourteen day stay in a specialist palliative care hospital bed was nearly £11K compared to an average of £6K for a fourteen-night stay in a hospice bed in North Wales. It is known that more tailored personal care can be given to the individual at the end of their life in a hospice setting than in a busy acute hospital. This report has demonstrated that hospice care costs less than specialised hospital care.

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### Appendix 1 Terms and abbreviations

**Aneurin Bevan University Health Board (ABUHB) -** is the local health board of NHS Wales for Gwent, in the south-east of Wales.

**Amyotrophic Lateral Sclerosis (ALS) -** is also known as Lou Gehrig's Disease, is a rare neurological disease that affects motor neurons—those nerve cells in the brain and spinal cord that control voluntary muscle movement like chewing, walking, and talking.

**Betsi Cadwaladr University Health Board (BCUHB) -** is the local health board of NHS Wales for the north of Wales.

Clinical Commissioning Group (CCG) - were created following the Health and Social Care Act in 2012, and replaced primary care trusts on 1 April 2013. They were clinically-led statutory NHS bodies responsible for the planning and commissioning of health care services for their local area. As of 1 April 2021, following a series of mergers, there were 106 CCGs in England. They were dissolved in July 2022 and their duties taken on by the new integrated care systems (ICSs).

Chronic Obstructive Pulmonary Disease (COPD) - refers to a group of diseases that cause airflow blockage and breathing-related problems. It includes emphysema and chronic bronchitis.

**COVID-19** – An infectious disease caused by the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) virus.

Cwm Taf Morgannwg University Health Board (CTMUHB) - is the local health board of NHS Wales for Merthyr Tydfil, Rhondda Cynon Taf, and Bridgend in the south of Wales.

**Cardiff & Vale University Health Board (CVUHB) -** is the local health board of NHS Wales for Cardiff and Vale of Glamorgan, in the south-east of Wales.

**Delayed Transfer of Care (DTOC)** - A delayed transfer of care occurs when a patient is ready for discharge from acute or non-acute care and is still occupying a bed. Delayed transfers of care should be minimised through effective discharge planning and joint working between services to ensure safe, person-centred transfers.

**End of life care** - is the support given in the final weeks and months of life (or for some conditions, years), and the planning and preparation for this.

**Freedom of Information (FOI)** - Freedom of information is freedom of a person or people to publish and consume information.

**Health Board (HB) -** NHS Wales delivers services through 7 local health boards and 3 NHS trusts.

**Health Care Support Worker (HCSW) -** work across a variety of settings, from mental health to children's services.

**Hospice at home -** Hospice at home services aim to enable patients with advanced illness to be cared for at home, and to die at home if that is their preference.

**Hywel Dda University Health Board (HDUHB) -** is the local health board of NHS Wales for the west of Wales.

**Integrated care systems (ICSs)** – were previously called Clinical Commissioning Groups.

**Local Health Board (LHB) -** is the policymaking, rule-making, and adjudicatory body for public health in the county or counties in its jurisdiction.

**Motor Neuron Disease (MND)** – is an uncommon condition that affects the brain and nerves. It causes weakness that gets worse over time.

**Palliative care (PC)** - is an interdisciplinary medical caregiving approach aimed at optimising quality of life and mitigating suffering among people with serious, complex, and often terminal illnesses.

**Powys Teaching Health Board (PTHB) -** is the local health board of NHS Wales for Powys in Mid Wales. PTHB is responsible for healthcare in Powys, covering the same area as Powys County Council.

**Personal Social Services Research Unit (PSSRU)** – PSSRU produce, publish and present information about health and care costs.

**Respite care** – is taking over the care normally provided by the carer to provide relief for the carer.

**Swansea Bay University Health Board (SBUHB) -** is the local health board of NHS Wales for Swansea and Neath Port Talbot, in the south-west of Wales.

**United Kingdom (UK)** – is made up of England, Scotland, Wales and Northern Ireland.

**Welsh Government** – is the devolved government of Wales (Welsh: Llywodraeth Cymru).

## Appendix 2 Proportion of Hospice Funding Tables (£ and %)

Table A1: Proportion of Hospice Funding (used for charitable expenditure) provided by statutory funding arrangements

Name of Hospice	Proportion (%) of Charitable Expenditure funded by statutory funding arrangements
Hosbis Dewi Sant/St David's Hospice	15.5%
City Hospice	37.3%
Hospice of the Valleys	30%
Nightingale House Wrexham	15%
Shalom House Tyddewi/St David's	71%
Paul Sartori Foundation	27.7%
St Kentigern	19%
St David's Foundation Hospice Care (without NHS care package)**	38%
St David's Foundation Hospice Care (with NHS care package)**	45%
Bracken Trust	10.3%
Severn Hospice	16%

<sup>\*\*</sup>Care package refers to a one-off NHS care package payment by the NHS to St David's Foundation Hospice Care in financial year 2018/19 reported in their Annual Accounts

Table A2: Total statutory funding (£'s) of hospices in Wales using data from 2019

Name of Hospice	Total Statutory Funding 2019
Hosbis Dewi Sant/St David's Hospice	£499,748
City Hospice	£572,907
Hospice of the Valleys	£365,892
Nightingale House Wrexham	£578,363
Shalom House Tyddewi/St David's	£106,000
Paul Sartori Foundation	£285,516
St Kentigern	£275,052
St David's Foundation Hospice Care (without NHS care package)**	£1,750,000
St David's Foundation Hospice Care (with NHS care package)**	£2,071,000
Bracken Trust	£22,149
Severn Hospice	£1,392,058

<sup>\*\*</sup>Care package refers to a one-off NHS care package payment by the NHS to St David's Foundation Hospice Care in financial year 2018/19 reported in their Annual Accounts

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