

# Compassionate care for all: improving community specialist palliative care for adults in north west London

Frequently asked questions (FAQs)

Service area 1: Care at home

Q: How will the new model improve care at home?

We're improving care at home by expanding services across all boroughs. Here's what will change:

The new model will provide a **7-day specialist palliative care service**, operating 8am-8pm, across all boroughs, expanding from the current 5-day service in some areas, such as Harrow. We're increasing support for care homes, in the form of training and support, to ensure residents get the right care and advice when needed.

**Hospice at Home services** will now provide 24-hour care in collaboration with your existing community care team. This includes overnight support and personalised care designed to help you stay in your home. This service will also be expanded to areas like Hammersmith & Fulham, Ealing, and Hounslow, which previously didn't have full coverage.

A **24/7 specialist telephone advice line** will be available for anyone, whether you're already known to palliative care services or new to them. This ensures that help is just a phone call away, anytime you need it. This is a change from current 24/7 specialist palliative care advice line services, which in the main only support known patients and have variation in the level of advice and support offered.

### Q: Can you tell us more about the hospice at home service?

The Hospice at Home service helps people receive care in the comfort of their own homes. It's focused on providing high-quality, compassionate care, especially for people in the final stages of life who wish to stay at home. The service includes:

- Personal care (e.g., bathing, dressing) and help with daily activities
- · Medication management and comfort care
- Overnight support, allowing carers and family members to rest
- Access to a full care team, including healthcare assistants, nurses, and palliative care consultants.

Hospice at Home is designed to ensure that patients feel comfortable and supported, working closely with your usual care team, such as GPs and district nurses.

Service area 2: Community specialist in-patient beds

Q: How will the new model improve access to inpatient beds?

Currently, there are 57 hospice inpatient beds available across north west London for patients with the most complex palliative care needs. These beds provide highly specialised care for people with complex needs in the final stages of life. Under the new model of care:

- We will keep these 57 hospice inpatient beds open, so access to specialist hospice care will remain the same
- In addition, we are introducing 46 new enhanced end-of-life care beds, which will be available across all boroughs, totalling 54 end-of-life care beds across north west London. These beds are designed for patients who need more support than can be provided at home but do not require the full level of care provided by a hospice
- This means that overall access to specialist palliative care beds will significantly increase, ensuring more people get the right care in the right setting.

These changes mean that more people will have access to the right level of care, whether at home, in a hospice, or in a dedicated care facility.

### Q: Can everyone have a hospice bed if they need one?

Hospice beds are for people with the most complex care needs at the end-of-life, and not everyone will need this level of care. But we understand that not everyone can or wants to stay at home. That's why we are adding 46 new end-of-life care beds, which offer extra support for people who don't need hospice care but can't stay at home.

Our goal is to make sure that everyone gets the care that best suits their needs—whether that's at home, in an enhanced end-of-life care bed, or in a hospice. This new model of care offers more options for more people, ensuring that the right level of support is available at every stage.

Service area 3: Hospice out-patient services, hospice day care services and well-being services (including psychological and bereavement support services for patients and families)

### Q: How will the new model improve outpatient care and well-being services?

While all boroughs already have access to hospice outpatient services and day care, we've found that some areas, like Ealing, Hounslow, and Harrow, have fewer services available. The new model of care changes this by:

- Making sure every borough has doctor and nurse-led clinics, so residents can access the care they need closer to home
- Expanding lymphoedema services (for patients with non-cancer-related swelling) in areas that currently lack this care
- Improving access to psychological and bereavement services for patients and their families, with options for face-to-face or virtual support, and group or one-on-one sessions.

Our goal is to ensure that everyone receives the same high-quality care, regardless of where they live.

We aim to make sure hospice out-patient multidisciplinary team (MDT) clinics (including but not limited to medical and nursing clinics, rehabilitation via therapists, and dedicated lymphoedema services) deliver the same core level of service. This refers particularly to the boroughs of Ealing and Hounslow where doctor and nurse led clinics are currently not available via Meadow House Hospice, as well as Harrow where there is currently a gap in provision of lymphoedema services for non-cancer patients. We propose to expand lymphoedema service provision for these non-cancer patients in Harrow.

We aim to make sure well-being services including hospice day care, family and carer practical support and education, complimentary therapies, and dedicated psychological and bereavement support services deliver a core level of service.

Particularly for psychological and bereavement support services for patients, their families, carers and those important to them which includes: a more streamlined pathway to access these services; increased personalisation of care for example offering one-to-one and group sessions, face-to-face and virtual support; and increased cultural and spiritual sensitivity to delivery of this care and support. While all boroughs currently have access to some psychological and bereavement services, this varies in level of support

### Q: Why are we consulting on these two options?

The financial and non-financial appraisal of the shortlisted options for delivering the model of care, identified the two highest scoring options as being:

- Option A: Full delivery of the proposed model of care with the suspended Pembridge Inpatient beds remaining closed
- Option B: Full delivery of the proposed model of care with the suspended Pembridge Inpatient beds reopening.

Of these two options, Option A scored highest and is therefore identified as the preferred option. In more detail:

### **Option A (Preferred):**

- Fully implement the proposed model, including 46 new enhanced end-of-life care beds, while maintaining the existing hospice beds without reopening the Pembridge Hospice inpatient beds.
- This option would be easier and quicker to implement and benefit more north west London residents as a whole.

#### **Option B:**

• Fully implement the proposed model, including 46 new enhanced end-of-life care beds and reopen Pembridge Hospice inpatient beds.

 This would require a reduction in hospice beds elsewhere and have a longer implementation timeline due to the need to recruit specialist palliative care consultants and 35 additional staff.

We are pleased that in both of these options, we are proposing to almost double the number of beds available to local residents and fill the gaps in service provision that have meant that some residents in some boroughs have a less good service. We believe this is the fair and right thing to do.

Whilst one of the two options (Option A) scored higher in the financial and non-financial appraisal to provide us with a preferred option, no decision has been made and we are seeking your views on both options to inform the final decision. This will be made after the consultation has closed and the feedback independently reviewed.

### Q: What is the cost difference between Option A and Option B?

A: To develop the pre-consultation business case (PCBC), a detailed financial appraisal was conducted to outline the overall finances and the cost difference between Option A and Option B. Option A costs £27.6 million, while Option B costs £29.7 million. The actual cost difference between the two options is £2.1 million.

# Q: Are both options financially favourable compared to the 'business as usual' option?

A: Yes, both options are financially favourable compared to the 'business as usual' option when the benefits are taken into account. Both options passed the core affordability test during the shortlisting financial assessment. Option A is £4.6 million favourable compared to the 'business as usual' option, and Option B is £2.5 million favourable.

### Q: How will you take into account if more people say they prefer one option over the other?

A: As with any public body running a consultation, we will take into account all of the feedback received based on the quality of the arguments put forward rather than numerical support for one option or another.

All feedback received will be independently reviewed and analysed by 3ST, an alliance of the voluntary and community sector across North West London who will produce a consultation outcome report.

Following receipt of the report, a decision-making business case (DMBC) will be developed that will show how views captured by consultation have informed the final proposal. The DMBC will demonstrate how the proposed change is sustainable in service, economic and financial terms and can be delivered. The DMBC will go then go through the ICB governance processes for final approval.

### Q: How will be people be able to gain access to the planned enhanced end-of-life care beds"?

A: The admission and discharge criteria for enhanced end-of-life care beds are set out in the new model of care:

- Patients should be registered with a local GP. Cases will be considered individually to ensure support is made available to those who need it, including for people experiencing homelessness
- Patients should have a life-limiting illness with a prognosis of a few months, possibly nearing the end-of-life stage
- They require enhanced palliative and 24-hour bed end-of-life care that their regular care team, like district nurses, GPs, hospice at home, social care package, or continuing health care, cannot provide
- Patients who can't or don't want to receive care at home due to medical needs, social circumstances, or lack of necessary equipment but don't meet the specific and complex specialist palliative care needs for hospice in-patient unit bed admission
- The anticipated length of stay is up to three months, but this may be less depending on the patient's needs
- Referrals for admission to these beds may come from the patient's GP, the adult community specialist palliative care team, hospice at home, nursing home, community district nursing, hospice in-patient unit, or hospital team
- Patients can be stepped up to these enhanced beds from a regular nursing or residential care home bed through referral by care home staff and the adult community specialist palliative care team
- Patients can also be stepped up to a hospice in-patient unit bed from these enhanced end-of-life care beds through referral from the community specialist palliative care team, GP, and community nursing
- The hospital or hospice in-patient unit can refer and discharge patients (step down) to these enhanced end-of-life care beds.

### Find out more about enhanced end-of-life care beds.

## Q: What is the proposed number of enhanced end-of-life care beds per borough?

A: There are currently eight enhanced end-of-life-care beds in Hillingdon. Based on this number and the population of each borough we are proposing the introduction of 46 additional end-of-life care beds meaning 54 in total.

Given the geography of north west London and availability of sites, some shared work across boroughs could be possible to give improved access for residents.

Brent	353,690	9
Ealing	380,722	9
Hammersmith & Fulham	188,103	5
Harrow	270,741	7
Hillingdon (existing beds)	315,198	8
Hounslow	300,880	7
Kensington & Chelsea	145,328	4

### Q. Why is option A the preferred option?

When we started looking at all the potential implementation options we originally identified 54. Following a robust assessment process this was narrowed down to two options that scored the highest against the agreed criteria.

Option A is the preferred option as we will be able to make the improvements and implement the new model of care quicker and will provide improved equity of access to the north west London population as a whole. The in-patient specialist hospice beds would remain as they are in option A, versus option B where the Pembridge Palliative Care Inpatient Unit beds would reopen. There are two aspects to this:

- Our analysis shows that the current 57 inpatient hospice beds that we have open are sufficient for the immediate and future needs. We would therefore need to reduce the number of beds in the other hospices in north west London, and would result in a loss of income for charitable hospices. Whilst re-opening Pembridge Palliative Care Inpatient Unit beds would improve access to residents in the immediate surrounding area, on balance it would reduce access to a broader range of the north west London population. Our travel analysis also shows that residents in the immediate area around the Pembridge Palliative Care Unit will still have better access to inpatient hospice beds that pockets of the north west London population elsewhere.
- In order to reopen the Pembridge Palliative Care Inpatient Unit beds, we need
  to recruit specialist palliative care consultant cover and 35 additional specialist
  staff. In current circumstances, where there is a national shortage of these
  really specialist staff and we have failed to recruit in the past, we believe it will
  be more difficult to implement option B and it is difficult to put a timescale to
  this.

### Q. Why is the Pembridge Palliative Care Inpatient unit not open?

The Pembridge Palliative Care Services in-patient unit has been suspended for use since the end of 2018 as a result of the inability to recruit and retain specialist palliative care consultant cover required to safely run the unit.

All other Pembridge Palliative Care Services (ie. 24/7 specialist telephone advice line, community specialist palliative care nursing day hospice services and outpatient services and other services) are unaffected and continue to operate.

NHS North West London has not made a decision to permanently close the Pembridge inpatient unit site and, together with the Central London Healthcare Trust (CLCH) who provide the service, have remained open to recruiting the specialist palliative care consultant to support the safe reopening of the in-patient unit.

We have heard from local residents there is still a strong desire for the Pembridge inpatient unit to be reopened and that options from the public for how we could reopen the unit could be more widely considered than they have been to date.

We had two meetings in late 2023 with patient representatives, CLCH and Imperial College Healthcare NHS Trust (ICHT) to discuss options for re-opening the in-patient unit. It was agreed that ICHT and CLCH would meet to discuss whether and how the two services could work together in a more integrated manner to support re-opening the inpatient unit in future with a more robust and resilient staffing model and whether joint recruitment to posts at Pembridge may be possible.

These discussions have now taken place. However, it proved very difficult to find a suitable solution and the impact of trying to do this would be significant on both providers and would risk destabilising Imperial's workforce significantly. NHS North West London is satisfied that the relevant conversations between ICHT and CLCH have taken place and no alternative solution has been deemed feasible, and that therefore the discussions have come to a close.

# Q: Please can you describe the steps that were taken to try to reopen the Pembridge Palliative Care Inpatient Unit beds?

A: Over recent years, extensive efforts have been made to recruit a Consultant in Specialist Palliative Care (SPC) to enable the reopening of the Pembridge Palliative Care Inpatient Unit. Despite these efforts, significant and ongoing barriers to recruitment, including national challenges in the specialist palliative care workforce, mean that a viable solution has not been found. Below is a timeline of key actions and their outcomes:

September 2018 – Present: Ongoing attempts to recruit a locum Consultant in SPC to cover Pembridge inpatient beds have been unsuccessful due to:

- A nationwide shortage of SPC Consultants interested in hospice-based roles.
- A lack of locums available to provide sufficient cover for safe operation.
- Difficulty securing locums willing to commit to contracts longer than three months.
- Persistent uncertainty regarding the unit's future.

2019: A strategic review of palliative care across the Tri-Borough CCGs (West London, Central London, and Hammersmith & Fulham) was conducted by Penny Hansford, former Director of Nursing at St Christopher's Hospice, South East London; as an independent reviewer. This launched a broader palliative care review programme, including Brent CCG.

2019–2020: Comprehensive public and staff engagement took place as part of the palliative care review programme. This work was paused in March 2020 due to the COVID-19 pandemic.

March–May 2021: Discussions were held with Imperial College Healthcare NHS Trust and St John's Hospice to explore cross-site SPC Consultant roles. Unfortunately, this proposal was not supported by acute colleagues who felt the

change may adversely impact their palliative consultant team by asking them to cover additional services.

May–July 2022: Internal initiatives sought to enhance the appeal of the Consultant role at Pembridge, including increasing leadership opportunities.

June–November 2023: The Consultant job description was updated to an expanded role to include community and bedded work in order to increase appeal. One application was received and subsequently appointed; however the domiciliary specialist palliative case lost their long term agency consultant in October therefore the new appointee was required to cover that role.

April 2024: Further discussions explored joint roles with Imperial College Healthcare NHS Trust. However, concerns about destabilising existing palliative care services prevented progress.

Despite exploring all feasible options, the recruitment challenges remain insurmountable in the current context. We acknowledge the impact this has on the community and understand the importance of accessible and high-quality palliative care.

### Q: What has the saving from closure of Pembridge Palliative Care Inpatient Unit been used for?

A: The funding for the Pembridge Palliative Care inpatient unit has been ring-fenced and reinvested back into community-based specialist palliative care provision, other than a small element of fixed costs for the actual Pembridge inpatient unit estate costs.

# Q: What arrangements were put in place for patients who would have gone to Pembridge Palliative Care Inpatient Unit if it had been open?

A: An arrangement is in place for patients who would have gone to the Pembridge inpatient unit to access a hospice inpatient bed in one of three other hospices providing services in north west London (St Luke's Hospice, St John's Hospice and Royal Trinity Hospice) and increased capacity for the community specialist palliative care team to support patients at home.

### Q. Are charitable hospices considered part of the private sector?

A. No, charitable hospices are not part of the private sector. They are non-profit organisations that provide essential healthcare services. While they operate independently, their services are funded by a combination of NHS and charitable funding, ensuring that patients receive care without direct costs.

#### Q. What is the difference between NHS-run and NHS-funded services?

A: NHS-run services are directly managed and operated by the NHS. Examples include:

- CNWL Hillingdon Community Specialist Palliative Care Team and Your Life Line
- CLCH Harrow Community Specialist Palliative Care Team
- CLCH Pembridge Palliative Care Services
- LNWH Meadow House Hospice (inpatient, community, and outpatient services)

NHS-funded services are services that receive some or all of their funding from the NHS. Charitable hospices receive part of their funding from the NHS and part from their own charitable fund raising with this differing by hospice.

Combined NHS and charitable funded organisations include:

- St Luke's Hospice Harrow
- Harlington Hospice
- Royal Trinity Hospice London
- St John's Hospice Hampstead

### Q: Why are some services run by charitable hospices instead of the NHS?

A: Charitable hospices often have deep roots in their communities and bring specialised expertise in palliative and end-of-life care. By co-funding these hospices, the NHS can ensure high-quality care while benefiting from the additional resources, fundraising efforts, and community support that these charities offer.

# Q: Will patients only be able to access a hospice bed within their borough or via whoever provides a hospice service for residents of their borough?

A: The new model of care proposal for hospice in-patient unit beds will deliver excellent care for all NW London residents. Irrespective of which borough they live in, should they need a specialist palliative care hospice in-patient bed they will have access to all 57 hospice in-patient beds available to north west London residents.