HOSPICE AND END OF LIFE SERVICES IN HILLINGDON

Committee name	Health and Social Care Select Committee
Officer reporting	Steve Curry, Chief Executive Officer, Harlington Hospice
Papers with report	None
Ward	All

HEADLINES

To enable the Committee to get a better understanding of the needs of residents and the services that are provided with regard to hospice and end of life services in Hillingdon.

RECOMMENDATION

That the Health and Social Care Select Committee question those present about hospice and end of life services in Hillingdon.

SUPPORTING INFORMATION

1. Current Services

In the London Borough of Hillingdon, services traditionally provided by a hospice are shared between Harlington Hospice and Central and North West London NHS Trust (CNWL). The provision and development of end-of-life care are coordinated via the Hillingdon Health and Care Partnership (HHCP).

The details of the services and their providers are as follows:

Service	Location	Provider
Community Specialist Palliative Nursing Team	Based in Uxbridge, covering the entire Borough	CNWL
24-Hour Specialist Palliative Nursing Response Team, including night visits and a 2-hour daytime response (YLL Your Lifeline)	Based in Uxbridge, covering the entire Borough	CNWL
Personal Care service for individuals in the last phase of life, including respite care for carers and Continuing Health Care (CHC)-funded care (Harlington Care)	Based in Michael Sobell House, Northwood, covering the entire Borough	Harlington Hospice
Night Hospice Service (22:00–7:00) with a nurse or healthcare assistant available in people's homes (Harlington Hospice at Home)	Based in Michael Sobell House, Northwood, covering the entire Borough	Harlington Hospice
Inpatient Hospice Service 14 beds	Michael Sobell House, Northwood	Harlington Hospice

Service	Location	Provider
Enhanced Nursing Care Beds (commissioned beds in private nursing care facilities with additional hospice-level support) (Primrose beds)	Hayes Cottage Nursing Home (2 beds) and Park Field Nursing Home, Uxbridge (6 beds)	Managed by Harlington Hospice
24-Hour Advice Line (open to the public and providing out-of-hours professional support)	Michael Sobell House, Northwood	Harlington Hospice
Children and Young People Bereavement Support (pre- and post-death support) CABS team	Lansdowne House, Harlington, and Michael Sobell House, Northwood	Harlington Hospice
HPAL Website (information on palliative care and a directory for end-of-life services in North West London for clinical staff and carers, also accessible to the public)	Online	Harlington Hospice
Adult Bereavement Support	Lansdowne House, Harlington, and Michael Sobell House, Northwood	Harlington Hospice

Due to a change in the patient record system, it has only been possible to provide a breakdown by ward of Hillingdon residents using the Harlington Hospice services since 1 January 2024. Data below is 1 January 2024 – 31 August 2024:

Ward	Clinics	Hospice at Home	Inpatients	Lymphoedema	Primrose (Care Homes) *	Psychological and Emotional Support	Wellbeing	Grand Total
Belmore		2	5	14		15	7	38
Charville		6	4	13		5	2	30
Colham & Cowley		7	6	21		10	2	44
Eastcote		6	8	16		8	6	39
Harefield Village		5	7	10		3	1	24
Hayes Town		1	1	8		12	2	24
Heathrow Villages		5	2	17		6	3	31
Hillingdon East		10	10	27		10	3	71
Hillingdon West		1	4	15		2	1	23
Ickenham & South Harefield		7	10	23		13	6	56
Northwood		3	7	22		6	2	37
Northwood Hills	1	3	4	16		4	5	29
Pinkwell		4	6	16		19	2	44
Ruislip		6	13	27		14	1	59
Ruislip Manor		4	3	13		1	1	21
South Ruislip		3	2	13		1	2	20

Ward	Clinics	Hospice at Home	Inpatients	Lymphoedema	Primrose (Care Homes) *	Psychological and Emotional Support	Wellbeing	Grand Total
Uxbridge	1	5	6	26		13	1	51
West Drayton		9	5	26		19	5	59
Wood End		8	5	8		16	2	50
Yeading		7	3	6		15		31
Yiewsley		2	1	17		10	1	30
Grand Total	**2**	**104**	**111**	**353**	**39**	**202**	**55**	**808**

* Awaiting data

2. Need for Hospice and Palliative Care in Hillingdon

HHCP partners have identified end-of-life care as a priority area for improvement, based on health system data and feedback from patients, their families, and service staff. The North West London Integrated Care Board (NWL ICB) has conducted a review of community specialist palliative care, and the new service model is currently out for public consultation. HHCP has also conducted a broader systems review of end-of-life care, including primary, general community, and acute care for individuals with palliative care needs. This report draws on the findings of both reviews.

Identifying people who could benefit from palliative care has been challenging. All health provider records use primary diagnosis coding, with few records updated as people transition from active treatment to palliative care.

2.1. Patients and Carers Feedback

In 2023, HHCP commissioned Hillingdon Healthwatch to gather feedback on end-of-life care in the Borough. While there was positive feedback on many of the services, some areas were identified where services fell short. Healthwatch summarized the issues as follows:

> "There is a lack of appropriate, timely, coordinated, and equal access to palliative and end-of-life care services, resulting in a higher than necessary utilization of A&E and urgent care services, including hospital admissions. There is also no clear model to actively case manage patients to earlier identify holistic support to improve patient care and reduce inappropriate use of the system. For patients known to services, they generally have a positive experience."

2.2. Health System Data

Harlington Hospice worked with NWL ICB palliative care commissioners to develop a set of codes for the NWL ICB WISC database to better identify individuals with palliative care needs. These codes have been used to develop the End of Life WISC dashboard.

In August 2023, the HHCP business information lead used the End of Life dashboard data to back-test patient records for 2022/23. **The findings showed that the 3,064 individuals**

identified were over six times more likely to have an emergency admission to hospital and a longer-than-average hospital stay. Spot audits of the Hillingdon Hospital Palliative Care Team caseload revealed that 71% of patients did not have an advance care plan. Without an advance care plan, individuals are less likely to receive the end-of-life care they need in their preferred setting and are more likely to have unplanned hospital admissions.

Data from the End of Life Dashboard for 2023/24 indicated that 3,771 individuals in Hillingdon would benefit from palliative care. Emergency admissions to hospital from this group totalled 2,375, equating to an average of 63 people in hospital every day.

3. Service Improvement

Feedback and data clearly indicate a need to improve the model of care. Key areas for improvement include:

- Early identification of individuals who would benefit from palliative care.
- 24/7 active care coordination and support throughout the last phase of life.
- Support that extends beyond medical needs, emphasizing a truly holistic care plan.
- Reducing inappropriate hospital admissions and over-treatment through systematic advance care planning.
- Ensuring all residents receive the same level of support, regardless of their location.

4. New Model of Care

Based on feedback and data, HHCP partners have developed a new model for end-of-life care. The vision for the new model includes:

- Ensuring that individuals at the end of their lives receive the right care at the right time in the right place through coordination and signposting.
- Embedding a systematic, person-centred approach across various services to deliver coordinated care, including acute support and proactive care planning to prevent crises and respect the wishes of clients and carers.
- Allocating clinical and administrative time to support cases and coordinate with other services to avoid delays in service delivery and manage system capacity challenges.
- Developing clear pathways that work well for staff and patients by minimising repetition and handovers.

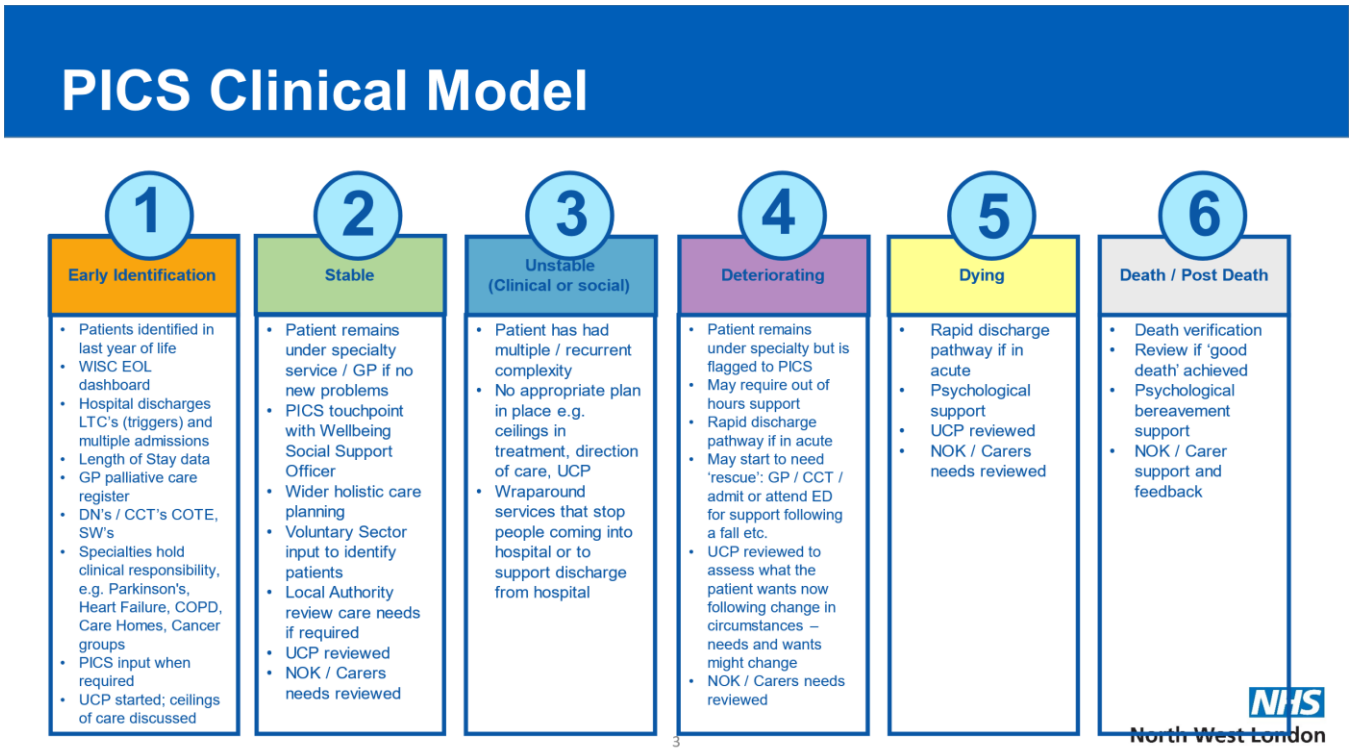
To implement this model, partners have agreed to integrate services into a single team called the Palliative Integrated Care Service (PICS). This will consolidate the individual services listed above into a single management structure to reduce duplication and maximize resource use. This will also include the Hillingdon Hospital Team. Harlington Hospice will be the lead partner responsible for the integrated services.

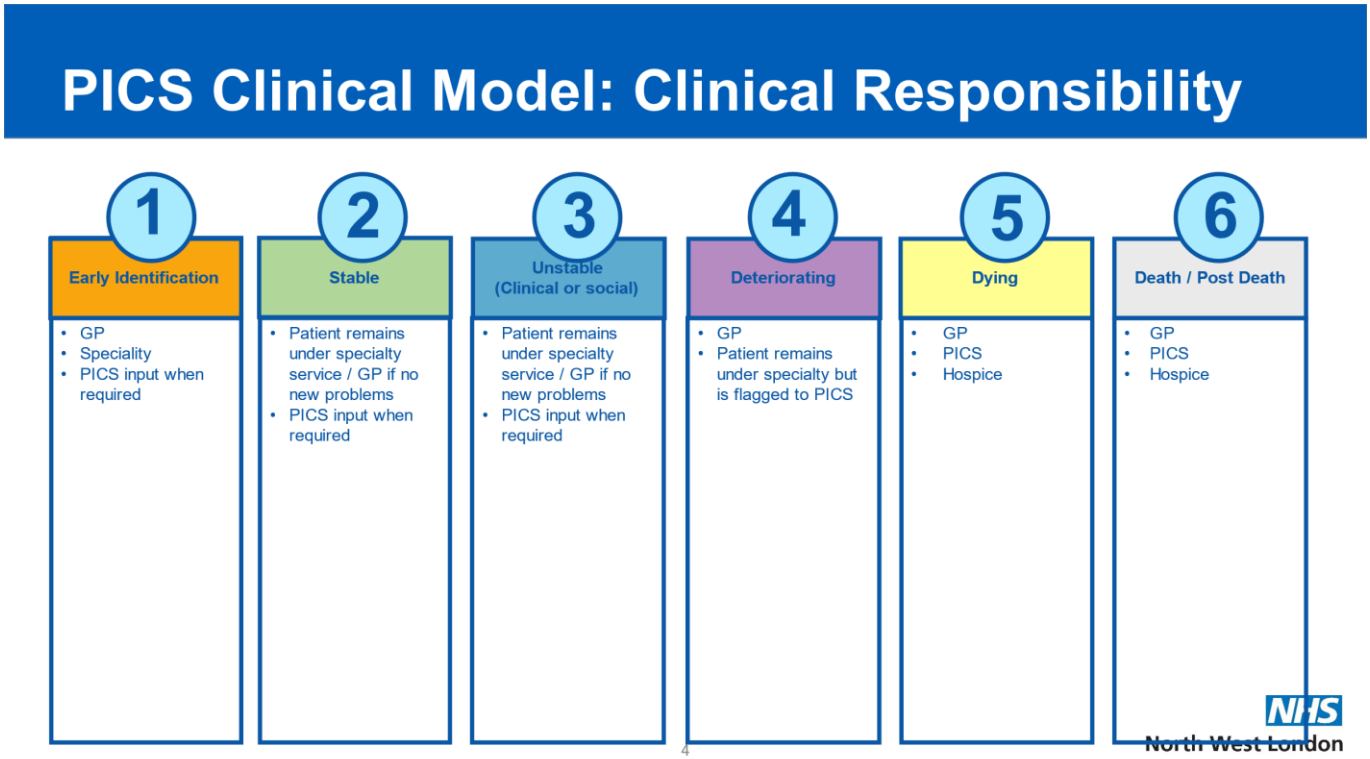
PICS will operate through a single coordination hub, with one telephone number for patients, their carers, and health and social care professionals. This will:

- Reduce time and resources spent on inter-service referrals.
- Coordinate active support for individuals needing palliative care.
- Proactively identify people who would benefit from palliative care early.
- Provide support for advance care planning and assist individuals in the last phase of life to receive care and die in their preferred setting.

This operational format is being developed alongside other HHCP integration priorities, particularly within the Neighbourhoods. A new patient pathway has been created to provide support from the PICS Hub at key points in individuals' lives.

The format of the clinical model and the assignment of clinical responsibility have been developed based on the phases of illness during the last stages of life. When there is an established relationship with a healthcare professional, this will be maintained to ensure continuity of care. PICS coordination will provide oversight and assurance that care is managed and will support and respond outside standard working hours.





5. Implementation to Date

The PICS Team has become operational, supporting patients and their families known to the Specialist Palliative Care services. This has enabled staff to train in new working patterns and test the model.

Harlington Hospice has transitioned to the same electronic patient record system used by CNWL. This change aims to enable record sharing, reduce the need for paper referrals, decrease the frequency with which individuals need to repeat their stories, and minimize administrative tasks and clinical risks associated with service transfers.

A Wellbeing & Social Support Officer has been employed by the Hospice to broaden the support offered by PICS, facilitating a whole-person and family-centred approach to care.

Project plans are in place to complete service integration before the end of the year.

6. Hospice Service Gaps

Data from Harlington Hospice shows that it currently has contact with 20% of individuals in the Borough who would benefit from end-of-life care and provides care to only 17% of Hillingdon residents who could benefit from its services. Hospice Trustees and the Executive Team are committed to expanding the services offered and have developed a new strategic vision to provide access to end-of-life care for all.

Key areas where the Hospice can enhance services in Hillingdon include increasing services that require hospice skills and expertise. The new strategy outlines plans to increase care for individuals who wish to remain and die at home and to expand hospice-managed community beds.

Harlington Hospice is implementing this strategy in phases.

6.1. Phase One - Quick Wins with Current Resources

Fast Track Continuing Health Care at Home

A pilot project to provide personal care, supported and supervised by the Hospice's medical and nursing team, was successfully completed in July 2024. This project focused on delivering personal care packages to individuals being discharged from Hillingdon Hospital and offering support to their families. Given that the need for timely discharge becomes increasingly critical as individuals approach the last weeks of life, the service has been designed to assess care needs at home, allowing for discharge on the day of referral.

Once the individual is home, the service reassesses care needs over a month to ensure the care provided is appropriate and sufficient to keep the person at home for as long as possible. Although the initial pilot was limited in scope, it is now being expanded as additional staff are recruited. Feedback has been overwhelmingly positive; all participating families indicated that they would recommend the service to others.

Additional Nurse Led Beds

Over the past year four additional beds have been opened at Michael Sobell House. These are for people that qualify for Continuing Health Care funding for nursing home care. This has provided much needed resources for people that are not suitable for mainstream Nursing home care and has increase the number of people that the hospice has supported in the ten medical lead hospice beds.

6.2. Phase Two - Service Expansion with Additional Resources

As the PICS model of care is implemented with increasing numbers of people being identified early and wholistic advance care and support plans are agreed, it will be possible to identify people that would benefit from direct admission to hospice beds. This will reduce unplanned hospice admissions, expected to reduce length of stay and provide focused specialist palliative care.

To reduce the unplanned hospice admission there will be a need for additional hospice beds. The current model of small specialist unit with the majority of costs covered by charitable fundraising income, is not sustainable care at scale. Harlington Hospice has identified a new model which combines the strengths of Hospice care with the financial viability of private nursing home provides.

Initial work with social financing organisations and Brunel University have confirmed the principles of the model. Further work on the design of the new buildings and negotiation of capital grants and funding to build or redevelop the properties.

Revenue funding will largely be via Continuing Health Care funding. NWL ICB managers have confirmed that a block contract will be given.

Partnership with Burnel University has developed; it has been agreed to explore development of the new services as an Academic Hospice. This would be embedding the services with Medical, Nursing and other health related Schools in Brunel. Plans are to providing student placements, link education facilities across classrooms, hospice services and vertical. If achieved this would

be a first for the UK.

6.3. Phase Three – Development of Additional Hospice Beds

Building the additional bedspaces will the final stage of the strategy. Identification of sites, ideally in the south, centre and north of the Borough is expected to be the biggest challenge.

7. Hospice Finances and Lansdowne House Sale

Harlington Hospice is in a similar financial situation to most Hospices in the England. Following the impact of inflation on both costs and income Harlington Hospice currently has a significate deficit. Trustees and Executives are prioritising the protection of services whilst undertaking a full financial review.

Decision to sale Lansdowne House is part of the ongoing review to reduce costs and ensure resources are allocated to meet the charities objectives. The building is under used and cannot be developed into a bedded service due to planning restrictions. Sale and relocation of the service is part of ensuring the financial security of the services.

Lansdowne House has always been a Day Hospice and has never had inpatient beds on site. Currently two of the Hospice services are run from Lansdowne House; these are:

Lymphoedema Outpatient Clinics – NHS commissioned service for primary and secondary Lymphoedema. GP referrals with individual treatment, self-treatment and support groups.

Emotional and Psychological Services – Supporting children, young people and adults with pre and post bereavement counselling and psychotherapy. Individual, family sessions and support groups. Funded from charitable sources.

With the opening of Michael Sobell House, the Harlington Hospice started to provide both of these services on this site. Reason for providing a second site was to reduce travel time for patients living in the north of the Borough.

Negotiations on relocation sites for the Lansdowne House services are taking place with partner organisations in the Borough. Travel time to the new location for the all people using the services is a key factor in the areas being explored.

The Hospice will work to have the new location in place before the sale of Lansdowne House. If this is not possible, rooms will be hired in community building for the counselling and psychotherapy services and the lymphoedema service will be provided in people homes.

Funding released from the sale of Lansdowne House can only be used for the provision of hospice care in the Borough.

On a new location for the Lansdowne House services has been established, information on the relocation of services will be communicated individually with everyone that uses the services. GPs and other Hillingdon partners will also be informed directly by the hospice and via changes to the HHCP service pathways.

8. Conclusion

Harlington Hospice is dedicated to providing comprehensive, compassionate end-of-life care for the residents of Hillingdon. Through the expansion of services, the implementation of new care models, and a commitment to continuous improvement, the hospice aims to ensure that all individuals in the borough have access to the care and support they need at the end of life.

By focusing on collaboration, innovation, and community engagement, Harlington Hospice is well-positioned to meet challenge of the growing needs of the community and to provide high-quality care for all who need it.