

The Margaret Centre, Whipps Cross Hospital, London E11 and Local Palliative and End of Life Care Services

Evidence Submitted to the Commission on Palliative and End of Life Care by Action4Whipps (A4W)

Introduction

1. The Margaret Centre is a much valued specialist palliative care and end of life care unit which is part of Whipps Cross Hospital in Leytonstone, London E11. Its future existence is currently uncertain. Action4Whipps (A4W) is a non-party political community group, made up of local people and service users, which has been campaigning for the last five years to secure the future of the Margaret Centre and improved community services, as part of the redevelopment of Whipps Cross hospital.

The Margaret Centre and the state of local community services

2. The Margaret Centre is a free-standing 11 bed specialist palliative care unit which is located on the site of Whipps Cross hospital. It was founded in the 1980s after a campaign by medical and other professional staff, supported by local charities, who saw the unmet needs of patients and their families when dying on a general medical ward. It mainly serves the London Boroughs of Waltham Forest and Redbridge – there is no other hospice provision in these boroughs.
3. The Margaret Centre was originally registered as a hospice but is now part of the hospital. It provides inpatient care for symptom control, end of life care and expert clinical management in a calm, welcoming environment with an inclusive ethos. In the past, it offered access to a range of therapies as well as psychological and bereavement support for patients and their families, together with training and education for staff and outreach palliative care support for patients in the community: although it seems that some of these services have now been run down. As an NHS unit on a hospital site, the Margaret Centre offers a fairly unusual, though not unique, model of provision. It is one which we think offers real advantages for both patients and staff, in terms of ease of movement and access by staff and patients between hospital and palliative and end of life care unit.
4. There is significant unmet need for high quality palliative and end of life care in the entire North East London area. In addition to the Margaret Centre, there are only two hospices directly serving the area: St Joseph's in Hackney (34 beds) and St Francis in Havering (18 beds). St Clare hospice in West Essex (8 beds) offers some support to people in parts of Redbridge. Community services are at best patchy: Waltham Forest is the only London Borough without a hospice at home service, and there is no access to 24/7 emergency palliative care for

patients at end of life being cared for at home. Too many people are admitted to hospital via A&E at end of their life and die on general wards.

Uncertainty over the future of the Margaret Centre

5. Whipps Cross hospital is due to be redeveloped as part of the New Hospitals Programme – work is now not expected to begin before 2032 and there is much uncertainty about how the plans will be taken forward. This means the future of the Margaret Centre is also unclear, and the Centre is at risk of being run down.
6. The original plans drawn up by Barts Health for the new Whipps Cross did not include the re-provision of the Margaret Centre. Instead, palliative and end of life care would be provided in single rooms dispersed throughout the new hospital. A4W was clear that this approach risked losing the many benefits of the care provided by the Margaret Centre as a specialist unit. Our campaign to re-provide the Margaret Centre has had huge local support: in February 2022 we presented over 2000 postcards signed by local people to the then CEO of Barts Health, and in November 2023 our petition to the North East London Integrated Care Board (ICB) had nearly 6500 signatures.
7. Following public pressure, the ICB has carried out a review of palliative and end of life care in the Whipps Cross catchment area which found a real gap in community provision locally, mainly due to the absence of a 24/7 service for patients and families in Waltham Forest. Plans have been drawn up for a new specialist community service but it is unclear whether this is now moving forward, due to funding constraints.

What's valued about the Margaret Centre

8. We know that local people greatly value the Margaret Centre for many reasons, including:
 - The calm, homely environment which enables patients, families and friends to spend valuable time together, with access to its own outside green space, and also to counselling and support;
 - There is access to a highly skilled, multi-disciplinary team of clinical and care staff with real expertise in end of life care - people say they feel in safe hands;
 - The unit working in an integrated way with NHS community teams to enable continuity of care and real choice when possible about where end of life care is provided.
9. It is hard to see that this service can be provided in single rooms in a big hospital.
10. Personal statements from family members with recent experience of the excellent care provided by the Margaret Centre are attached as an Appendix, together with a brief account from someone whose husband died on a general ward because there no room was available in the Margaret Centre.

What needs to Improve

11. Our vision is for an integrated local service which provides high quality support in the community, with the Margaret Centre as an excellent specialist NHS unit on the hospital site at its heart. We think having a hospice on a hospital site has real advantages and should be given serious consideration as a model for future provision.

12. To achieve our vision, we need at national and local level:
 - Proper funding for palliative care so that ICBs can implement the commissioning duties placed on them by the Health and Care Act 2022;
 - A workforce strategy to address the shortages and skills gaps of staff for end of life and palliative care;
 - Collection and publication of data on palliative care and hospice provision so there can be transparency about local variation in access to services.

13. This approach would enable people to have real choice over where and how they die, so that they can access a specialist unit if they need or wish to do so. The rationale that has been stated for potentially not re-providing the Margaret Centre on the hospital site is that 'most people want to die at home'. We absolutely support people's choice to die at home, but we know that will not be possible for everyone in our community. We believe what matters is that high quality care is available in all settings, whether home or hospice, to support people and their families at the end of life to have as good a death as possible.

Ann Gross on behalf of

Action4Whipps

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