

Community-based specialist palliative care improvement programme

Work with us to understand how we can improve the experience for all adults who use community-based specialist palliative care services in North West London

North West London Integrated Care System

November 2021

Summary Issues Paper

It is widely recognised that when caring for someone in the last year of their life, we have only one chance to get it right.

Anyone at the end of their life should be able to be where they want to be, with the people they want to be with. They (and their family, loved ones and carers) deserve the best quality care and support, regardless of their circumstances. With a rapidly ageing society and changing patterns of illness, many more people with multiple long-term health conditions will live for longer. As a result, the need for high-quality palliative and end-of-life care is expected to increase dramatically by 2040.

Too many people experience poor care as they approach the end of their life, with many people spending their last months and weeks in hospital, often dying there, which is not what they want. Not only is this distressing for the patient and their loved ones, but this is also NHS funding that could be spent elsewhere.

Palliative and end-of-life care is a national priority, as well as a priority health and social care partners in North West London. In North West London we have some excellent palliative and end-of-life care services for adults (aged 18 and over), provided by very committed partner organisations, but we know that we need to improve the care we provide in hospitals, community settings (such as hospices and day centres), primary-care settings and patients' own homes. We want to make sure all patients have equal access to accessible, consistent, high-quality care across all palliative and end-of-life care services.

More also needs to be done to make sure the care provided by different organisations is more joined up. This includes making sure all patients have a personalised care plan that has been agreed with them, and that the plan is available to the different care sectors supporting them and their family.

Currently, the most fragile part of the palliative and end-of-life care services in North West London is the community-based specialist palliative care for adults. In North West London we have eight community-based specialist palliative care providers providing services. These include seven hospices with inpatient units, as well as separate community specialist palliative care nursing services.

The providers deliver a wide range of services including specialist inpatient and community-based specialist palliative care nursing, day hospices and outpatient services, as well as some additional specialist services including lymphedema, well-being services and complementary therapies. Some of our providers only provide community-based specialist palliative care nursing services and do not have hospice inpatient units.

Three providers: Central London Community Healthcare NHS Trust, London North West University Healthcare NHS Trust and Central and North West London NHS Foundation Trust receive all their funding from the NHS. The other five providers are charitable hospices and receive their funding from a combination of NHS and charitable income.

- Royal Trinity Hospice is based in South London. It provides services to parts of Hammersmith & Fulham, Westminster and Kensington & Chelsea.
- St John's Hospice is based in Westminster. It provides services to Brent, Hammersmith & Fulham, Westminster and Kensington & Chelsea.
- Marie Curie Hospice is based in Hampstead and provides services to Brent. Marie Curie's London Nursing Service provides end-of-life rapid response and nursing services to Ealing and Hounslow.
- St Luke's Hospice is based in Harrow. It provides services to Harrow and Brent (North).
- Harlington Hospice is based in Hillingdon. It also provides the Michael Sobell House Inpatient Unit at Mount Vernon Hospital in Hillingdon. Both services serve Hillingdon.
- Meadow House Hospice is based at Ealing Hospital, and is run by London North West University Hospital Trust. It provides services to Ealing and Hounslow.
- Pembridge Palliative Care Service is in North Kensington. It provides services to Hammersmith & Fulham, Westminster, Brent (South) and Kensington & Chelsea (please note, the inpatient bed part of this service is currently suspended). Harrow Community Specialist Palliative Care Team is also provided by Central London Community Healthcare NHS Trust, and provides services in Harrow only.
- The Hillingdon Community Palliative Care Team and Your Life Line Service are provided by Central and North West London NHS Foundation Trust. These services are provided in Hillingdon.

The NHS and its partners are committed to making improvements in community-based specialist palliative care for adults before looking at other areas of palliative and end-of-life care.

We also want to raise awareness of the importance of palliative and end-of-life care in general, and discuss what we want to see in the future from high-quality, safe, community-based specialist palliative care for adults, which also delivers an excellent patient experience. We want to:

- make sure everyone receives the care they need, when they need it, regardless personal characteristics such as their gender, ethnicity, social standing or where they live (this is known as equity of access), and improve the quality of care our residents and their families and carers receive; and
- improve the experience for our patients, and their families and carers, by developing services that reflect what is important to them at the end of their lives, from diagnosis through to death.

We are not reviewing children's and young people's palliative and end-of-life care services, community nursing which provides generalist palliative and end-of-life care services, or acute hospital services which provide specialist palliative care services.

However, we will be working hard to make sure that our work links closely and joins up with hospital specialist palliative care and all other generalist palliative and

end-of-life care services in North West London. We will also work with a number of NW London ICS's other service-improvement initiatives that are already looking to reduce differences in and improve the quality of non-specialist (generalist) palliative and end-of-life care services. This includes the NW London Community District Nursing Review and NW London Enhanced Health in Care Homes programme.

Palliative and end-of-life care can be generalist or specialist. By community-based specialist palliative care services, we mean care and support services that are not provided in an acute hospital or GP surgery. Instead, they are provided in a patient's own home, a care home, a hospice, a community hospital or health centre.

Specialist palliative care professionals, such as palliative care doctors, nurse specialists, therapists and psychologists, are experts in providing palliative and end-of-life care and have specific training and experience. They usually become involved in a patient's care to help manage more complex care problems that go beyond the expertise and knowledge of a patient's generalist and usual care team (for example, their GP and district nurses). They work closely with the patient's GP and district nurse to offer advice on controlling pain and managing symptoms, provide emotional and practical support for patients, their loved ones and carers in preparing for the end of their life and, after the patient dies, offer bereavement support to their loved ones.

Generalist palliative and end-of-life care is provided on a day-to-day basis by many health and social care professionals, such as GPs, district nurses, social workers and care home staff. A patient's family and carers can also provide generalist palliative and end-of-life care in the patient's home.

What we want to do

We want to work with local residents, clinicians and partners from volunteer, community and faith organisations to jointly identify and decide what high-quality community-based specialist palliative care looks like. We will then develop a new model of care that broadly defines the way that services are delivered, in a way that can be maintained, is culturally sensitive and better meets our diverse population's needs. The new model of care will be delivered across the whole of North West London to make sure that everyone receives the same consistent high standard of care.

There are eight broad reasons why we need to improve the way we deliver our community-based specialist services if we are to make sure everyone receives the same level of high-quality care, regardless of their circumstances.

1. To build on the valuable learning and feedback received from previous reviews of palliative and end-of-life care services carried out in Brent, Hammersmith and Fulham, Kensington and Chelsea, and Westminster, and the further engagement activity carried out in Ealing, Harrow, Hillingdon and Hounslow.
2. To bring services in line with national policy such as the national Six Ambitions for Palliative and End of Life Care and the NHS triple aim of

improving access, quality and sustainability, and to make sure providers follow the National Institute of Care and Excellence (NICE) guidelines for palliative and end-of-life care services, as far as possible.

3. To meet patients' changing needs arising from changes in the population. By 2040, the number of deaths within England and Wales is expected to rise by 130,000 each year. More than half of the additional deaths will be people aged 85 or older, so there will be an increased need for palliative and end-of-life care services.
4. To reduce health inequalities and social exclusion, which act as a barrier to people receiving community-based specialist palliative care.
5. To make sure that everyone receives the same level of care, regardless of where they live. At the moment there are differences in the quality and level of community-based specialist care that patients, families and carers across North West London receive. This means that depending on where a patient lives, they and their family and carers may not get the support they need, and may not be able to have their wishes supported at the end of their life. We want to do all we can to make sure this is not the case.
6. To make it easier for people to access services, particularly across our more diverse communities. Some of our services are not joined up and do not work well together, and we need to change this.
7. To cope with the increasing financial challenge the NHS is facing and the effect this has on community-based specialist palliative care.
8. To reduce the difficulty we are having finding, recruiting and keeping suitably qualified staff, and the knock-on effect this has on our ability to provide services.

What people have said before

When we have talked to people about community-based specialist palliative care services, we have heard what a crucial role the services play. The feedback confirmed that people really value their local specialist services and people with experience of these services are very positive about the care they have received.

We have also heard that services need to be made available to more people 24 hours a day, particularly that out-of-hours services (those provided between 5pm and 9am) need improving to make them more inclusive and adaptable, and to offer more choice and be more co-ordinated. People told us it is important to improve access to these services so more people receive care and are supported to die in their preferred setting, whether this is at home, in a hospice or in hospital. It is also important that people don't have to travel too far to access services.

The feedback showed that people have different views on how we should make these improvements.

We want to build on the feedback and what we have learnt from it. We also want to fully understand the role culture and religion can play in influencing the way people relate to their health, the support they want to receive and the way they experience loss and grief. We will then use this insight to develop services that can take this into account.

This involves a respectful and responsive approach to the health beliefs and practices, and cultural and linguistic needs, of diverse population groups. However, it goes beyond just race or ethnicity and can also refer to characteristics that are protected by the Equality Act, such as a person's age, gender, sexual orientation, disability and religion, and also social exclusion and socio-economic deprivation (deprivation caused by factors such as being unemployed or on a low income, or living in a deprived area), education and geographical location. (For more information, visit www.equalityhumanrights.com/en/equality-act)

When we have completed our research and received everyone's feedback, we will look to develop the model of care that will deliver the high-quality safe and fair care that people deserve. Our next step will be to look at what services are needed in the future to deliver this new high-quality model of care and make sure it can be maintained in the long term, and to bring forward proposals that set this out.

So, for now, we are not looking at or discussing what current community-based specialist palliative care services look like or what their future should be, or how many beds we need in a community setting. That will come in due course when we have agreed what good-quality care looks like and the model of care we need to develop in order to provide it.

In summary, we aim to start a conversation about what we need to do to improve the quality of care our residents and their families and carers receive when they need community-based specialist palliative care.

From this starting position, we want to work with patients, clinicians and the wider community to develop and introduce a new model of care which is fairer, more joined up, high quality and can be maintained in the long term. It must also meet the clinical and individual needs of patients from diagnosis through to the end of their life, and reflect the choices that people want to make on the care they receive and where they receive it.

We have published an issues paper which provides more detail. You can read it at www.nwlics.nhs.uk/cspc

Get involved

We want your help in finding out what the issues are and coming up with possible solutions. Over the coming months we will have lots of ways that you can get involved and opportunities to give your views.

To find out how to get involved visit www.nwlics.nhs.uk/cspc or email nhsnwlicc.endoflife@nhs.net

Timeline

November 2021 – February 2022
Patient engagement period starts

January- February 2022

Writing up a report based on feedback from the issues paper and engagement exercises
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March 2022

Publication of outcome report and next steps – testing outcomes with public and stakeholders (feedback loop)
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