

Appendix D

Palliative care services

Re-designing services for people with an incurable illness or in their last phase of life in Brent, Hammersmith & Fulham, Kensington & Chelsea and Westminster







Your feedback on potential scenarios

Thank you if you have been involved in the process so far and for your patience. We are confident that by continuing to work together with local patients, carers and partners we have an opportunity to improve palliative care services across the four boroughs.

What this document is for

The local NHS is reviewing specialist palliative care services across Brent, Kensington & Chelsea, Hammersmith & Fulham and Westminster.

This document sets out our current thinking about how we may organise specialist palliative care services in future. It is intended to provide a background to our current situation and form a basis for further discussion.

We want to involve our patients and local people in agreeing the way forward, so we have produced this document as a way of discussing potential scenarios for improving specialist palliative care.

This is not a consultation document. At this stage we want to open up a discussion which we hope you will want to take part in.

Contents

- Why do we need change?
- . What challenges are we trying to address?
- Timeline of the process so far and next steps
- What we have heard so far public engagement
- Palliative Care Services
- Potential scenarios
- Survey Let us know what you think

Accessibility

We want as many people as possible to tell us their views, if you need this information in a different format like a printed or large print copy, easy read, audio recording or a translated version, please let us know what you require and we'd be happy to help.

- Email the project inbox at nwlccgs.triborough.palliativecare@nhs.net
- Call our office to speak to us to discuss on 0203 350 4366.

What do we mean by palliative care services?

- Palliative care is support for people living with an illness which isn't curable and aims to improve a patient's quality of life. Examples of these illnesses include advanced cancer, motor neurone disease (MND) and dementia. You can receive palliative care at any stage in your illness. Having palliative care doesn't necessarily mean that you're likely to die soon some people receive palliative care for years.
- Palliative care also includes care of people who are in the last months or years of their life, known as 'end of life'. End of life care aims to help people to live as comfortably as possible in their time left. It involves managing physical symptoms and getting emotional support for the patient, their family and friends.
- Palliative care takes into consideration a patient's physical, emotional, psychological, social and spiritual needs. This is called a holistic approach, because it deals with people as a "whole" person, not just your illness or symptoms.

What is the difference between general and specialist services?

- Palliative care is often delivered at a person's home (including care or nursing home) by local <u>'general' services</u> such as your GP, community and district nursing teams.
- Depending on a person's condition, needs and preference <u>'specialist care'</u> may also be required. This is often provided by hospice services and staff. Hospice care is a style of care, rather than something that takes place in a specific building. It can be delivered at home by community nursing teams or through in-patient or day care services.
- Specialist palliative care teams are made up of many different healthcare professionals who co-ordinate care for an individual. This may include consultants, specialist nurses, occupational therapists or physiotherapists trained in palliative medicine.
- As specialists, they also advise other professionals on palliative care such as GPs and community nurses.
- For more information on these terms specialist palliative care and other terms we may reference in this document please see the accompanying information pack or visit nhs.org.uk.

Doesn't everyone need specialist services?

- Not everyone will need specialist palliative care and will be managed by their 'local general' team. Some people dependant on their situation and the complexity of their needs and circumstance will do and this would be classed as 'specialist palliative care'.
- People also have the right to express their wishes about where they would like to receive care and where they would like to die.

This review focusses on specialist palliative care services (often provided by hospices) in these areas, the aim however is that any proposed changes to specialist care supports improvements in 'general' care, as described above, so that <u>everyone</u> has access to the right care when they need it.

Why do we need change?

Inpatient care within our local hospices resoundingly provides high quality and expert care to those patients with the most complex medical needs. Patients, families and carers who have used inpatient care rate this care as excellent and it is clear that all of our local providers of specialist palliative care are well-loved and respected by the communities they serve.

We are now bringing together the findings from the independent review (available on our website) undertaken earlier this year with the views of patients, the public and professionals working in providing palliative care. The most consistent feedback from professionals and the public however is about the inconsistency in services provided to people in different areas, and the difficulty for some people in accessing these services. Poor co-ordination and communication between services is also a key theme, as well as timeliness and the lack of emergency response when most needed.

The independent review also highlighted that our current inpatient services may not be appropriately sized for the needs of our population and that it's important that we invest in a mix of services to ensure improved consistency and better meet people's preferences, in their last phase of life.

What challenges are we trying to address?

Access to services - only 48% of people with a palliative care need are accessing services when they need them. Reaching only 48% of patients is not good enough. It is paramount that we increase the reach of palliative care services to all patients who need it, regardless of their condition.

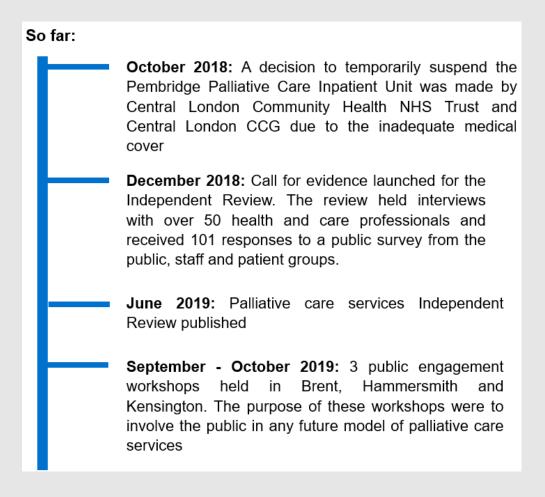
Inconsistency between services – depending on where you live you will have more or less access to specialist palliative care services and this is not acceptable. For example, while some hospices can support people to die at home if they wish, others do not. There is also variation in what services can be accessed out of hours and how quickly, for example in the middle of the night or at the weekends.

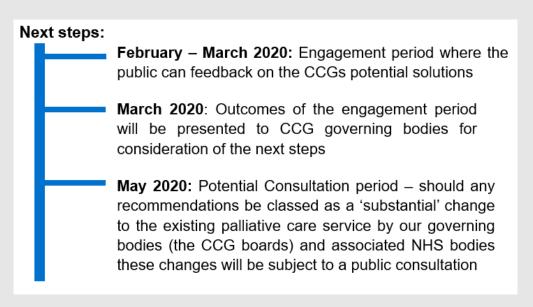
Underinvestment in community services contributes to differences in what services are available for people to access. Our vision is that everyone gets the palliative care that they need. We aim to increase this number up to a **minimum** of **75% initially**. Investing in community services will enable us to reach more people in their last phase of life.

A lack of co-ordination between services can result in care being delayed or interrupted which causes anxiety and stress for patients, carers and families and unnecessary discomfort to the patient.

National staff shortages in palliative care specialists - this has been a challenge locally and due to a specialist palliative consultant not being available led to the suspension of the in-patient unit at the Pembridge palliative care centre, highlighting the fragility of our local system.

Timeline of the process so far





What we have heard so far

Since December 2018 we have engaged; local patients, families, carers, residents, the voluntary and community sector, and patient representative groups across the four boroughs. Initially we launched a 'Call for evidence' to hear from local people and professionals about their views on services and how they are working. This information formed the basis of an Independent review. Between September and October 2019 three well attended public workshops were held to look at people's experience of palliative care services from end to end; focussing on access, care and the transfer of care and bereavement.

Key themes

There is also a findings report of key themes – this can be accessed **here**.

Summary of	themes from the workshops:
	Care works well once a service or pathway has been accessed with inpatient hospice services offering peace of mind for family, friends and carers. However many people aren't in contact with any services at all
	Care is not standardised across different areas in the four boroughs
î	Access to information and support to help navigate available services is inconsistent
	Care planning should be transparent with family, friends and carers and start at an earlier stage
	More could be done to ensure that minority groups are aware of palliative care services and ensuring that these services are personalised for a diverse range of communities
 	Travel times to hospice services have a significant impact on carers and families. This should be a focus for any future model of care
	More could be done to improve integration and coordination between services
	Bereavement services need to be in place at the right time and be promoted better to friends, family and carers

Feedback from our engagement: below is a summary which details how we are listening to your feedback and improving patient & public involvement in the process.

You said	You would like more information about the consultation process
We did	We have provided the above timeline of the review process so far and the next steps for the process. We are not in consultation now but if significant change is proposed to these services then we consult the public which would happen later this year.
You said	You would like an opportunity to discuss the future of the Pembridge Palliative Care Centre
We did	In the survey below also available online we would like to hear your thoughts and feedback on the 4 proposed scenarios. Please use this opportunity to voice any concerns you have around the suspension of the Pembridge Palliative Care centre.
You said	You would like to be more involved in developing future scenarios for palliative care services
We did	We advertised for patients and the public to join a Patient and Public Palliative Care Working Group to ensure local people have a voice. We are working together with this group to discuss possible scenarios which we are now sharing with you in this document.
You said	You would like more information about palliative care to help you make an informed decision about the future of these services
We did	We have produced an information pack to support this document that has a glossary of the different aspects of the palliative care review. If you require more information around a certain topic please let us know through the contact details at the bottom of this document.
You said	You would like to be more involved in the process
We did	We are committed to involving residents and patients throughout this process as much as possible. We gathered people's feedback as part of the independent review and in Autumn 2019, we ran a series of workshops on how we can improve palliative care services.
	From this feedback and through working with our Patient and Public Palliative Care Working Group, we have now developed

some potential scenarios, outlined in this document that we

latest updates and we will add you to our mailing list.

would like to hear your feedback on. You can also sign up for the

Current services

Here is a description of the different elements of specialist palliative care services:

• Community services

You may not need to move away from home to receive care, community nurses can come to your home at any stage in your condition and provide nursing care for you there.

Inpatient services

This is care of patients whose condition requires an admission to a hospice or hospital bed.

Day services

Services and activities that can be accessed during the day including clinical, financial, emotional and spiritual support when an admission is not needed.

• Hospice@Home

You may need more specialist care from community palliative care nurses who visit you at home, this tends to be in the last phase of life and therefore may be more intensive.

Out of hours

This is the period from when the day and community services close until the following morning.

An overview of what is currently being commissioned across these four boroughs by each of the main specialist palliative care services:

	Inpatient unit (IPU)	Community visiting service	Day service opening hours	Hospice@home	Out of hours (after 5pm)
Marie Curie: 11 Lyndhurst Gardens, Hampstead, London NW3 5NHS	26 beds 24/7 admissions available	Not provided to 4 boroughs	5 days a week service 9-5pm Mon – Fri No weekend services	Not provided to 4 boroughs, except Marie Curie Night Nursing Service available.	24/7 clinical advice line available Mon – Sun. No visiting service.
Pembridge Palliative Care Centre Services: St Charles Centre for Health & Wellbeing, Exmoor St Ladbroke	13 beds 24/7 admissions available *currently Suspended due to no consultant cover – all other services	7 days a week 8:30 -5pm Mon- Fri 9 – 5pm Weekends & Bank holidays	4 days a week service, 8.30am – 4pm No weekend services	Not provided to 4 boroughs. (accessed via other providers)	24/7 clinical advice line available Mon – Sun. No visiting service.

Grove, London W10 6DZ	operating as usual from this location*				
Royal Trinity Hospice: 30 Clapham Common North Side, Clapham Town, SW4 0RN	28 beds 24/7 admissions available	7 days a week 9-5pm Mon – Sun (including bank holidays)	5 days a week service, 9-5pm No weekend services	Not provided to 4 boroughs. (accessed via other providers)	24/7 clinical advice line available Mon – Sun. No visiting service.
St John's Hospice: 60 Grove End Rd, St John's Wood, London, NW8 9NH	18 beds 24/7 admissions available	7 days a week 9-5pm Mon - Sun	4 days a week service. 8.30 – 5pm No weekend service	Service is provided to Westminster, Kensington and Chelsea and south Brent residents.	24/7 clinical advice line available Mon – Sun. No visiting service.
St Luke's Hospice: Kenton Grange, Kenton Rd, Harrow HA30YG	12 beds 24/7 admissions not available. Admissions are available Mon – Fri, 9am – 4pm. and only if planned for weekends.	5 days a week 9-5pm Mon– Fri (7 day a week service April 2020)	5 days a week service, 9 – 4:00pm No weekend service	Service is provided to north Brent resides.	24/7 clinical advice line NOT available. Advice available Mon – Fri 9am – 5pm. No out of hours or weekend cover. No visiting service

Potential scenarios

Working with our local hospice providers in the area and from the information we have gathered from our working group and the local community around specialist palliative care services, we have proposed some potential scenarios that we would like to hear your views on. These potential scenarios aim to address the challenges we face which are:

- Current services are only reaching half of people with palliative care needs
- Services offered across the four boroughs are inconsistent
- There is an underinvestment in our community services which means we may not be able to meet people's preferences in their last phase of life
- A lack of co-ordination between services and support out of hours
- A national shortage of specialist staff to cover these services safely

Please complete the feedback survey at the end of this document or our online survey here.

Potential scenario 1 – services remain the same

This scenario would keep all specialist palliative care services as they are including the reopening of the inpatient unit at the Pembridge, subject to the appointment of a palliative care consultant. In-patient, day and community care services would continue as they are.

Benefits	Disadvantages
No change to the location of any services.	 Services won't increase the number of patients that they see, currently services only have the capacity to support around half of patients with a palliative care need.
 This would mean re-opening the in- patient unit at the Pembridge Palliative Care Centre. 	 Improvements needed raised by patients and staff regarding communication and coordination of services will be addressed but limited.
 No increase in travel for specialist in- patient services. 	 Services will not be in line with national guidance.
	 Access to day services will remain inconsistent.
	 Access to community services will remain inconsistent.
	 'Out of Hours' service will remain inconsistent.
	 Hospice @Home not available to all.
	 No guarantee of when it will be possible to recruit a specialist palliative care consultant into this post.

Potential scenario 2 – Some improvements to day and community services with inpatient services remaining the same

This scenario would keep in-patient services as they are now, including the re-opening of the inpatient unit at the Pembridge palliative care centre subject to the appointment of a palliative care consultant. Community and day services would be standardised across the boroughs.

This scenario would lead to some but limited improvements in the co-ordination of out of hours advice.

Benefits	Disadvantages		
Community services would be open consistently 7 days a week.	Services won't increase the number of patients that they see significantly, currently services only have the capacity to support around half of patients with a palliative care need.		
 Day care services would increase from 4 to 5 days a week with consistent opening hours. 	Access to community services will remain inconsistent.		
Some, limited improvements to out of hours services.	Improvements needed raised by patients and staff regarding communication and coordination of services will be addressed but limited.		
 This would mean re-opening the in- patient unit at the Pembridge Palliative Care Centre. 	Services will not be in line with national guidance.		
 No increased travel for specialist in- patient services. 	'Out of Hours' service will remain inconsistent.		
 No change to the location of inpatient or day care services. 	Hospice @Home not available to all.		
 Improved co-ordination of services with providers working together. 	 No guarantee of when it will be possible to recruit a specialist palliative care consultant into this post. 		

Potential scenario 3 – A re-design of all elements of specialist palliative care services

This scenario would see in-patient services delivered from four rather than five hospices but without reducing the number of beds that the NHS funds.

This would enable CCGs to fund community services 7 days a week, with 24/7 admissions for patients, consistent day care and out-of-hours services, and Hospice@Home available to all.

Benefits	Disadvantages
 A greater level of access and consistency of services available to all. 	 The hospice locations where patients can access inpatient care would reduce from 5 to 4.
A greater level of funds for community and day-care services would be available so that more people can benefit from these services and services would work better together.	 As a result of reducing the hospice locations where patients can access inpatient care, some patient's carers and family will have to travel further or longer to visit patients who are receiving inpatient care.
 Community services would be available 7 days a week and the hours would increase to 8am-8pm. 	 The hospice location likely to close is the Pembridge in-patient unit. However this requires further consideration and has not been confirmed.
 There will be no reduction in NHS funded hospice beds. 	
Hospice @Home available to all.	
 Day care services would increase from 4 days to 5 days and extended to be consistent. 	
 Increased investment will improve co- ordination of care for patients and families with 24/7 palliative care needs. 	
 Increased investment will deliver responsive out of hours urgent and emergency palliative care, joined up with London Ambulance Service and NHS 111. 	
Specialist services will deliver increased training and education in palliative care for GPs, District Nurses and Care Homes and enable easier access to advice from the specialists when required.	
 Increased investment will deliver improved palliative care for homeless patients and other hard to reach groups, with support from outreach teams. 	

Potential scenario 4 – A re-design of all elements of specialist palliative care services including access to a new nurse-led in-patient service

This scenario would see in-patient services delivered from four rather than five hospices but without reducing the number of beds that the NHS funds. This would enable CCGs to fund community services 7 days a week, with 24/7 admissions for patients, consistent day care and out-of-hours services, and Hospice@Home available to all.

Patients who do not require specialist inpatient care but cannot be supported at home or have a preference to die in a hospice environment, can access respite and end of life care in their local area via a nurse led in-patient service.

care in their local area via a nurse led in-patien	
Benefits	Disadvantages
 A greater level of funds for community and day-care services would be available so that more people can benefit from these services and services would work better together. 	 Patients who require specialist consultant-led inpatient care will be affected and have to travel to an alternative hospice service.
A greater level of access and consistency of services available to all.	 The hospice location likely to close is the Pembridge in-patient unit. However this requires further consideration and has not been confirmed.
 Community services would be available 7 days a week and the hours would increase to 8am-8pm. 	
 There will be no reduction in NHS funded hospice beds. 	
 Hospice @Home available to all. 	
 Day care services would increase from 4 days to 5 days and extended to be consistent. 	
 Increased investment will improve co- ordination of care for patients and families with 24/7 palliative care needs. 	
 Patients who do not require specialist consultant-led inpatient care can access respite and end of life care in their local area via a nurse led service. 	
 This would overcome the current issue with specialist staff shortages. 	
 Increased investment will deliver responsive out of hours urgent and emergency palliative care, joined up with London Ambulance Service and NHS 111. 	
 Specialist services will deliver increased training and education in palliative care for GPs, District Nurses and Care Homes and enable easier access to advice from the specialists 	

when required.	
when required.	
 Increased investment will deliver improved palliative care for homeless patients and other hard to reach groups, with support from outreach teams. 	

Thank you for reading this document

Please now complete the feedback survey at the end of this document or complete the online survey here and let us know what you think about these scenarios.

We are happy to consider additional potential scenarios that might help to address the challenges outlined above – please include any suggestions in your response.

What happens next?

Once we have heard your views a proposal will be put forward to CCG governing bodies for consideration of the next steps. Should they take the view that a significant change from the current service provided is required, then we would move to a public consultation which would ensure further engagement opportunities for local people to be involved in, to develop the future model of care.

Thank you for your on-going participation

Brent CCG

Central London CCG

Hammersmith & Fulham CCG

West London CCG



Survey

Complete online, return FREEPOST - NW LONDON or email nwlccgs.triborough.palliativecare@nhs.net

Now you've read our aims and possible scenarios for the future, we want to know what you think. **This is not a consultation,** but an engagement period to get your thoughts to help shape the future design of these services. These scenarios are based on the challenges outlined above and what will reach the most amount of people across these boroughs.

Section 1 - Should we change our services

Have you or a family member or friend used the following services in Westminster, Hammersmith & Fulham, Kensington & Chelsea or Brent? (Please circle as appropriate)

Yes / No

Which of the following services did you use?

- General local palliative care services Yes / No
- Specialist palliative care (often provided by a hospice) Yes / No
- End of life care (often provided by a hospice) Yes / No
- Unsure Yes / No

If yes to any of the above, please tell us the name of this service.

Do you agree that we need to help more people to access palliative care services and to make what is available more consistent for everyone? (*Please circle as appropriate*)

Yes / No

Please rank the importance of the following aspects of palliative care for you? (Definitions available on page

(1 = most important, 6=least important)

Community Care	
Out of hours care and support	
Access to specialist advice	
Services delivered at home	
Day centre services	
In-patient services	

What is the most important thing that palliative care services offer to those that need to	hem?
--	------



Section 2 – your views on each scenario

Potential scenario 1

Services remain the same

This scenario would keep all palliative care services as they are including the re-opening of the inpatient unit at the Pembridge, subject to the appointment of a palliative care consultant. In-patient, day and community care services would continue as they are.
Comments:
Concerns:
Suggestions to improve the scenario:
Potential scenario 2
Some improvements to day and community services with in-patient services remaining the same.
This scenario would keep in-patient services as they are now, including the re-opening of the inpatient unit at the Pembridge subject to the appointment of a palliative care consultant. Community services would also be standardised to 5 days week.
This scenario would also lead to some improvements in the co-ordination of out of hours advice.
Comments:
Concerns:
Suggestions to improve the scenario:



Potential scenario 3

A re-design of all elements of palliative care services

This scenario would see in-patient services delivered from four rather than five hospices but without reducing the number of beds that the NHS funds.

This would enable CCGs to fund enhanced community services 7 days a week, with 24/7 admissions for patients. It would also provide an out-of-hours nurse visiting service and Hospice @Home available to all.

Comments:
Concerns:
Suggestions to improve the scenario:
Potential scenario 4
A re-design of all elements of palliative care services including access to a new nurse-led in- patient service
This scenario would see in-patient services delivered from four rather than five hospices but without reducing the number of beds that the NHS funds. CCGs would then fund enhanced community services.
Patients who do not have complex medical needs, but whose preference is to die in a hospice environment could receive care by a nurse-led service at a bed in North Kensington provided by the Pembridge Palliative Care Centre.
Comments:
Concerns:
Suggestions to improve the scenario:



Section 3 – your preferred scenario

What is your preferred potential scenario? (Please circle as appropriate)

1	2	3	4	
Please	rank ead	l ch scena	rio? (1 =] most preferred scenario, 2 = preferred scenario 3 = le
preferre	ed)		`	

Potential scenario 1	
Potential scenario 2	
Potential scenario 3	
Potential scenario 4	

Is there another scenario you would like to be considered?
Any other comments?
Section 4 – About you
Which borough do you live in?
Where is your closest hospice?
How did you hear about this survey?
How would you like us to involve you and the wider community in the future?
If you would like to join our mailing list please include your email below:

Contact - any questions call 0203 350 4366 or nwlccgs.triborough.palliativecare@nhs.net



About you

To ensure we are representing our diverse community, we would be grateful if you could complete the below questions - the details you provide are strictly confidential. It's a legal requirement for us to ask these questions, but you are not obliged to answer any you do not wish to.

Gender (please circle):

Man / Woman / Non-binary / Prefer not to say If you prefer to use your own term, please specify here:

Is your gender identity the same as the gender you were originally assigned at birth (please circle as appropriate):

Yes / No / Prefer not to say

Age group (please put an x in the correct box):

Under 18	18 - 24	25 – 34	35 – 44	45 – 54	55 – 64	65 – 74	75 or over	Prefer not to say

Which of the following best describes your sexual orientation (please put an x in the correct box):

Heterosexual/straight	Lesbian/Gay Women	Gay Man	Bisexual	Prefer not to say

f you prefer to use your own term, please specify here:						

Which of the following best describes your religion or belief (please put an x in the correct box):

No religion	Buddhist	Christian	Hindu	Jewish	Muslim	Sikh	Prefer not to say



Other (please state)	

How would you describe yourself?

Using the following classifications, how would you describe your ethnic origin (please tick appropriate box).

White	Black or Black British	
White British	Caribbean	
Irish	African	
Gypsy/Irish traveller	Other Black background	
Polish	All Black groups	
Other white background		
All white groups		
Mixed	Other	
White and Black Caribbean	Somali	
White and Black African	Irish traveller	
White and Asian	Romany	
Other mixed background	Arab	
	Other ethnic group (please describe below)	
Asian or Asian British	Prefer not to say	
Indian		
Pakistani		
Bangladeshi		
Other Asian background		
All Asian groups		

Do you consider yourself to have a disability/impairment?							
Yes	No						

Contact us

- Email this back to our inbox at nwlccgs.triborough.palliativecare@nhs.net
- Post your survey back to us at FREE POST: HEALTHIER NW LONDON.
- Any problems call us on 0203 350 4366.