



**North West London
Integrated Care System**

Working together for better health and care

Community-based specialist palliative care improvement programme

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

November 2021

North West London Integrated Care System is a collaboration of NHS, local authority, voluntary and community sector organisations

HOW TO USE THIS DOCUMENT

This paper sets out a range of challenges facing the NHS and many other partners providing community-based specialist palliative care in North West (NW) London. It sets out why we think we need to change things if we are to improve the quality, safety and equity of care provided to patients, families and carers and ensure they have excellent experience of that care.

It is not part of a public consultation process. The NHS has published it with the support of many of our local system partners (NHS and non-NHS) to encourage people to share their thoughts and consider the facts and questions we have raised, in order to support improving your local health services.

Should our discussions about the best way to make changes lead to proposals emerging for major service change, we would carry out a formal public consultation on the options available. We are not at the stage yet of knowing whether this will be needed.

We have tried to make this complex topic and associated issues in this document as easy to understand as possible, but have also made a summary document and easy read version available as well. Additionally, we have indicated where further reading or information can be found and have also collated many of these referenced documents and links on our website www.nwlondonics.nhs.uk/get-involved/cspc.

Please check the site for new updates as we will add more information as it becomes available.

CONTENTS

1. INTRODUCTION	4
2. WHO WE ARE	10
3. THE SCOPE OF OUR WORK AND UNDERSTANDING	
WHAT WE MEAN BY ‘PALLIATIVE CARE’	12
3.1. Defining palliative care, specialist palliative care, end of life care, community-based specialist palliative care, and who provides this care?	14
3.2. What do we mean by palliative care, including generalist and specialist palliative care?	15
3.3. Where is palliative care provided?	16
3.4. Who provides palliative care?	16
3.5. What is generalist palliative care?	16
3.6. Who provides generalist palliative care?	16
3.7. What is specialist palliative care?	16
3.8. Who provides specialist palliative care?	17
3.9. Who needs specialist palliative care?	18
3.10. What do we mean by community-based specialist palliative care?	18
3.11. What support can community-based specialist palliative care services provide?	20
3.12. How to access community-based specialist palliative care?	20
3.13. What do we mean by approaching end of life and end of life care?	21
3.14. Who provides end of life care?	21
4. CURRENT COMMUNITY-BASED SPECIALIST PALLIATIVE CARE SERVICE PROVISION FOR ADULTS IN NW LONDON	22
5. WHY THINGS NEED TO CHANGE?	24
5.1 Learning from previous service improvement reviews and engagement	25
5.2 National policy	27
5.3 Changing needs of patients and population growth	28
5.4 Health inequalities	31
5.5 Improving the quality of care, and patient and family and carer experience	33
5.6 Fragmentation and the need for more joined up services	34
5.7 The workforce challenge	36
5.8 The financial challenge	36
6. WHAT WE NEED TO DO NEXT?	39
6.1. The timeline	41
6.2. Get involved	41
7. GLOSSARY	42

INTRODUCTION

Thank you for taking the time to read this document.

Death and dying is inevitable. It is widely recognised that when caring for someone in the last year of their life there is but one chance to get care right¹. Anyone at the end of their life should be able to be with the people they want to be with, and where they want to be.

1

They, 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 palliative and health conditions will live for longer.

The need for high quality end of life care by 2040 is projected to increase dramatically. Too many people experience poor care as they approach the end of their life and with many people spending their last months, weeks in hospital and often dying there, which is not what they want. Not only is this distressing for patients 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 for NW London CCG and the NW London Integrated Care System (ICS). In NW London we have some excellent palliative and end of life care services (for adults (18+) with very committed partners, but we know that we need to make improvements to the care we provide in hospitals, community settings such as hospices and day centres, primary care and the patient's own home. We want to ensure all patients have equal access to accessible, consistent, high quality care across the whole of palliative and end of life care.

More also needs to be done to ensure the care provided by different organisations is more joined up. This includes looking at the IT challenge of not all services having appropriate access to clinical information held electronically by partner providers for patients under their care. We need to ensure that all patients have a personalised care plan that has been agreed with the patient and are then available to the different care sectors supporting these patients and their families.



Currently, the most fragile part of palliative and end of life care services in NW London is community-based specialist palliative care for adults (18+). The NHS and its partners are committed to making improvements in this area of service provision first before looking at other areas of palliative and end of life care.

This issues paper is designed to raise awareness of the importance of palliative and end of life care in general and also facilitate discussions to help us decide what high quality, safe, community-based specialist palliative care for adults, which also delivers excellent patient experience. We should be clear that we are not going to be reviewing children and young people's palliative and end of life care services, nor are we reviewing community nursing or acute hospital services providing generalist palliative and end of life care services.

We will be working hard to make sure that our work links closely with developments in hospital specialist palliative care, all other generalist palliative and end of life care services, and related transformation programmes in NW London.

¹ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf

Some background

Approximately 600 000 people die in England each year, two-thirds of whom are aged 75 years and older. Life expectancy has risen over the past 25 years, and as such, the proportion of people aged 75 years and older has risen and is projected to continue to rise. As a result, the number of deaths in this age group is rising at an accelerated rate. The population of England is ageing, and this has important implications for the provision of palliative and end of life care, which the NHS in partnership with social care, the voluntary, charitable and community sector intends to personalise and improve in the coming years, according to policy set out in the [NHS Long Term Plan](#).

High-quality, personalised palliative and end of life care means ensuring that all physical and psychological needs of patients and those people who are important to them are met, not just their physical needs. It also requires a compassionate approach and the ability to see each patient as an individual². While high-quality clinical care is vital, it is equally important to ensure that it is well coordinated and joined up across different services and settings.

Failing to do so not only deprives our patients of the best end of life care but can leave a devastating legacy for the people important to them. Good care is focused on “What matters to me” (from the refreshed Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026).³

The World Health Organisation has also said that the global need for palliative care will continue to grow as a result of the ageing of populations and the rising burden of non-communicable diseases and some communicable diseases, and this is also the case in the UK.⁴



Remembering that our initial focus is community-based specialist palliative care, our aim is to deliver a high standard of clinical care with good patient, family and carer experience. We want to:

- Improve the equity of access to these services, and quality of care our residents and their families and carers receive.
- Improve the experience for our patients, families & carers by developing services that reflects what is important to them at the end of their lives, from diagnosis through to bereavement.

Everyone, should be able to be involved in decisions about their own care and develop care plans, together with those important to them and the health and care professionals responsible for their care, to support them to receive care or die in their preferred place.

² Marie Curie - <https://www.mariecurie.org.uk/blog/what-does-it-take-to-deliver-high-quality-end-of-life-care/147878>

³ Ambitions for Palliative and End of life care: A national Framework for local action 2021 - 2026 <https://learninghub.nhs.uk/Resource/2308/Item>

⁴ WHO - <https://www.who.int/news-room/fact-sheets/detail/palliative-care>



Palliative and end of life care comprises both generalist and specialist palliative care practice. By community-based specialist palliative care, we are referring to services that are not delivered within a hospital or a GP surgery, but rather in a patient's own home, a care home, a hospice and a community hospital/health centre.

Specialist palliative care professionals are experts in providing palliative and end of life care and have specific training and experience in this field of practice such as palliative care doctors, nurse specialists and psychologists.

They usually become involved in a patient's care to support the management of more complex care problems and that go beyond the expertise and knowledge of a patient's generalist and usual care team. They also work closely alongside your GP and district nurse to offer advice on pain control and symptom management, emotional and practical support for patients and their loved ones and carers in preparing for the end of life and bereavement support after death.

Generalist palliative and end of life care is provided on a day to day basis by many health and social care professionals (such as your GP, district nurse, social workers, care home staff. It can also be provided by a patient's family and carers in their home.

What we want to do

We want to work with local residents, clinicians and partners from voluntary, community and faith organisations to jointly identify and decide what high quality community-based specialist palliative care looks like, and through this develop a new model of care that is sustainable, culturally sensitive and better meets our diverse population's needs. It will also be delivered across the whole of NW London so everyone receives the same consistent high standard of care.

We will work to integrate community-based specialist palliative care provision and support for patients at end of life in their local 'place' and the role of Primary Care Networks and Borough Based Partnerships (formerly Integrated Care Partnerships) will be critical for this. This means local priorities are recognised within an overarching NW London commitment to avoid inequalities and support consistent and common offers for all NW London residents.

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. We want to build on the valuable learning and feedback received from previous reviews of palliative care services carried out in Brent, Hammersmith and Fulham, Kensington and Chelsea and Westminster and engagement activity carried out in Ealing, Harrow, Hillingdon and Hounslow.

2. Align with national policy such as the national Six Ambitions for Palliative and End of life Care⁵ and the NHS triple aim of improving access, quality and sustainability, and adhere to guideline recommendations from National Institute of Care and Excellence (NICE) guidelines for palliative and end of life care services as much as possible.

3. The changing demographics and needs of patients. The number of deaths within England and Wales will rise by an additional 130,000 deaths each year by 2040, and more than half of which will be people aged 85 years or older leading to increased need for palliative and end of life care.

4. We know that health inequalities act as a barrier to people receiving community-based palliative care.

5. We have variation in the quality and level of community-based specialist care that patients, families and carers receive across NW London which means that depending on where you live, some people and their families and carers do not get the support they need, and are not able to have their wishes supported at the end of their lives. We want to do all that we can to achieve this.

6. Some of our services are fragmented, not joined-up and do not work well together - not all services having access to clinical information held electronically by other providers. People sometimes find services hard to access, particularly across our more diverse communities, which cannot continue.

7. The increasing financial challenge the NHS is operating under and what it means for community specialist palliative care.

8. The difficulty we are having finding and recruiting and retaining a suitably qualified workforce and the knock on effect for service delivery.

When we have talked to people before about community-based specialist palliative care services, we have heard what a crucial role they play for people. 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 also heard that services need to be made available to more people 24 hours a day, but in particular during out of hours 5pm – 9am, be improved to be more inclusive, adaptable, offer more choice and be more coordinated. They referenced how it is important to improve access to these services so more people receive care and are supported to die in their preferred setting as much as possible. Learning also reflected the importance of not having to travel too far to access services.

The feedback did indicate that there are differing views about how we make these improvements, and create more equitable and sustainable services for all.

We also want to fully understand the role culture and religion can play in influencing the way people relate to their health. This influences how they may want to receive support, and the way they experience loss and grief. We will use this insight to develop services that meet the needs of our diverse community.

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. It can also refer to such characteristics as age, gender, sexual orientation, disability, religion, social exclusion and socio-economic deprivation, education, geographical location, occupation and protected characteristics.

The engagement plan proposal we are introducing for this programme of work is designed around the following four principles:

- **Connecting:** by bringing together local people, frontline staff, partners and community and faith leaders as equal partners to articulate the challenge and frame solutions.

- **Strength-based:** by recognising the contribution that local community and faith groups as well as patients, families and carers in supporting improved provision of community-based specialist palliative and end of life care services.

- **Continuous and iterative:** by engaging to build and refine inclusive, sustainable and cost-effective options for future models of care.

- **Evidence-based:** by looking at evidence-based solutions that acknowledge both the interaction between health literacy and responsiveness of services to address the underlying equity of access and inequality in outcomes issues faced by people rather than reacting to individual events or individual episodes of care.

It is only when we have completed this engagement and received everyone's feedback that we will look to develop the model of care that will deliver the high quality safe and equitable 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 bring forward proposals. So for now we are not looking at or discussing what current community 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 what the model of care we need to develop to deliver this is.

In summary, our aim to start a conversation about what we need to do to improve the quality of care our residents, 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 for community-based specialist care which is more equitable, more joined-up, sustainable, and high quality. It must also meet the clinical and individual needs of patients from diagnosis through to bereavement and also reflects the choices that people wish to make on the care they receive and where they receive it.

Thank you for your interest and your involvement in these important issues, we look forward to hearing from you in the coming months to help the NHS in developing a new and exciting future for community-based specialist palliative care for adults in NW London.

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Chief Nurse,
NW London ICS

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WHO WE ARE

This improvement programme will be carried out by NHS NW London Clinical Commissioning Group (NW London CCG) under the leadership of the NW London Integrated Care System. (NW London ICS).

2

NW London CCG comprises of the London boroughs of Brent, Ealing, Hammersmith and Fulham, Harrow, Hillingdon, Hounslow, Kensington and Chelsea and Westminster.



The NW London ICS consists of all NHS organisations and local authorities in NW London who have been working informally as an integrated care system (ICS), ahead of legislation to put ICSs on a statutory footing. Legislation is expected during 2021, with ICSs becoming legally recognised bodies from April 2022. The following are partners in the NW London ICS.

NW London CCG, Central and North West London NHS Foundation Trust (CNWL), The Hillingdon Hospitals NHS Foundation Trust, Central London Community Healthcare NHS Trust (CLCH), Hounslow and Richmond Community Healthcare NHS Trust Imperial College Healthcare NHS Trust, Royal Brompton and Harefield Hospitals, Chelsea and Westminster NHS Foundation Trust, London North West University Healthcare NHS Trust (LNWH), West London NHS Trust, Brent Council, Harrow Council, London Borough of Hounslow, Ealing Council, Hammersmith & Fulham Council, Hillingdon Council, Royal Borough of Kensington & Chelsea, and Westminster City Council.

The purpose of the NW London ICS is to reduce inequalities, increase quality of life and achieve outcomes on a par with the best of global cities.

Our priorities are:

- To improve outcomes in population health and health care.
- To tackle inequalities in outcomes, experience and access.
- To enhance productivity and value for money.
- To help the NHS support broader economic and social development.

To find out more about NW London CCG visit www.nwlondonccg.nhs.uk

To find out more about NW London ICS visit www.nwlondonics.nhs.uk

THE SCOPE OF OUR WORK AND UNDERSTANDING WHAT WE MEAN BY PALLIATIVE CARE

The majority of issues outlined later in this paper are relevant to the whole of palliative and end of life provision for NW London.

3

However, some of these issues are very pertinent and pressing for our community-based specialist palliative care provision and the focus of our improvement programme is to improve the accessibility, quality and sustainability of our community-based specialist palliative care for adults (18+). This is the most fragile part of the pathway and service provision at this time.

The programme does not include children and young people's palliative and end of life care services. It will also not be reviewing acute hospital specialist palliative care provision or generalist community palliative and end of life care services. We will however be working very closely with the NW London specialist palliative care hospital teams and colleagues in other areas to address any interdependencies.

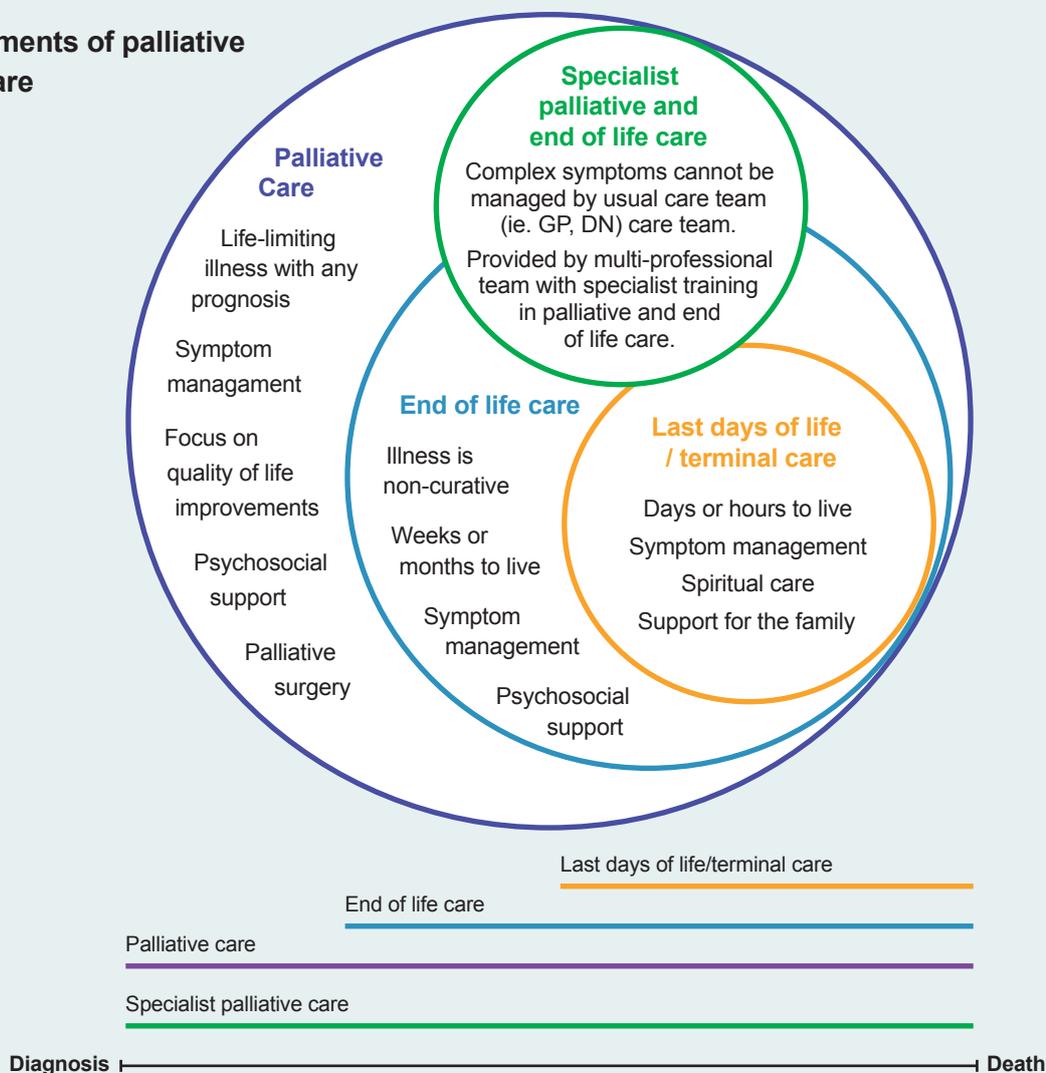
Given that the majority of people with palliative and end of life care needs do not require community-based specialist palliative care input, the focus of this programme is not going to solve all of the issues in palliative and end of life care provision as a whole, in particular reducing hospital admissions in the last year of life. The aims of the programme are to have more accessible community-based specialist palliative care provision that has a wider reach for our NW London population, with the expectation that this will contribute to a reduction in hospital admissions at end of life and improve integration of care.

The above terms and services can be confusing for people. This section provides definitions of the terms, explains more about who provides this type of care and how people can access it.



3.1 Defining palliative care, specialist palliative care, end of life care, community-based specialist palliative care and who provides this care?

The different elements of palliative and end of life care



The information below has been sourced from Marie Curie⁶, a resource called Homeless Palliative Care Toolkit⁷, created by a partnership between Pathway, Marie Curie Palliative Care Research department (UCL), St Mungo’s and Coordinate My Care and various other NHS national palliative and end of life care team resources.

Though more specific definitions can be helpful, a simple view is “palliative and end of life care” is care that optimises mental and physical well-being for people whose health is declining irreversibly and to their family, friends and carers who are supporting them in these circumstances, as well as ensuring the person is supported to die with dignity in line with their expressed preferences.

⁶ <https://www.mariecurie.org.uk/help/support/diagnosed/recent-diagnosis/palliative-care-end-of-life-care>

⁷ www.homelesspalliativecare.com

3.2 What do we mean by palliative care, including generalist and specialist palliative care?

Palliative care is a treatment, care and support approach for people of all ages with a life-limiting illness (such as cancer, organ failure (cardiac, renal, respiratory, liver disease) or a degenerative neurological disorder for which cure is no longer possible), as well as the needs of their families, friends and carers.

It is about improving the quality of life of anyone facing a life-limiting condition and those important to them, through the prevention and relief of suffering for all. Palliative care is person centred and is all-inclusive, considering physical, emotional and spiritual needs. This is called a holistic approach, because it deals with you as a “whole” person, not just your illness or symptoms. A person can receive palliative care at any stage in their life-limiting illness.

Palliative care can involve:

- Managing physical symptoms such as pain to ensure the person is as comfortable as possible.
- Emotional, spiritual and psychological support and comfort. Making sure that a person is cared for in a way that fits their beliefs.
- Social care including help with things like washing, dressing and eating and supporting the person is connected to those that are important to them.
- Support for family, friends and carers.



Palliative care is frequently misunderstood as only being required by people who are dying and need end of life care. Palliative care does include end of life care (for people who are nearing the end of life), but it is not only about this. Receiving palliative care doesn't necessarily mean that a person is likely to die soon, some people receive palliative care for years. A person can also have palliative care alongside treatments, therapies and medicines aimed at controlling their life-limiting illness, such as chemotherapy or radiotherapy.

Compassionate care and open and sensitive communication, along with personalised advance care planning are a key part of palliative care. Advance care plans support the recording of a person's personal wishes and needs should their condition deteriorate, so that these can be made available to health and social care professionals to help to preserve the person's personal choices regarding their care towards and at the end of life.

The World Health Organisation definition of palliative care can be viewed here on the [World Health Organisation definition of palliative care website](#) or in the glossary.

3.3 Where is palliative care provided?

Palliative care is provided to people living in their own home, in the community, care homes and in hospital, and is provided regardless of the person's diagnosis or which setting they are in.

3.4 Who provides palliative care?

People who face life-limiting illness require different levels of health and social care at different points in the course of their illness. Apart from care and treatment that is specific to their life limiting condition(s), they are likely to have needs that are often referred to as palliative or end of life care, especially as they approach the last year(s) and end of their lives.

A whole range of health and social care staff provide palliative care (for example - GPs, community and district nurses, care home staff, hospital teams, hospice teams, social workers, family members). The professionals involved in the palliative care team will depend on what sort and level of care and support a person and those important to them needs. The palliative care that they receive for these needs can be described as either generalist or specialist palliative care depending on the level of expertise required to support them and the professionals delivering the care.

3.5 What is generalist palliative care?

Palliative care that does not require input from professionals with specialist training and knowledge is termed "generalist or core-level" palliative care. For the purpose of this document we will use the term generalist palliative care. Generalist palliative care forms the majority of universal care and support services required by people with life-limiting conditions. All professionals and staff in health and social care have a role in the effective provision of generalist palliative and end of life care services across all care settings such as a hospital or community.

3.6 Who provides generalist palliative care?

General health and social care professionals give day-to-day palliative care to people as part of their roles. A person might see these people regularly as part of your usual care:

- GP

- district or community nurses

- hospital emergency department staff and ward teams

- care home staff

- social workers

- health care assistants

- family and friends

- religious and spiritual care professionals

- ambulance service professionals.

Generalist palliative care professionals should be involved as early as possible after a person has been diagnosed with a life-limiting illness. They will assess the person's needs and wishes, and those of your family and friends. They might also refer the person to specialist care services if needed.

3.7 What is specialist palliative care?

Throughout the course of a person's life-limiting illness, sometimes irregularly, sometimes for long periods, they may require expert assessment, advice, care and support from professionals who specialise in palliative care.

Specialist palliative care is the active, total care of patients with palliative care progressive, advanced disease and their families. Care is



provided by a multi-professional team who have undergone recognised specialist palliative care training.⁸

This care is known as specialist palliative care. It can also be called specialist level palliative care. For the purpose of this document we will use the term specialist palliative care. Specialist palliative care can help people with more complex palliative care needs that cannot be met by the person's usual generalist palliative care team (i.e. GP, district nurses or care home staff).

The focus of specialist palliative care is on quality of life in terms of a person's physical, psychological, social and/or spiritual needs. Examples include complex physical symptoms, rehabilitation or family situations and ethical dilemmas regarding treatment and other decisions. Input from specialist palliative care professionals to the care of a person must be based on the needs of the person and not the illness they have.

3.8 Who provides specialist palliative care?

Specialist palliative care is provided by specially trained multi-professional specialist palliative care teams with professionals who will have

undergone specialist training and experience in this area. These professional teams are generally based in a hospice, in the community, an NHS specialist palliative care unit or an acute hospital.

They can be made up of different healthcare professionals and co-ordinate the care of people with life-limiting illness. Specialist palliative care professionals are experts in providing palliative care and are involved in managing more complex care problems and providing joined up care. A person might see one or more specialists in the team following referral such as:

- palliative care doctors in hospital or community settings

- palliative care nurses and clinical nurse specialists (CNS)

- physiotherapists, occupational therapists and dieticians

- social workers and counsellors.

A specialist palliative care team can provide a range of support, which is likely to vary from location to location, or be offered on a continuous basis or as and when needed. This means service provision could dip in and out over time according to a client's changing needs and the progression of their illness. As specialists, they also advise other generalist palliative care professionals on palliative and end of life care.

The specialist palliative care team's support is also likely to increase as a patient approaches the end of life care stage of palliative care.

⁸ Tebbit, National Council for Palliative Care, 1999

3.9 Who needs specialist palliative care?

The majority of palliative and end of life care is delivered through universal care and support services and targeted palliative and end of life care. A minority of patients who have life limiting illness and who are dying will require specialist palliative care. However, patients can move from specialist to generalist palliative care and vice versa as their needs change. This is demonstrated in the diagram of universal palliative and end of life care services below.

3.10 What do we mean by community-based specialist palliative care?

Specialist palliative care can be provided in different settings including in a person's home, in hospital, in a residential care home or nursing home, in a hospice, some out-patient clinics and day centres, and community health care centres.

Whilst we have described above the entirety of palliative and specialist palliative care, there are many patients with specific needs that can best be supported by community-based specialist palliative care services.

Universal Palliative and End of Life Care

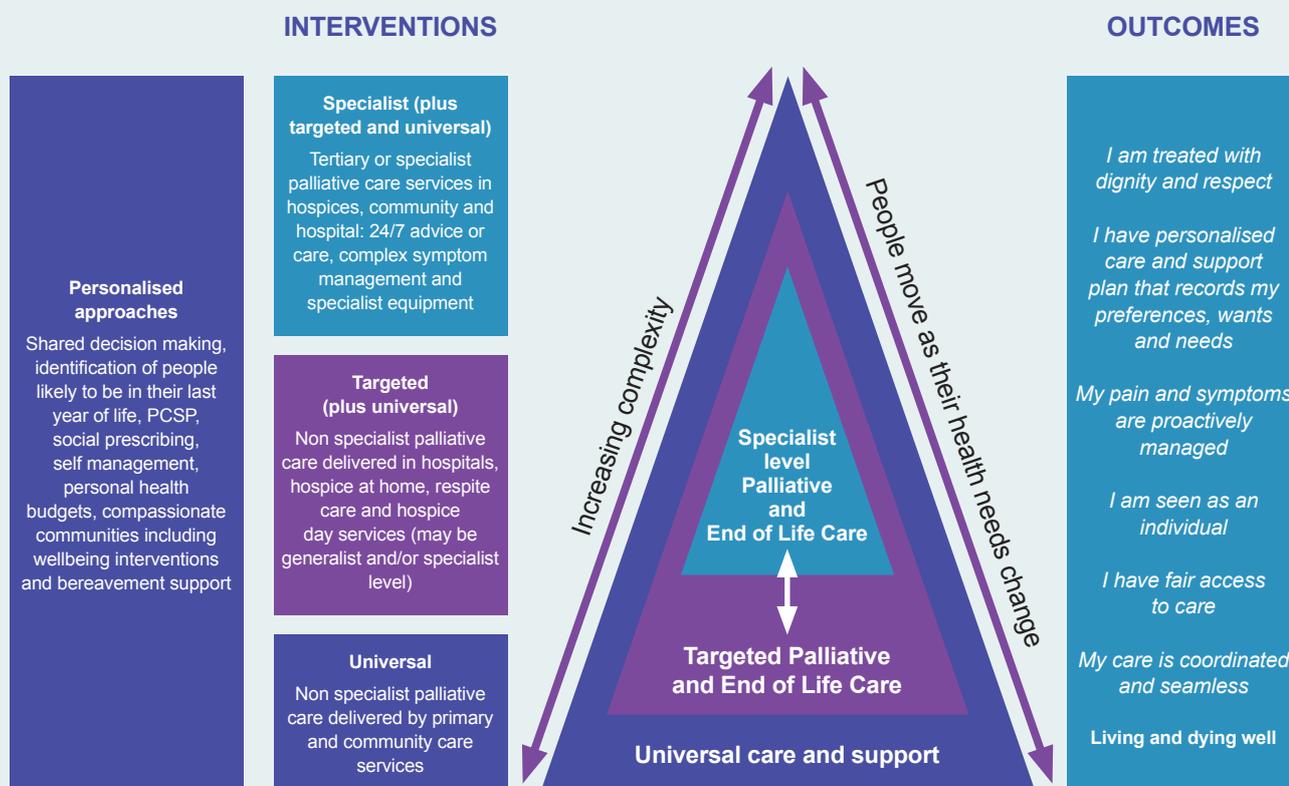


Diagram above reference: NHS National Universal model of Palliative and End of life care (PEOLC) 2021



For this document when we refer to community-based specialist palliative care services we mean those services provided in a community setting which is outside of the acute hospital or GP surgery.

Community-based specialist palliative care is care that is delivered in the patient's home, a care home, other usual place of residence, a hospice or a community health centre. It does not refer to specialist palliative care in a hospital setting.

Community-based specialist palliative care may contain, but is not limited to one or more of the following elements:



COMMUNITY-BASED SPECIALIST PALLIATIVE CARE TEAM

Specialist team consists of doctors, nurses and therapists with specialist expertise in palliative care. The nurses and therapists visit patients in their homes (home in community, care homes, usual place of residence) with input from the team's specialist doctors. Also provide 24/7 advice to patients, families and carers as needed.



DAY HOSPICE SERVICES AND OUTPATIENT DAY CARE

Provide care for patients who need more prolonged treatment or investigations than outpatients, but who do not need to stay in the hospital or hospice overnight.



SPECIALIST INPATIENT HOSPICE BED-BASED CARE UNITS

Specialist palliative care health needs identified. Person is admitted to hospice inpatient bed for symptom management overseen by a specialist consultant and/or specialist nursing team.



HOSPICE AT HOME OR BOTH

Hospice@Home is tailored to the need of the patient and can provide to provide a few hours of care through to being able to deliver twenty four hour care in the terminal phase of a patient's illness. Care is usually provided for up to two weeks.

Carers assist with all aspects of personal care from bathing and preparing meals to escorting patients to appointments for treatments such as chemotherapy or easing patients' discharge from hospital to their homes. Another important part of the service is to lessen the strain for family members who are caring for the patient.



SPECIALIST RESPITE AND SHORT BREAKS RESPITE CARE

For complex cases where case management at usual place of residence is difficult. This may be planned or urgent care and take place in the person's home or in a setting outside of the home such as a hospice or long-term care facility.

3.11 What support can community-based specialist palliative care services provide?

Community-based specialist palliative care can provide a number of services to the patients they care for including:

- **Specialist advice and support:** for example, co-ordinated support for patients with a high level of need, and the people supporting them, at their place of residence (hospice at home), or advance care planning.

- **Symptom management:** a patient's GP or hospital consultant can seek the advice and support of the community and hospital specialist teams around symptom management (e.g. pain or nausea), particularly where the symptoms are complex.

- **Day care and in-patient hospice services:** including review and assessment of physical needs, emotional and psychological support, creative and complementary therapies and advice on benefits. Support may also include short stays within the in-patient hospice unit for symptom management or respite, or to be cared for at the end of life.



3.12 How to access community-based specialist palliative care?

Anyone can refer any person with a life-limiting illness to community-based specialist palliative care services, although it is usually done by healthcare professionals. Examples of who can refer to community-based specialist palliative care:

- GPs or district nurses

- hospital doctors or nurses

- other specialist palliative care teams (ie. hospital or in community)

- patients themselves or their carers.

In general, the referral criteria for these services includes:

- The person being referred has an active life-limiting illness; a limited prognosis (likely course of the condition); and the focus of care is on quality of life.

- The person being referred has complex needs that cannot be met by those providing care (e.g. GP, hospital consultant, district nurse). These needs may be physical, psychological, social and/or spiritual. Examples include complex physical symptoms (ie. pain), difficult family and home situations, and ethical considerations.

- Family and carers who need extra support.

The person being referred to specialist community-based palliative care services should give their informed consent to the referral or if unable to do so, the referral should follow a 'best interests' decision (according to the Mental Capacity Act 2005). A referral may



be made at any point in the patient's illness pathway if the patient has needs requiring the input of a specialist.

3.13 What do we mean by approaching end of life and end of life care?

People are considered to be approaching the end of life when they are likely to die within the next 12 months. Although for people with some life limiting illnesses, this can be hard to predict and it could be years or months. This includes people with:

- Advanced, progressive, life-limiting illness.
- General frailty and co-existing conditions that mean they are expected to die within months.
- Existing conditions if they are at risk of dying from a sudden acute crisis in their condition.
- Life-threatening acute conditions caused by sudden catastrophic events.

End of life care is support for the people who are in the last year (s) and months, or days of their life. A person can receive end of life care at

home, in a care home, in a hospice or in hospital. End of life care is an important part of palliative care for people who are considered to be in the last year of life, and should follow from the diagnosis of a person entering the process of dying. As this timeframe can be difficult to predict and some people might only receive end of life care in their last weeks or days of life.

End of life care aims to help people live as well and comfortably as possible until they die and to die with dignity. The individuals providing the end of life care should ask the person about their wishes and preferences for their care, and take these into account as they work with the person to plan their care (i.e. support the person to complete an advance care plan and provide care in line with this in as much as possible).

End of life care should also support the person's family, carers or other people who are important to them, and continues for as long as a person needs it. It can also involve support with practical things like making a will or getting financial support.

3.14 Who provides end of life care?

Many different health and social care professionals may be involved in your end of life care, depending on your needs. For example: hospital doctors and nurses, your GP, community nurses, hospice staff, social care staff, physiotherapists, your family and friends, and ambulance crew.

If a person is receiving end of life care at home, in a hospice or in a care home, their GP has overall responsibility for their care but will liaise with the rest of their care team which could also involve the community or hospital specialist palliative care team. Community nurses (i.e. district nurses) usually visit the person at home, and family and friends may be closely involved in providing end of life care.

CURRENT COMMUNITY-BASED SPECIALIST PALLIATIVE CARE PROVISION FOR ADULTS IN NW LONDON

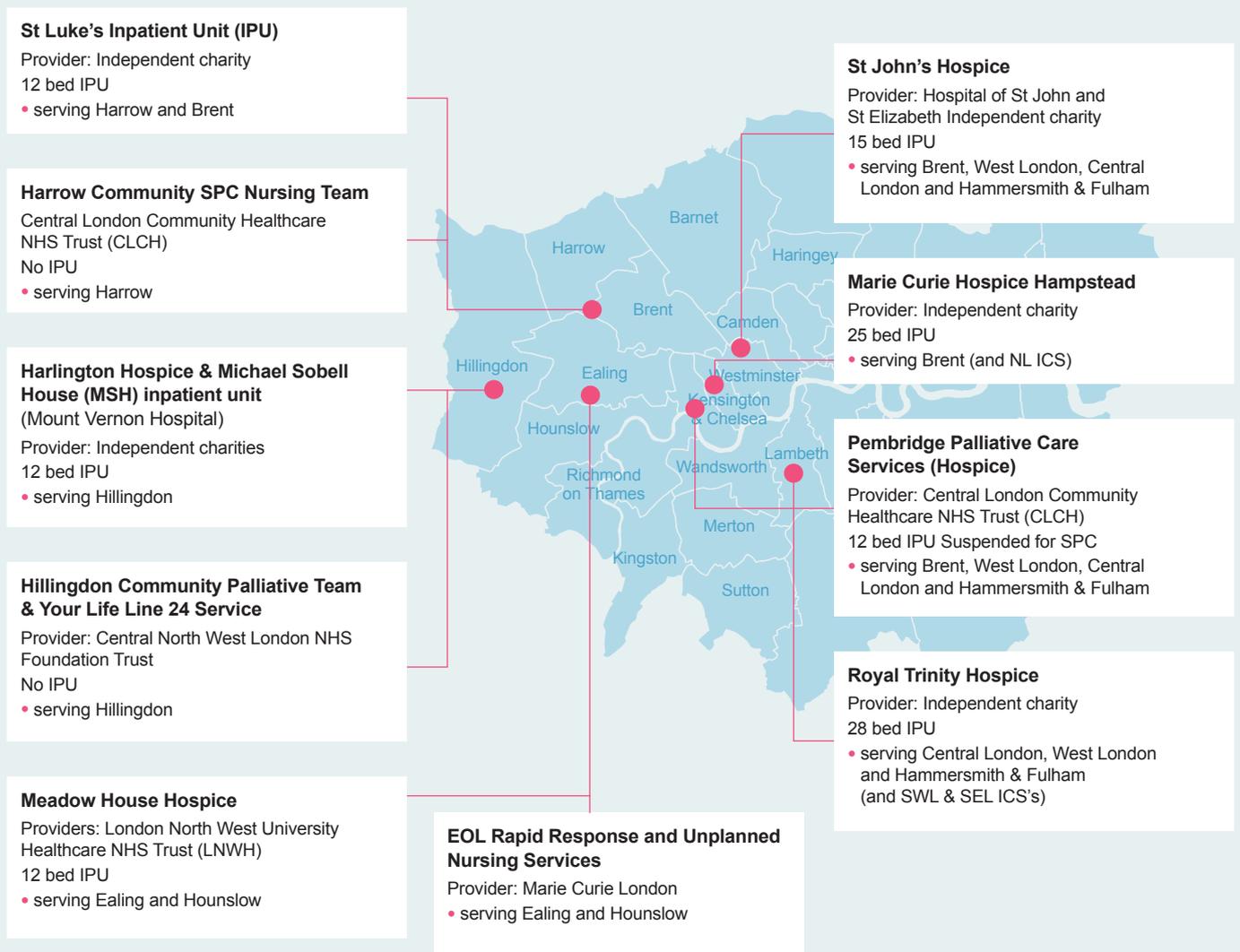
NW London has eight providers of community-based specialist palliative care services, which includes seven hospice providers.

4

Between them they provide a combination of main clinical services (specialist inpatient beds, community specialist palliative care nursing, day hospice and outpatient services as outlined in the table on page 19), amongst some other services (ie, Lymphoedema well-being services, complementary therapies etc). Some of our providers only provide community-based specialist palliative care nursing services and do not have inpatient units.

Whilst three providers are 100% NHS funded (Pembroke Palliative Care Services provided by CLCH, Meadow House Hospice provided by LNWH and the Hillingdon Palliative Care Team and Your Life Line Team) the remaining five main hospice providers are funded through a combination of NHS and charitable income.

NW London’s adult community-based specialist palliative care (SPC) provision (services by provider and location)



WHY THINGS NEED TO CHANGE?

There are eight broad reasons why things need to change for in NW London Community-based Specialist Palliative Care provision.

5

In the following section we list the reasons why things need to change and want to hear your views on these issues and any others that may be important to you:

5.1 Learning from previous service improvement reviews and engagement

Residents across NW London have previously taken the opportunity to tell the NHS what they want from services and our intention is to build on this work as we had some very valuable learning.

This future transformation work will build on this previous review of adult community-based palliative care and end of life services improvement work that commenced in Brent in 2018, as well the [Independent Strategic Review of palliative care services⁹](#) delivered by Penny Hansford in the London Boroughs of Hammersmith and Fulham, Kensington and Chelsea, and Westminster in 2019, and the subsequent engagement carried out in 2020.

The new programme of work will be expanding NW London wide, to include the other four London boroughs (Harrow, Hounslow, Ealing and Hillingdon) and community-based specialist palliative care providers not involved previously in the review and engagement work.

A summary of the feedback received is below and the full report can be found at www.nwlondonics.nhs.uk/get-involved/cspc:

- There was strong agreement from all that palliative care services are important to support people to die with dignity.
- More needed to be done to communicate and raise awareness of palliative care services so that residents could more easily access them,



health professionals were more comfortable to talk about death and dying and that it enabled earlier care planning.

- Residents wanted to be reassured there was enough capacity to care for people who needed support from community-based specialist palliative care services.
- Residents want to know more about the evidence the CCG was using.
- There was agreement that palliative care needed to reach more people, especially Black, Asian and Minority Ethnic (BAME) communities, but that we also needed to do more to take into account peoples cultural and religious needs.
- People wanted to know more about the problems in recruiting and retaining staff.
- Residents wanted to understand any funding issues and how that might impact service delivery.

⁹https://www.centrlondonccg.nhs.uk/media/95631/2-PJH4-Independent-review-palliative-care_Report.pdf

- There was concern about the impact that any change in services would have for travel and transport, with many elderly people not owning their own car and relying on public transport.
-

- Whilst many were happy with the care they had received, there was general acceptance that things needed to change if we were to improve access for all.
-

- Residents wanted easily understandable information and for their views and opinions to be taken into account.
-

- Strong local desire to maintain inpatient services at Pembridge and opposition to the suggestion it would close.
-

This work was paused in early 2020 as a result of the Covid-19 pandemic.

In 2019, Hillingdon CCG spoke to local residents about their experiences of palliative and end of life care which highlighted:

- The diverse nature of their communities and their needs.
-
- The importance for the care giver (the health professional) to be sensitive and aware of the needs of the patient, which may include their cultural and faith aspirations).
-
- The importance for patients and their families to be aware and involved in their care, so that their voices are heard and their wishes are respected.
-
- More needed to be done to ensure that everyone knew about the care is fully benefiting from the support that is already in place.
-

This previous engagement work has provided us with very valuable learning which we will bring forward into this system wide review. However, the new programme gives us the opportunity to make sure:

- The previous work came to the correct conclusions that are applicable across NW London as a whole,
-

Or

- develop new proposals as to the future of our adult community-based specialist palliative care.
-

Your views

The publication of the Issues Paper gives you the opportunity to have your say on community-based specialist palliative care services but do you have a view on the outcome of the previous engagement work carried out?



5.2 National context

The Long Term plan and the recently refreshed [Ambitions for palliative and end of life care: A national framework for local action 2021 to 2026](#) are the most current national directives guiding both palliative and end of life care.

These along with The National Institute for Health and Care Excellence (NICE) guidelines and standards, national palliative and end of life commissioning resources, and other relevant key documentation will form the basis on which the adult community-based specialist palliative care improvement work is progressed.

The [NHS Long Term Plan](#)¹⁰ defines the ‘must dos’ so the NHS can be fit for the future based on the experiences of patients and staff. The plan commits to provision of more personalised palliative and end of life care and specifically asks commissioners to consider end of life care in the following areas:

- Increasing the offer of personal health budgets (section 1.41).
- Increase personalised care and support planning (section 1.42).

The Ambitions for palliative and end of life care framework was co-produced by a partnership of 27 national organisations, including health and social care bodies across the statutory and voluntary sectors. It provides a national framework for us to base local delivery of palliative and end of life care and consists of six ambitions, that describe what good looks like in palliative and end of life care for people of all ages, including their carers and others who are affected.



The six ambitions are:

1. Each person is seen as an individual
2. Each person gets fair access to care
3. Maximising comfort and wellbeing
4. Care is coordinated
5. All staff are prepared to care
6. Each community is prepared to help

The Ambitions framework emphasises the contribution of specialist palliative care services as an integral part of the overall care in meeting a person’s changing needs as their illness progresses. As well as the needs of families, carers and those important to the person, and other professionals who have the main responsibility for their care.

¹⁰ <https://www.longtermplan.nhs.uk>

The National Audit of Care at the End of Life report for England and Wales 2019/2020 makes a number of recommendations on the future delivery of palliative care and end of life care relevant to this review:

- Put in place systems and processes to support people approaching the end of life to receive care that is personalised to their needs and preferences.
-
- Review capability and capacity across all care settings, to provide appropriate care at the end of life, and to support people important to the dying person through to bereavement, with the aim of better meeting people's needs and preferences.
-
- Ensure systems and processes for anticipatory prescribing for patients transferring from hospital to home or care home to die are aligned across the health and social care system.
-
- Require and support health and care staff to gain competence and confidence in communicating effectively and sensitively with the dying person and people important to them in the last days and hours of life.
-

In addition, there is an extensive library of research and papers on what good palliative care looks like and the issues that act as a barrier preventing people accessing palliative care on the NW London ICS website at www.nwlondonics.nhs.uk/get-involved/ics

Learning from the Covid-19 pandemic

We also need to learn from the challenges and long-standing health inequalities that have been highlighted, and opportunities which have arisen from the Covid-19 pandemic to improve palliative and end of life care. We need to



ensure that positive innovations and solutions can be sustained and continuous improvement takes place.

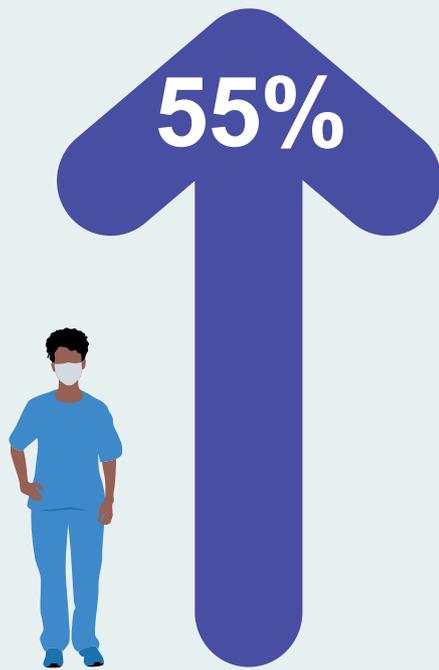
Your views

What is your view on the information provided and do you have anything you would like us to consider as we discuss the importance of community-based specialist palliative care?

5.3 Changing needs of patients and population growth

In the UK we have a rapidly ageing population with multiple morbidities and life-limiting illnesses. The health needs of people across the country including NW London are changing and the demands on our health services are increasing. Improvements in care and treatments mean that more people are living longer with more chronic illness. The NHS in the short and long-term will need to look after more people with greater needs.

In 2019 the UK population was 66.65m people with 530,000 deaths that year. That is 0.8% of the population. National population estimates show that the number of deaths within the UK will rise by an additional 130,000 deaths



The number of people receiving palliative care services is set to **increase by 55%** over the next ten years.

each year by 2040 and more than half of these deaths will be in people aged 85 years or older.

In 2017 it was estimated that these changing disease patterns and demographics would mean at least a half a million people in England and Wales would need palliative or end of life care every year by 2040, with cancer and dementia the main drivers of increased need. In mid-2018, there were 1.6 million people aged 85 years and over. By mid-2043, this is projected to nearly double to 3.0 million¹¹.

NW London population growth rate by borough and age

By 2023 it is expected that the over 65's population across NW London will be 30,3990,

a 14.8% increase on 2017 figures. Five of the eight boroughs will see an increase of more than 15%, with the most significant change being in Brent

NW London deaths

The average number of deaths per year in NW London between 2015-2020 was 11,565. The actual number of deaths in NW London in 2019/2020 was 11,960 for all deaths. 27.81 % of these deaths were due to cancer and 72.19% non-cancer related. Of all the 11,960 deaths in 2019/202:

- 52.69% deaths took place in hospital

- 24.45% at home

- 14.53% at care homes

- 4.87% at hospice

- 3.56% in other locations.

In 2019/2020, NW London statistics for deaths showed that:

- A similar proportion of deaths in hospitals took place in comparison to the whole of London which is only lower by 1.59%,

- 8.01% more deaths took place in hospital for London than the England national average of 44.68%.

- Death at patient's home, NW London was almost on a par with London at 24.45% and England national average at 24.13%.

- Care home deaths, NW London was 7.26% lower than the national England average of 22.60%.

¹¹ ONS - <https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationprojections/bulletins/nationalpopulationprojections/2018based>

The tables below show that the over 65's population will grow at a much higher rate than younger age groups.

	2018		2019		2020		2021		2022		2023	
	Under 65	65+										
Brent	0.28%	3.27%	0.72%	2.29%	1.05%	2.60%	1.31%	2.94%	1.23%	2.63%	1.03%	3.18%
Ealing	-0.59%	2.85%	0.68%	2.48%	1.56%	2.48%	1.94%	2.44%	1.79%	2.45%	1.62%	2.17%
Hammersmith and Fulham	0.78%	2.68%	0.66%	2.08%	2.30%	2.08%	2.17%	2.18%	1.89%	2.20%	1.67%	2.97%
Harrow	0.16%	2.04%	0.72%	1.73%	0.51%	1.99%	0.57%	2.27%	0.51%	1.97%	0.40%	1.86%
Hillingdon	0.54%	1.36%	0.97%	1.38%	0.66%	1.49%	1.11%	1.86%	0.96%	1.88%	0.78%	2.17%
Hounslow	0.27%	2.63%	0.99%	2.19%	1.28%	2.22%	1.75%	2.32%	1.54%	2.57%	1.38%	2.55%
Kensington and Chelsea	-0.38%	2.55%	0.26%	2.12%	-0.18%	2.05%	-0.31%	1.73%	-0.42%	1.84%	-0.60%	2.14%
Westminster	3.37%	4.02%	0.67%	2.73%	0.16%	2.60%	-0.28%	2.52%		2.13%		2.30%

Borough	2023 Predicted Population Over 65's	% Increase on 2017 ¹
Brent	7,028	18.1%
Ealing	6,879	16.2%
Hammersmith and Fulham	2,911	15.1%
Harrow	4,777	12.5%
Hillingdon	4,241	10.6%
Hounslow	4,887	15.4%
Kensington and Chelsea	3,126	13.1%
Westminster	5,255	17.4%
North West London	39,114	14.8%

- In hospice deaths, NW London is 0.86% below the average for London of 6.13%.

The way we have organised our hospitals, community-based services and primary care in the past will not meet the needs of the future. The demands on our system's health services are greater now than ever. The way in which we deliver our community-based specialist palliative care services needs to change in order to meet changing demands, and to improve the quality and safety of services and the experience that patients and their families and carers receive

According to a research study published in the open access journal BMC Medicine in 2017¹², population and mortality trends in England and Wales suggest that 25 percent more people will die each year by 2040, but with at least 42 percent more people needing palliative care due to a sharp increase in the number of people dying from chronic illness, particularly cancer and dementia .

The study concludes that we must prepare for the projected growth in dementia and cancer if we are to provide appropriate care to people dying in the future, and therefore current models

¹²How many people will need palliative care in 2040? Past trends, future projections and implications for services. Etkind et al. BMC Medicine May 2017 <https://bmcmmedicine.biomedcentral.com/articles/10.1186/s12916-017-0860-2>



of palliative care must adapt in accordance to these projected changes, with more attention being given to the needs of people and those close to them when facing progressive illness, particularly those dying from chronic and complex illnesses, and age related syndromes such as frailty and dementia¹².

Your views

Our population is getting older and we will see increasing demand for community-based specialist palliative care. Do you have a view on this and what needs to be done?

5.4 Health inequalities

In 2020, The Marmot Review - 10 years on¹³, was published and follows the original findings from Marmot's review into health inequalities¹⁴. The original report highlighted that across England, people who live within some of the poorest areas will die, on average, seven times earlier than those who are from the richest neighbourhoods. It went on to say that people who live in the poorest neighbourhoods not only die sooner but also spend more of their lives living with a disability or complex health condition.

There is also a lot of evidence that people with protected characteristic and certain populations such as the homeless, Lesbian, Gay, Bisexual, Transgender, Queer & Questioning (LGBTQ), BAME and people with learning disabilities are not well served by community-based specialist palliative care services and are not accessing the care they need, may not always be receiving care that meets their needs.

We still have significant health inequality across England, and, unfortunately high levels of deprivation across NW London. Some key health inequalities challenges that NW London are facing:

- Of our eight boroughs, Brent and Hammersmith & Fulham are amongst the most deprived local authorities in the country.

- Westminster has the highest overall number of people sleeping rough, many of which, will have mental health needs and will be less likely to access primary care services.

- Westminster and Hillingdon boroughs have the highest police use of Section 136 of the Mental Health Act which gives them the power to detain someone if they think they have a mental illness and you need care or control.

- 29% of children in Westminster are from low income families, versus 13.9% in Harrow.

- 78.9% of people are in employment in Harrow, compared to 64.4% in Westminster.

- Rates of emergency hospital admissions for self-harm are twice as high in Hounslow as they are in Harrow.

¹³ <https://www.health.org.uk/publications/reports/the-marmot-review-10-years-on>

¹⁴ <https://www.local.gov.uk/marmot-review-report-fair-society-healthy-lives>

¹⁵ NW London Inequalities analysis.pdf

- 17.1% of people in Hillingdon smoke, versus 9.2% of people in Ealing.

-
- Hounslow has significantly lower life expectancy for both men and women compared to the London average.

-
- Although Kensington and Chelsea have among the highest life expectancies in the country, there are very large inequalities within parts of these boroughs.

-
- Hillingdon, Harrow, Ealing and Hounslow boroughs most frequently record higher rates per thousand for the most common long term conditions. Kensington and Chelsea and Hammersmith & Fulham boroughs have high recorded rates per thousand for correlated long term conditions, anxiety and depression.

-
- We know that our BAME communities are often disproportionately affected by Covid-19. At around the peak of first wave of the pandemic, compared to White Londoners, Black Londoners had around two and a half to three times the risk of dying with Covid-19 (within 28 days of diagnosis) and people of Asian ethnicity had up to twice the risk.

Nationally, those in the most deprived decile have almost twice the mortality rate of those in the least deprived. During Covid-19 Wave 1, this inequality became even wider.

The mortality in NW London in Wave 1 of Covid-19 was greater than the national average. There were a much greater proportion of deaths in the community and fewer in care homes¹⁵.

Marie Curie identified 45 literature reviews describing unmet needs and disparities in palliative and end of life care for BAME groups.



These reviews found BAME people had:

- poorer access to care
- disparities and unmet needs when in receipt of care.

Most people would like to be with their loved one at the end of their life. This can be harder if their loved one is further away from where they live due to distance and travel costs and this can be doubly challenging for people who are on low income.

It also recognised the importance of understanding social inequities such as deprivation, differences in access to care in general, social exclusion and racism, when analysing unmet needs and disparities¹⁶.

Your views

We have large health disparities in NW London and we know that some in our community do not always get good access to care. Are there other issues we should consider and what is your view on possible solutions?

¹⁶ Palliative and end of life care for Black, Asian and Minority Ethnic groups in the UK, Demographic profile and the current state of palliative and end of life care provision. <https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/june-2013/palliative-and-end-of-life-care-for-black-asian-and-minority-ethnic-groups-in-the-uk.pdf>



5.5 Improving the quality of care, and patient and family and carer experience

Patients, carers and families in NW London, depending on where they live, currently receive a different level of service and care when accessing our community-based specialist palliative care services. We also accept that some of these services are not in line with best practice. For instance, [NICE end of life out of hours care quality statement 4](#), states that all adults approaching the end of life, and their carers supporting them should have access to specialist support 24 hours a day, seven days a week, but one of our eight boroughs currently does not have a seven day community-based specialist palliative care nursing service in place.

We also know that only seven of our eight boroughs provide 24/7 specialist palliative care telephone advice, with one of the providers not offering this out of hours (after 5pm). There is also variation in the offer of well-being and bereavement support services across the providers.

The type of care and support on offer also varies between the providers. For example, lymphoedema and hospice@home services are not commissioned across all of the providers

meaning that patients have unequal access to services depending on where they live.

Whilst emergency admissions for patients in their last year of life journey are sometimes necessary. In NW London we often see people being admitted to hospital when they either don't need or don't want to be there as there is a lack of alternative provision and support available in the community that would prevent that admission.

This is especially true for people towards the end of their life and this is not considered to be good end of life care. We know from existing surveys that most people would prefer to die at home if this is possible to achieve. Yet national studies show that people in their last year of life experience an average of 2.28 hospital admissions and spend 30.1 bed days in hospital.

This is more likely to be avoided if patients are identified earlier as approaching their end of life and have adequate and appropriate care, is timely and that high quality advance care planning has taken place to support their wishes and preferences being communicated across the system and being upheld as much as possible.

The percentage of deaths with 3 or more emergency admissions in the last 3 months of life is national key performance measure of end of life care services. It can indicate issues with identification of end of life, planning and availability of services outside of hospital, coordination and information sharing.

Between April 2020 and March 2021, there were 6213 patients in NW London who had admissions to hospital in the last year of life, of which 709 (11%) of these patients had three or more admissions in their last 90 days of life. This totals to 91,876 bed days used, with an



average length of stay being 14.79 days for these patients in their last 90 days of life.

As a result, more of our patients are dying in hospital which is not what the majority of patients and families want. Providing care in hospital is often much more expensive than providing good quality services in the community or in the patient's own home.

We need to question whether the services and the way in which we are delivering them for the residents of NW London are good enough or if we need to change the way we do things if we are to deliver services that are equitable, high quality, safe and meets the needs of our diverse communities.

The CQC report, A Different Ending¹⁷ indicates that because commissioners and providers do not fully understand or consider all the specific needs of the different groups in their populations, people in certain groups in society experience poorer quality care at the end of their lives.

We know in NW London that even where we have high quality care and services they do

not always reach wide enough to support all our diverse communities who are not accessing the care that is available and that the services that are available do not always fit their preferences and needs. Improving the delivery of community-based specialist palliative care services will not reduce all end of life care hospital admissions and deaths, but will definitely help to reduce some unnecessary hospital admissions and support more people from our diverse communities to die in their preferred place.

More must be done to ensure that everyone who lives in NW London has equal access to high quality, accessible community-based specialist palliative and end of life care, that is consistently better for all. The needs of people of all ages who are living with dying, death and bereavement together with their families, carers and communities must be addressed, taking into account their priorities, preferences and wishes.

Your views

What is your view on how we can improve the quality, safety and equity of the services we provide as well as improved patient experience? What does good look like to you?

5.6 Fragmentation and the need for more joined up services

[NICE Quality standard 13, statement 3](https://www.nice.org.uk/guidance/qs13/statement-3)

[www.nice.org.uk/guidance/qs13/chapter/](https://www.nice.org.uk/guidance/qs13/chapter/Quality-statement-3-Coordinated-care)

[Quality-statement-3-Coordinated-care](https://www.nice.org.uk/guidance/qs13/chapter/Quality-statement-3-Coordinated-care) says that “Adults approaching the end of their life should receive care that is coordinated between health and social care practitioners within and across different services and organisations.”

The rationale being that adults approaching the end of their life are likely to receive planned and emergency care from a range of services and in a number of settings. Coordination of these services is necessary to ensure that there is a

¹⁷ https://www.cqc.org.uk/sites/default/files/20160505%20CQC_EOLC_OVERVIEW_FINAL_3.pdf

shared understanding of the person's holistic needs and that the person receives end of life care that meets their specific needs and personal preferences. Coordination also leads to care being provided more quickly, as it is needed.

Improved information sharing across organisations will help to ensure that adults approaching the end of their life do not have to repeatedly provide information that can be shared between services. Coordination will help to ensure that people are not over-burdened with appointments and home visits. Appointments can be reviewed and optimised if possible, for example, coordinating appointments to avoid multiple visits.

In NW London we have multiple providers of community-based specialist palliative care. Community-based specialist palliative care nursing teams for some boroughs are also provided by separate providers to those providing bedded inpatient hospice care.

During our previous engagement on palliative and end of life care in 2019/20, we heard from our residents and clinicians that the existing fragmentation of services makes it difficult for



patients, families and clinicians to navigate services, particularly out of hours when seeking expert and timely advice in the event of a crisis.

We also know our services do not always work well enough together to support the needs of our patients who can be asked multiple times for the same information by people involved in their care. Patients are bounced between services and care settings without services seeming to talk to each other. There is also the additional IT challenge of not all services having appropriate access to clinical information held electronically by partner providers for patients under their care. We aim to work collaboratively to address these issues.

Patients need integrated services that work across organisational boundaries to support the best care for them and their families. If we are to improve the quality of care patients receive in the place they want to receive their care, we need a more joined up approach between services so they all have a joint understanding of the clinical needs of the patient and importantly what their wishes are.

Personalised care, built around individualised quality advance care planning recorded on London's shared urgent digital care plan platform (currently Coordinate My Care), must be central to any improvements to the model of care for our services.

There are also likely to be missed opportunities for hospices and other providers to realise economies of scale through shared resources and collaborative working. In some instances, NW London is not the main commissioner, further complicating the landscape.

Your views

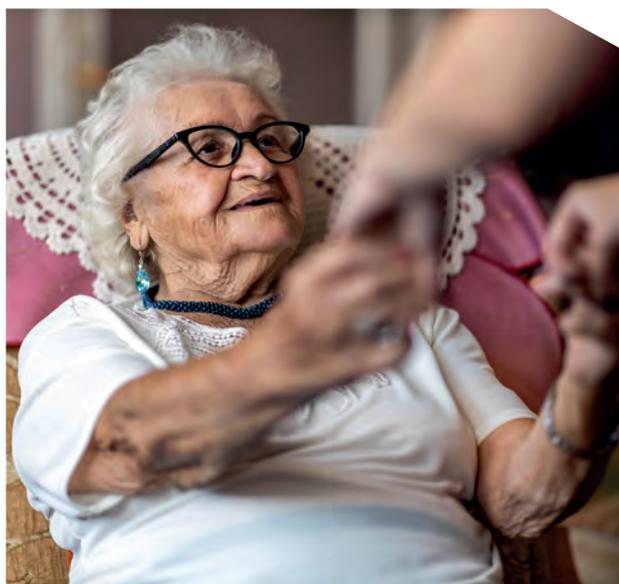
Our services are more fragmented than they should be. What is your view on this and what we should do to make them more joined up?

5.7 The workforce challenge

Nationally the safe and effective delivery of quality 24/7 palliative care in all settings is currently difficult to achieve consistently as a result of a national shortage of key palliative medical staff including specialist palliative care (SPC) consultants and specialist palliative care clinical nurse specialists (CNS) leading to gaps in the provision of specialist palliative care.

This is also true in NW London where we have a number of key vacancies across the patch for acute and specialist palliative care provision. Despite ongoing efforts by providers they have had trouble recruiting and retaining these key staff into permanent positions and this means services are not as sustainable and robust as they should be.

To cover this gap we employ lots of temporary doctors and nurses which is expensive and makes the service fragile should they leave at short notice, which does



happen. One of our challenges is to build a model of care and services which has more permanent staff who are motivated to stay in NW London. This will lead to a more resilient service that is able to meet the needs of our patients, families and carers.

We need to explore ways to make better use of the expertise we currently have to deliver care, which could include consideration of new roles like social prescribers and GPs with specialist interest in community specialist palliative care.

Your views

What is your view of the workforce challenges we face and what do you think possible solutions are?

5.8 The financial challenge

Nationally, NHS spending has not been cut. It has risen slightly above inflation every year since 2010. But the costs of providing care are rising much more quickly than that, due to innovative but costly new technologies and rapidly increasing demand from a rising and ageing population. This has been further accelerated by the Covid-19 pandemic and there are increasing conflicting demands on the money that we have.

The NHS in North West London the NHS has an underlying deficit of £453 million in 2021/2022. We are spending more money than we have and our challenge is continuing to deliver high quality care for local residents whilst trying to balance the books. Our focus is efficiency and better resource management whilst supporting the need to move resources within NW London ICS to help reduce inequality of service and access, and improve the quality of our services.

The amount that is being spent across NW London on community-based specialist palliative care in 2021/2022 is around £18



million. Whilst the amount we spend is not likely to fall, we cannot be sure we will be able to get an increase in funding as we move forward. We must take this into account when developing services if we are to develop equitable and sustainable services for the future. We also need to take into account that if we delivered everything that everyone wanted our services would not be affordable.

Most NHS care takes place outside hospital, with community-based services being more convenient for patients. However, most of the NHS funding is currently spent in hospitals, with emergency admissions for patients in last year of life having a significant financial burden.

If we are not able to invest additional resources into community-based specialist palliative care services, we will need to review how we spend the money across all elements of the services we have, to ensure the services we provide both meets the clinical and individual needs of patients and reflect the choices that they wish to make. Increasing palliative and end of life care interventions in primary, social and community care settings are potentially cost-saving or cost-effective¹⁸.

A Sue Ryder report from March 2021, states that currently 245,000 people in England are expected to receive palliative care in the coming year and this is expected to increase to 379,000 people per year by 2030. The current national funding model for charitable hospices mean they only receive around one third of the money required to fund their end of life services from the government.

The running costs of the palliative care sector are estimated to be £947 million a year between now and 2030. If government funding remains the same, the hospice sector will be required to fundraise £597 million every year in order to keep hospices open.

Historically, the provision of specialist palliative care services by the independent sector has been partially funded by the NHS (with a share ranging between less than a fifth to two fifths of total expenditure) with the rest of the funds raised from donations, fundraising activities, charity shops etc. Information gathered from Hospice UK (the national hospice membership charity) showed that, even before the start of the COVID-19 outbreak, around 90% of surveyed hospices reported a lack of resources to meet increasing demand for services, and one fifth were thought to be at risk of imminent closure due to extreme financial difficulties¹⁹.

Financial pressure on the charitable hospice sector was already increasing in 2019/20 due to rising demand for services before the Covid-19 pandemic significantly impacted charitable income for NW London hospice providers with almost all fundraising activities coming to a halt.

¹⁸ Public Health England: Cost-effective commissioning of end of life care Understanding the health economics of palliative and end of life care https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/612377/health-economics-palliative-end-of-life-care.pdf

¹⁹ It is time to end the hospice funding crisis - <https://www.sueryder.org/news/hospice-funding-crisis>

In NW London, hospices have taken steps to reduce their expenditure, but this still does not provide sufficient protection from further economic downturns resulting from subsequent Covid-19 waves or from a wider recession. This leaves our charitable hospice sector vulnerable and fragile, and work needs to be done to ensure we have robust and sustainable services for the future.

There is also considerable variation in NW London's community-based specialist palliative care contracts including:

- The amount of activity they have to deliver and workforce capacity to deliver this.

- Some are block contracts where we pay an agreed amount for the service they provide and some are paid based on the amount of activity they deliver.

- Some hospices are commissioned by different NHS boroughs and other ICS's to provide different service models from one site.

- There is no consistent service specification between the CCG and all providers who are providing these similar services.

- The amount we pay per day for an in-patient bed varies across providers.

- There is limited incentive for cross organisational collaboration and efficiencies.

This inconsistency creates a fragmented and inequitable service offer for NW London residents, and is not the most cost-effective or innovative way of using the current funds available for this provision. In the landscape of constrained resources and increasing demands for these community-based specialist palliative care services, all system partners need to



come together to creatively develop new ways of working to support more effective use of our existing resources.

Your views

The NHS is under pressure and we cannot spend more money than we have. What do you think that means for community-based specialist palliative care and what are the possible solutions?

WHAT WE NEED TO DO NEXT?

We now need the input of patients and carers along with the wider clinical staff across the GP community, mental health services and hospitals, the community, voluntary and faith sectors, in generating ideas to help us to improve the quality, safety and equity of care provided to patients, families and carers with excellent experience of that care.

6

We want to know what you feel good care looks like and from that, working with our partners and taking into account all the issues raised in Section 5 will develop a model of care that will enable us to deliver that excellent care. It is only when this has been done will we look at what services we need to deliver the care and access whether we have the resources to deliver it, including workforce and finance.

Our aim through this work is to develop a new integrated model of care, single service specification for our services and a consistent approach to population health needs and person centred outcome measures.

- We plan to have wide reaching, robust and transparent communication and engagement with public and patients, including community, voluntary and faith groups.
- Publication of this Issues Paper and other supporting documentation is designed to facilitate discussions and support innovative thinking.
- Co-develop and implement with partners, a new integrated model of care for community-based specialist palliative care and a single service specification for our services that better meets our population needs.
- Collaboratively design more responsive, sustainable and resilient services with a wider reach.
- Achieve consistency and equity in access to services across NW London and level up to good practice where possible.

- Facilitate better co-ordination of care, improve communication and integration with other services across community and acute care settings.

- Collaborative working and pathway development with other ICS programmes including cancer, enhanced health in care homes, continuing health care, community nursing and acute discharge improvement work.

- Work in partnership with health, social care and the voluntary, community and faith sectors.

- Explore development of compassionate communities with more integrated/ partnership working with Vvoluntary and community sector.

- We will develop a consistent approach to person centred outcome measures, population health needs assessment, benchmarking and monitoring.

- We are working closely with our care home partners to utilise digital technology to support the development of shared care records for improved communication of patient wishes and well-being. We also aim to develop innovative ways using digital technology to facilitate improved education via specialist palliative care colleagues for our generalist palliative care workforce

Your views

What is your view on our proposed approach as set out above? Are there other issues that we should consider? What is your view of the possible solutions?

6.1 The timeline



6.2 Get involved

We want your help in exploring 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.

The easiest way to keep up to date is to sign up to Community-based Specialist Palliative Care News, the e-newsletter that we will use to keep people up-to-date. To sign up to receive the e-newsletter [click here](#).

We have also developed a dedicated section on the NW London ICS website www.nwlondonics.nhs.uk/getinvolved/cspc which contains all the most recent information and the documents and links we have highlighted through-out this document.

The website will also host links to surveys and registration for events once these become available.

Community and voluntary sector organisations will be running events for service providers and also holding focus groups for service users and carers.

If you would like to get involved in these activities, then please contact us.

Should we come to the conclusion that we need to develop proposals for services changes, we would need to consider whether we would need to go out for further engagement or consultation.

To respond to the questions raised in this Issues Paper, or to share any questions or concerns you have, go to www.nwlondonics.nhs.uk/getinvolved/cspc

Email us: nhsnwlcg.endoflife@nhs.net

If you or someone you know wants this Issues Paper translated or in another accessible format, please contact us via the details on the back cover.

GLOSSARY OF TERMS

7

Advance care planning (ACP)

Advance care planning (ACP) is the term used to describe the conversation between people, their families and carers and those looking after them about their future health and care wishes and priorities. It is a way for a person to think ahead, to describe what's important to them and have this recorded to ensure other people know their wishes to help that person to live well right to the end of their life.

Advance Care planning is a key means of improving care for people nearing the end of life and of enabling better planning and provision of care, to help them live well and die well in the place and the manner of their choosing

Community-based specialist palliative care

By community specialist palliative care, we are referring to settings where this care is delivered that are not within a hospital or a GP surgery, but rather in a patient's own home, a care home, a hospice and a community hospital or centre.

Compassionate care

Care that is person centred (care that is focused on the needs and preferences of the individual) and involves the person delivering the care demonstrating characteristics such as empathy, sensitivity, kindness and warmth towards their patient²¹.

Generalist palliative care

Generalist palliative and end of life care is provided on a day to day basis by many health and social care professionals (ie. GP, District Nurse, Social workers, care home staff. It can also be provided by a patient's family and carers in their home.

Health inequalities

Health inequalities are unfair and avoidable differences in health across the population, and between different groups within society. Health inequalities arise because of the conditions in which we are born, grow, live, work and age. These conditions influence our opportunities for good health, and how we think, feel and act, and this shapes our mental health, physical health and wellbeing²².

Life limiting illness

A life-limiting illness is an illness that can't be cured and that a person is likely to die from. You may also hear the terms 'terminal', 'progressive' (gets worse over time) or 'advanced' (is at a serious stage) to describe these illnesses. Examples of life-limiting illnesses include advanced cancer, motor neuron disease (MND) and dementia²³.

Model of care

A "Model of Care" broadly defines the way health services are delivered. It outlines best practice care and services for a person, population group or patient cohort as they progress through the stages of a condition, injury or event. It aims to ensure people get the right care, at the right time, by the right team and in the right place²⁴.

²¹ <https://jcompassionatehc.biomedcentral.com/articles/10.1186/s40639-015-0015-2>

²² Definition of Health Inequalities, NHS England <https://www.england.nhs.uk/ltphimenu/definitions-for-health-inequalities>

²³ Marie Curie - <https://www.mariecurie.org.uk/help/support/diagnosed/recent-diagnosis/palliative-care-end-of-life-care?msclkid=f18fe3a5a903141b6eef82d67ac30640>

²⁴ Government of Western Australia, Department of Health (2012) <http://www.agedcare.health.wa.gov.au/home/moc.cfm>

Palliative care

The World Health Organisation (WHO) defines palliative care as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

Palliative care is for individuals of all ages with a life limiting (non-curable) illness aiming to improve the quality of life of patients, their families and their caregivers as it:

- Provides relief from pain and other distressing symptoms.
- Affirms life and regards dying as a normal process.
- Intends neither to hasten or postpone death.
- Integrates the psychological and spiritual aspects of patient care.
- Offers a support system to help patients live as actively as possible until death.
- Offers a support system to help the family cope during the patient’s illness and in their own bereavement.
- Uses a team approach to address the needs of patients and their families.
- Enhances quality of life and may also positively influence the course of illness.

- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, and includes those investigations needed to better understand and manage clinical complications.

Personalised care

Personalised care is about giving people the same choice and control over their mental and physical health that they have come to expect in every other aspect of their life. It accepts a one-size-fits-all health and care system cannot meet the complex needs and expectations of the individual. Personalised care is based on ‘what matters’ to people and their individual strengths and needs.

Personalised health budget

A personal health budget is an amount of money to support your health and wellbeing needs, which is planned and agreed between you (or someone who represents you), and your local NHS team. It is not new money, but it may mean spending money differently so that you can get the care that you need.

Psychosocial

The term psychosocial refers to the psychological and social factors that influence mental health. Social influences such as peer pressure, parental support, cultural and religious background, socioeconomic status, and interpersonal relationships all help to shape personality and influence psychological makeup.

Psychological

Psychological means mental or emotional rather than physical

Quality of life

In healthcare, most researchers and clinicians agree that quality of life (QOL) is related to symptoms, functioning, psychological and social wellbeing, and probably to a lesser extent to meaning and fulfilment. However, during end-of-life care spirituality and existential issues become more prominent, as well as family members' perception of quality of care²⁵.

Spiritual care

Spiritual care is that care which recognises and responds to the needs of the human spirit when faced with trauma, ill health or sadness and can include the need for meaning, for self-worth, to express oneself, for faith support, perhaps for rites or prayer or sacrament, or simply for a sensitive listener. Spiritual care begins with encouraging human contact in compassionate relationship, and moves in whatever direction need requires²⁶.

Universal Care and Targeted care

Universal care is open to all of general public and free to access.

Targeted care is commissioned provision that is group/diagnosis/age-related²⁷.

²⁵ Kaasa S, Loge JH. Quality of life in palliative care: principles and practice. *Palliat Med.* 2003 Jan;17(1):11-20. doi: 10.1191/0269216303pm662ra. PMID: 12597461.

²⁶ NHS Education for Scotland, 2009

²⁷ https://www.england.nhs.uk/wp-content/uploads/2017/06/516_Statement-of-resources_S7.pdf

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