



# Considering care at home at the end of life



Our vision at North London Hospice is to provide the best of life, at the end of life, for everyone.

The care you receive may vary depending on your changing needs, which may evolve over time. While we work closely and collaborate with all services, we do not have control over how they operate or deliver their respective services.

As your illness progresses, the kind of support you need may change. It may be helpful to think about what's important to you and where you would like to be cared for in your final days.

Many people choose to die at home, where they feel safe and comfortable, in familiar surroundings with friends and family around them. There are some important facts to consider when thinking about being cared for at home and it's not always possible to predict what help you will need. It is also important to remember that whilst home may be your preferred choice, this may not always be possible, and this will be considered with you and your family.

## Professional Support

If you decide to be cared for at home, there are different health and social care professionals that will support you. The professionals involved in your care will depend on:

- Your current needs and wishes
- What sort of care and support you need
- Your medical condition

**These are some of the professionals that may offer support at home:**

### GP Surgery

Your GP will play a pivotal role in supporting you and your family and carers. GPs are embedded in the community and act as the focal point for your care. Your GP will work closely with other care providers to coordinate your care and ensure flexible and continuous support. This may include carrying out on going assessments of your condition and needs, and prescribing medication to help any symptoms. Your GP, along with others in your care team, will discuss your plan of care to ensure you and your family receive the care that matters most to you and have

access to the services you may need. Should you require urgent medical advice, the GP out of hours service is also available.

## District nurse (DN)

The District Nurse team may also be involved in your care. Like the GP, your District Nurse will assess changes to your condition and develop a care plan that is specific to your personal needs. The District Nurse service is responsible for nursing interventions such as support with wound care, catheter care, or the administration of complex medications. The frequency of visits from the District Nurse team will vary depending on your individual needs and should be discussed directly with the District Nursing service.

The District Nursing service also operates a call out service outside the usual working hours. There are less staff working out of hours and calls will be prioritised, so the response times may vary.

This can have an impact on how quickly a clinician will be able to visit you. Also, everyday factors such as rush hour traffic may affect the time it takes for support to arrive. **Whilst we work with the District Nurse team, the hospice is independent of this service.**

## Community Pharmacist

Pharmacists are based in the community and can support you by giving out (dispensing) prescribed medication and answering any queries in relation to your medication that you or your family/ carers may have. You may require specialist medication, which could mean your pharmacist needs to order it, or you may need to visit a different pharmacy to collect it if you require it urgently.



# The role of North London Hospice

North London Hospice has different services that can support you and your family/carers as your illness progresses. Once referred to the North London Hospice you will be contacted by one of our team to assess your needs and explain to you in more detail how our services may support you. There may be times when specialist palliative care is no longer needed, and patients may therefore be discharged from the service, back to their GP.

**North London Hospice may support you through a range of services, including:**

## North London Hospice Community Team

The hospice community team is made up of several different professionals, including nurses, doctors, physiotherapists, occupational therapists, social workers, peer groups and volunteers. The team will work together to focus on what is important to you and aim to maximise your quality of life, by offering expert symptom management, information, advice and care planning. The hospice team understand any fears and anxieties that you or your family may be experiencing during this time, and they will provide support to help alleviate some of the emotional burden. The day team is available from 8am to 8pm. As a guide, our last visit is at 3pm and there is telephone service 24 hours a day where you or your family can speak to someone.

## Palliative Care Support Service (PCSS)

In the last days of life, the hospice's PCSS may be able to provide additional care to help at home. The team consists of Registered Nurses and Healthcare Assistants who provide hands-on nursing care at home for people who require short-term additional support. The care is usually provided overnight between 10pm and 7am. Please note that the availability of this service is limited and Healthcare Assistants cannot administer medication.

To find out more about these services, please go to the North London Hospice website <https://northlondonhospice.org/>

## Inpatient Unit

We have a 15-bed Inpatient Unit that provides support for complex symptom management and end-of-life care. It is only intended for short stays, typically around 14 days. Prioritisation for admission is based on the individual needs of each patient.

# Further Considerations

## Your Home Environment

You may need to consider changes to your home so you can be cared for safely. This may mean, for example, turning a downstairs living area into your bedroom, so that you don't have to climb the stairs or to allow more room for any equipment that you may require to support your care.

Healthcare professionals can help you make these decisions and assess your needs in order to provide you with equipment such as handrails, a hospital bed and a commode that can make staying at home easier.

Of course, it isn't practical for everyone to make these changes, and you or your family/carers may not want to make adaptations to your home. You may want to take some time to consider if these changes are possible and how they make you or your family/carers feel. If managing your care at home becomes difficult, you may need to consider support from professional carers or explore options for care in a residential care or nursing home.

## Limitations Of Home Healthcare Support

Whatever support is put in place, it's usually not possible for health and social care professionals to be with you all the time. Therefore, it's important to consider if you would feel comfortable and safe without continuous healthcare support and whether you can manage any symptoms that may arise until a professional can visit. You may wish to consider if there are family or carers that would feel confident to help you during this time and what support you would be happy to receive, or they would be happy to give. You may also need to consider the feelings of your loved ones. Some carers may find it too frightening and difficult to care for you at home and worry that they wouldn't know what to do.

## **Paying For Care**

Healthcare, such as help from your GP or district nurse is free. North London Hospice is a registered charity and our services are provided free of charge. Whilst around a third of our funding comes from the NHS, we rely on the generosity of our community through donations to make up the shortfall in funding. Other services outside of the hospice however, such as social care, may incur a cost, but this depends on your circumstances.

## **Social Carers**

A referral for social care can be made to your local authority by your GP, The North London Hospice, the District Nurse or you can self-refer through your local council. There would be an assessment including a financial assessment and you may have to pay for all or contribute to your care.

Carers can assist you at home with daily living activities such as washing and dressing, helping with housework or preparing food. The care provided and frequency of visits will be assessed, and these may change to support your needs as your illness progresses.

## **National Health Service (NHS) Continuing Health Care (CHC)**

You may be eligible for NHS continuing health care, which is free healthcare provided by the NHS to people who have significant nursing needs, and this can cover costs such as home carers. This is different from the social care provided by the local authority as mentioned in the section above. If you are eligible for CHC you will not require a financial assessment. A healthcare professional will complete an initial assessment which will look at your nursing needs and how complex they are. Your eligibility will be assessed against a standard set of criteria and is not based on your diagnosis or condition.

If you have a rapidly deteriorating condition and may be entering a terminal phase of illness, a fast-track pathway tool can be used to determine eligibility for CHC funding. The fast-track tool can be used to support patients in their own home or in a care home setting. A care plan can be discussed with your clinician, and this will be based on your nursing needs arising from the rapidly deteriorating condition.

Eligibility based on the fast-track tool is reviewed by CHC on a three-monthly basis. In cases where patients have stabilised or are no longer felt to be rapidly deteriorating, funding can be removed.

Whilst we may complete the fast-track form/ care plan, the decision for eligibility and funding approval sits within CHC.

If you are not eligible for CHC funding, you will be informed of the reason why. If you are refused CHC funding at this stage, it does not mean you cannot get it later, although there will need to be significant change in your nursing care needs for this to be considered.

If CHC is agreed and your condition improves or stabilises then a decision may be made to withdraw the CHC provision, at which point the Local Authority will take responsibility for your care and you will need a financial assessment.

Assessments for CHC can be complex. You can read more about continuing care on the NHS website <https://www.england.nhs.uk/healthcare/> or an organisation called Beacon which provides free independent advice on NHS CHC. Visit Beacon website <https://beaconchc.co.uk> or call the free helpline on 0345 548 0300.

## **Care Coordination**

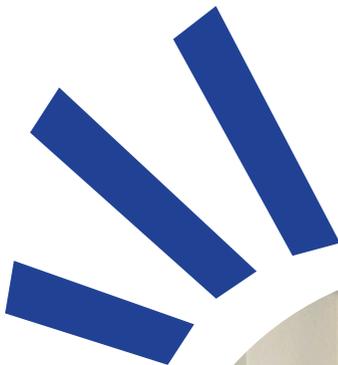
With your permission, a Universal Care Plan will be set up to help co-ordinate the health and social care providers who are involved in your care. This plan is an electronic record informing professionals about your care preferences (particularly useful out of hours). Your healthcare professional will ask your permission to share your details on the system.

## **Changing Your Mind**

There may be more questions or concerns that you or your family or carers may have when considering care at home. Your healthcare professionals will be happy to discuss these with you. It is also important to know that you can change your mind about being cared for at home at any point in your care journey. The healthcare team will also be happy to discuss alternative places of care with you.



# North London Hospice



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makes hospice  
care happen

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