

BRENT BOROUGH

A RESOURCE PACK FOR ANYONE CARING FOR OR SUPPORTING PEOPLE AT THE END OF LIFE IN THE COMMUNITY (ADULTS 18 YEARS AND OVER)

Document History

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Introduction

This guide is designed for anyone who is caring for or giving support to someone who is terminally ill or in their end of life.

It is widely recognised that when caring for someone in the last year of their life, we have only one chance to get it right (LACDP June 2014). Also, the last days and hours of an individual's life can be a challenging time for all involved.

Providing effective, high-quality care for someone during the end of their life is a highly skilled role. Without support and information, social care professionals and carers can find the experience overwhelming, trying to react to changing needs. The ability of social care professionals and carers to cope can be increased by having information available that will help them do the things that need to be done.

This guide has been developed to provide additional support to anyone trying to support a person in their end of life. The guide contains a series of online links to training materials, useful telephone contacts, bereavement support service and other available support for those caring for people in their end of life.

There is a freely available resource for patients and carers called HPAL <https://hpal.medindex.co.uk/p>. The aim is to provide brief expert information on a range of palliative and end of life topics. There will be a link to this website for each content of the guide, and this [whole guide](#) can also be found electronically on the HPAL site.

There is also a [directory](#) of useful services - click on Services, click on Brent and there will a list of palliative, carer, bereavement, pharmacy plus useful national services.

Section 1

Definition of Palliative Care

Palliative care in general is the care and support given to individuals with advanced, progressive, and/or incurable conditions (i.e. cancer, heart failure and lung disease). Our aim is to provide these individuals and their families with the best possible quality of life we can, managing pain and other symptoms in the last weeks, months or years of their lives.

Palliative care can involve:

- Managing physical symptoms such as pain to ensure the person is as comfortable as possible. This may include medications which may be referred to as Anticipatory Medications.
- 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, eating and supporting them with other elements of their life that are important to them.
- Support for family, friends, carers and those important to the patient.

Most times, palliative care is provided to people living in their own home, in the community, care homes and in hospital. In certain situations, some people may receive care in a hospice.

Who provides palliative care?

A whole range of health and social care staff provide palliative care (i.e. 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 level of care and support a person and those important to them need. 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.

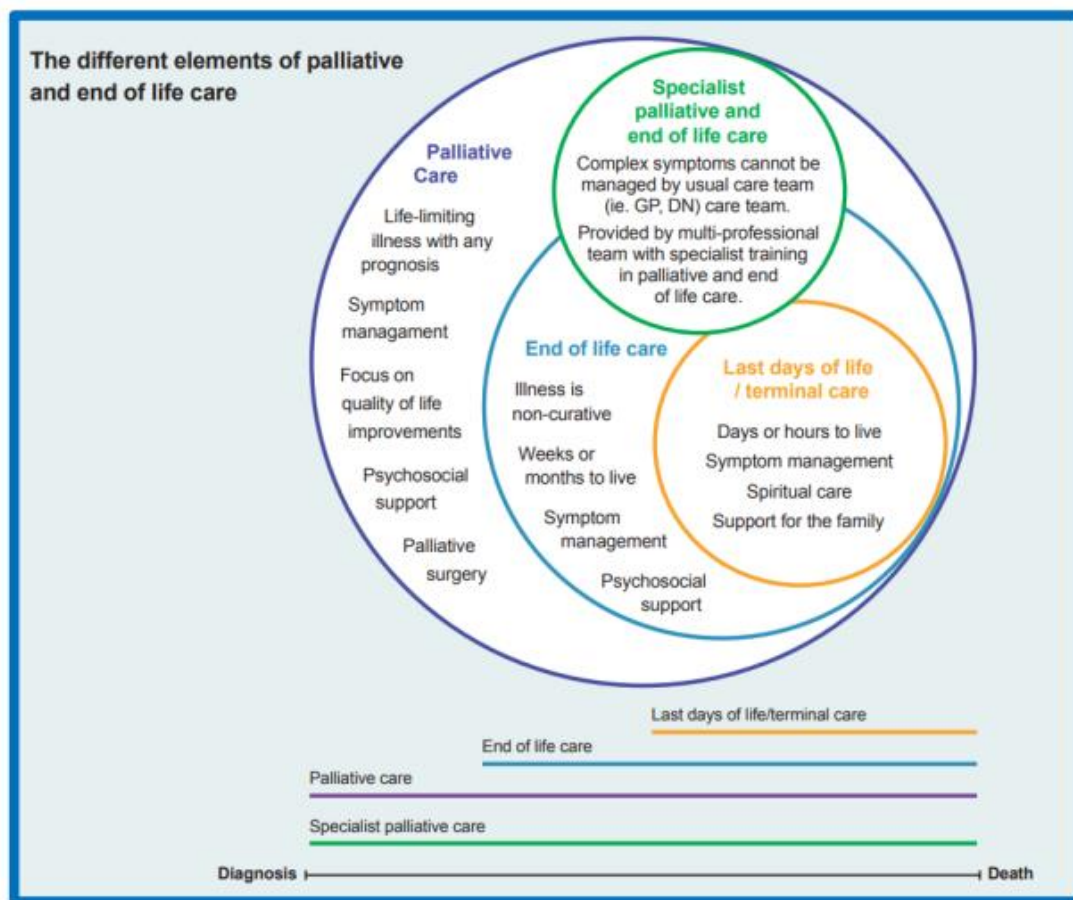
Generalist palliative and end-of-life care

Is the main foundation level of palliative and end-of-life care support and is provided by healthcare professionals such as a general practitioner (GP), community nurses (including district nurses), care home staff, therapists, domiciliary home care staff (for example care agency staff either arranged by the council, through NHS funded continuing health care or privately) and hospital ward staff who have a general understanding of and training in palliative care. For the majority of people with life-limiting or advanced illnesses, this level of care is sufficient throughout their palliative and end-of-life journey.

Specialist palliative and end-of-life care

Is an advanced and specialist level of palliative and end-of-life care provided by expert health care professionals who have received specialised training. Care is provided by a specialist palliative care multidisciplinary team including but not limited to doctor, nurses, therapists, social workers and psychologists. They work with a patient's regular care teams in the community to provide additional support and guidance for complex symptoms and challenges. This type of care is required by individuals with advanced and life-limiting illness that have complex needs and can be medical and social. This care is usually provided in specialist palliative care units, hospices, or at the patient's

own home via the specialist multidisciplinary team across services. This type of specialist care is not required by everybody with palliative care needs and at the end-of-life. Source: Adapted from diagram produced by Providence Health Care



Source: Adapted from diagram produced by [Providence Health Care](#)

We have three specialist palliative care services in Brent:

- St. Luke's Hospice Harrow
- Central London Community Healthcare NHS Trust (CLCHT) Pembridge Hospice
- St. John's Hospice

These services offer support in a number of ways based on patients and those that matters wishes alongside their care needs. This may include:

- Care at home:
 - o Adult community specialist palliative care team
 - o Hospice at home
 - o 24/7 Specialist palliative care telephone advice
- Community specialist in-patient beds
 - o Hospice in-patient unit beds
- Hospice out-patient services (including psychological support and bereavement support services), hospice day care services and well-being services
 - o Hospice out-patient clinics (including (including psychological and bereavement support, and lymphedema services)
 - o Hospice day care services
 - o Well-being services

	St John's	StLuke's Harrow	Pembridge CLCHT
In-patient	Yes	Yes	Currently Not Available
Out patient	Yes	Yes	Yes
Day/Wellness centre – which may include complementary therapies, social care support, group classes	Yes	Yes	Yes
Community Specialist Palliative care	Not Applicable	Yes	Yes
Hospice at Home	Yes	Yes	Delivered by St John's
Bereavement	Yes	Yes	Yes
Lymphedema	Yes	Not Applicable	Not Applicable

Table. 1: summary of services offered by each Specialist Palliative Care organisation in Brent

Advance Care Planning

Advance Care Planning (ACP) is a voluntary process of person-centred discussion between an individual and their care providers about their preferences and priorities for their future care, while they have the mental capacity for meaningful conversation about these. The process, which is likely to involve a number of conversations over time, must have due consideration and respect for the person's wishes and emotions at all times. As a result, the person should experience a greater sense of involvement and the opportunity to reflect and share what matters most to them.

The outputs of these discussions may include one or more of the following:

- An advance statement – of wishes, preferences and priorities, and may include nomination of a named spokesperson
- An Advance Decision to Refuse Treatment (ADRT)
- Nomination of a Lasting Power of Attorney (LPA) for health and welfare who is legally empowered to make decisions up to, or including, life sustaining treatment on behalf of the person if they do not have mental capacity at the time, depending on the level of authority granted by the person.
- Context-specific treatment recommendations such as emergency care and treatment plans, treatment escalation plans, cardiopulmonary resuscitation decisions, anticipatory medications.

Who might benefit from ACP conversations?

These are relevant for any individual who wishes to plan for their future care or who may be at increased risk of losing their mental capacity in the future, including:

- people facing the prospect of deteriorating health due to a long term condition or progressive life limiting illness, e.g. dementia, frailty, kidney, heart or liver failure, lung disease, progressive neurological conditions, incurable cancer
- people with declining functional status, increased burden of illness or persistent physical or mental health symptoms
- people facing key transitions in their health and care needs, e.g. multiple hospital admissions, shifts in focus of treatment to a more palliative intent, moving into a care home, etc.
- people facing major surgery or high risk treatments, e.g. bone marrow transplant
- people facing acute life threatening conditions which may not be fully reversible

Why is this important?

ACP benefits everyone: a person, their family, carers, those important to them and health professionals.

- It ensures people caring for a person are aware of their wishes when it comes to their treatment and future care.
- Planning ahead can help carers know how a person would like to be cared for when they become unable to make their own decisions.
- Taking part in ACP improves ongoing and end of life care. Families of people who have taken part in ACP experience less anxiety, depression, stress and are more satisfied with care.

It is important to understand that the benefits of advance care planning aren't just for people who will lose capacity in the future. For many people, thinking about their priorities or what's important

can often make them feel more in control, at peace, and ready to live life as fully as possible until they die. Additionally, it offers individuals the opportunity to ask questions about what might happen in the future so they can feel more prepared.

The diagram below shows the Gold Standard Framework for Advanced Care Planning

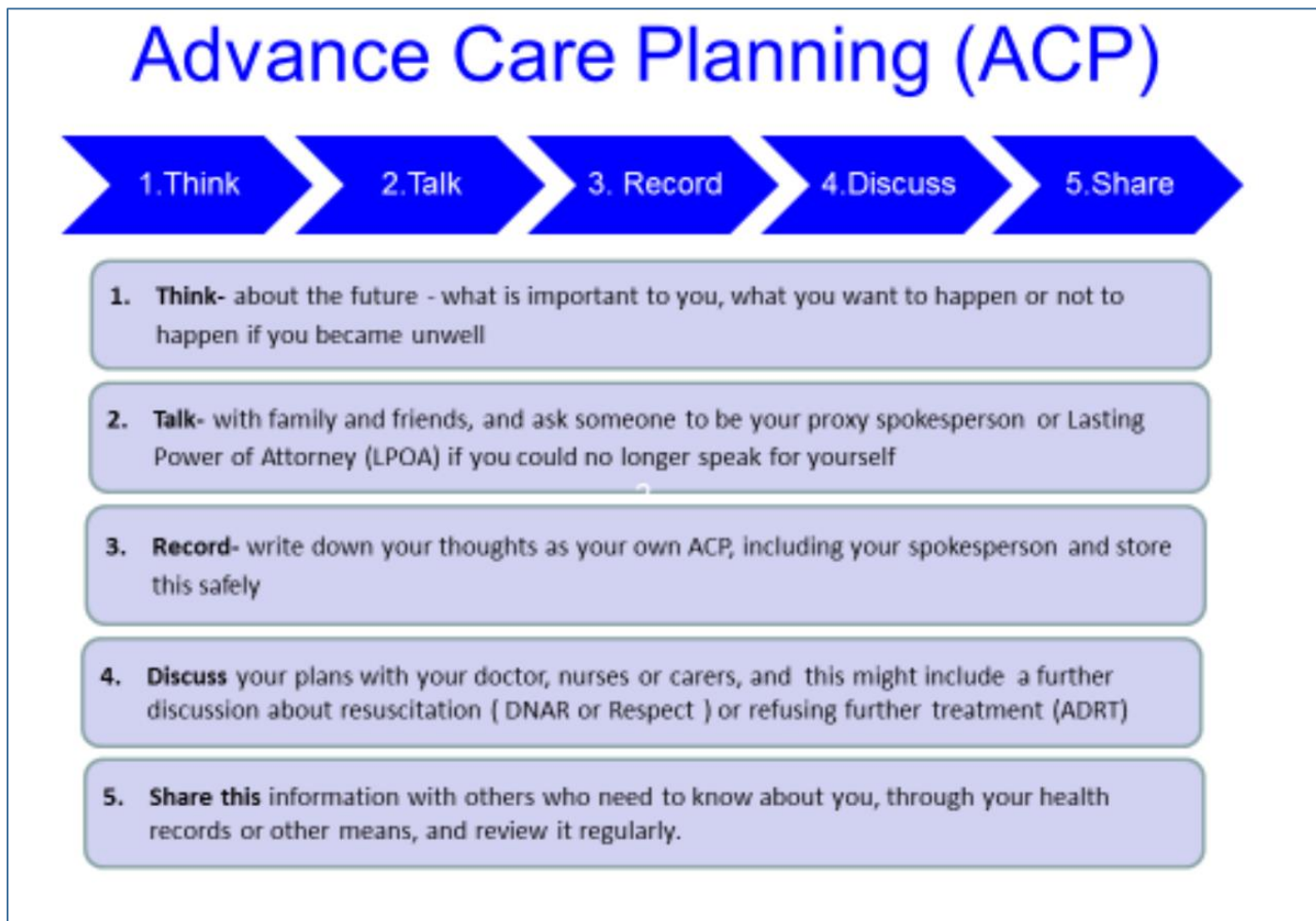


Fig. 3. Gold Standard Framework. Retrieved from www.goldstandardsframework.org.uk

How to begin an ACP?

Hospice UK co-produced an online tool that helps anyone who wishes to know more about Advance Care Planning and what it involves. [Planning Ahead: What matters most to you | Welcome \(advancecareplanning.org.uk\)](http://www.planning-ahead.org.uk). If you prefer, you can work through this tool without making choices just by ticking 'I'm not sure yet' on each page. Then you can think about the information, choose who to talk to, and decide whether to come back to make decisions. Just use the tool the way you find most helpful.

None of the choices you make using this tool will be binding. You can change your mind at any time, and lots of people do. If you are relatively fit and well right now, you may make different choices from the options you would choose if you had a serious or even a life-limiting illness.

There are no right or wrong answers. It's all about making personal choices that make sure that your future care matches up with the things you think are the most important.

This tool is simple to use. It may take you 15 minutes or so, perhaps longer if it sets you off on big discussions. There are 8 questions about your preferences. Each question will take some thought. You can skip any question you're not ready to answer yet.

Do not attempt cardiopulmonary resuscitation (DNACPR) decisions

CPR is an emergency procedure that can be performed on a person when they stop breathing (respiratory arrest) or the heart stops beating (cardiac arrest). CPR is performed to get a person to start breathing and heart beating again. This can involve chest compressions (repeatedly pressing down hard on the chest, use of a device to stimulate heart using electrical shocks (more than once), equipment that helps move oxygen around the body or administering medication intravenously.

DNACPR sometimes called DNAR (do not attempt resuscitation) or DNR (do not resuscitate) means if the person's heart or breathing stops the healthcare team will not try to restart it.

A DNACPR decision can be made by a person in their end of life and/or the doctor or healthcare team if they believe that CPR would not prolong the person's life or would do more harm. This decision is usually recorded on a special form.

Documenting and sharing an advance care plan

In London the current care planning technology is the Universal Care Plan (UCP). By documenting your care plan onto the digital UCP it ensures all health and care professionals, including London Ambulance Service are able to view your plan. Since January 2024, everyone who has a UCP can view their plan from within the NHS App. [About – Universal Care Plan \(onelondon.online\)](https://onelondon.online)

How can you support someone with advance care planning?

Please contact the person's health or social care professionals to discuss further. In Brent you can contact the person's GP or the district nursing team for assistance. Make sure the person's wishes are recorded and shared so they can be acted on if, or when, they're needed. It is important to understand that an advance care plan can be updated if the person's situation changes. It is the responsibility of the health or social care professionals to review and make changes when required.

Section 4 - [Last Days of Life for Palliative care for Brent \(medindex.co.uk\)](https://www.medindex.co.uk)

What to do when someone is dying

The final last days of life are precious. We want to ensure that we provide the right level of support for you and your loved one and this booklet aims to help prepare you for what to expect.

We hope that the information provided helps you know what is normal and how you can help or seek advice for any signs which indicate pain or distress.

Everyone's experience of dying is unique. Not everyone will experience the same bodily changes and some people may not exhibit any changes at all. It is normal for these changes to come and go over a period of days, and if they do go, this does not usually mean that the person is recovering.

Anticipatory Medication - [Anticipatory Prescribing: information for patients and carers \(medindex.co.uk\)](https://www.medindex.co.uk)

It is essential to anticipate symptoms in advance and prescribe carefully to keep people safely at home in their final days.

Prescribing a small number of medications, which may be injections, to cover common symptoms such as pain, nausea and vomiting, anxiety and breathing problems is important.

They are very useful if someone is unable to swallow their medicines towards the end of life.

The intention is to relieve suffering not to hasten death. Please see the above link for a patient/carer leaflet with more information.

Changes in the last days of life - [Symptoms for Palliative care for Brent \(medindex.co.uk\)](https://www.medindex.co.uk)

Eating and Drinking

In the last days of life, the person's appetite is likely to be much reduced including interest in drink. The focus of care for the person may change and tends to be centred on helping them to be as comfortable as possible.

This can be worrying for families and carers but it is a natural and expected part of the dying process. Most people at the end of life do not experience hunger or thirst. The body is slowing down, and if someone eats or drinks more than they really want to it can cause them discomfort.

Families and carers may be concerned about the effects of reduced food intake or dehydration on the person who is dying, and it is natural for families to want to continue providing nourishment at this time.

Things that may help

- Let the person choose if and when they want to eat or drink
- Offer small amounts of food, especially the person's favourite flavours
- Don't worry about providing a balanced diet
- You can give the person small snacks and nutritious drinks
- Offer small pieces of ice or small ice lollies instead of drinks
- Use a small spray bottle to mist the mouth with water, being careful not to give too much
- Frequent mouth care (gently brushing teeth with a soft toothbrush) can prevent the person feeling thirsty, even if they cannot drink very much (see mouth care advice below).

Some examples of small snacks and nutritious drinks are found in the appendix C.

Please discuss concerns with the district nurses or the person's GP.

Mouth care in palliative care

Mouth care is an essential aspect of palliative care in all care settings and should be considered part of daily routine in patient care. There are several mouth problems common in palliative care which can have negative impact of someone's quality of life, both physically and emotionally. These include dry mouth, painful mouth, infections, bad breath (halitosis), changes in taste, and drooling or excessive salivation.

Examine the mouth of the person with a terminal illness regularly and ask if they have any of the common mouth problems listed above. You can also ask them whether it's painful to speak or swallow. Assess whether the person is able to manage their own mouth care or if they need any help.

Mouth Care

Some of the basic mouth care which should be provided includes:

- Keep the mouth and lips clean and moist.
- Support with frequent small drinks
- Encourage them to avoid sugary foods and drinks between meals
- Apply gel to dry lips after brushing teeth – avoid the use of petroleum gel or Vaseline on anyone receiving oxygen therapy due to fire hazard
- Provide mouth care when the person is semi-upright, to avoid choking. If that's not possible, make sure fluid isn't building up in their mouth as you give mouth care

With natural teeth?

If the person can manage, clean teeth with fluoride toothpaste at least twice daily

Encourage to spit out excess toothpaste after brushing

Although not rinsing after brushing can protect the teeth but it can also be drying and uncomfortable. Advise the person to do what feels the most comfortable.

Remove partial dentures and clean separately

You can use silk or very soft toothbrushes such as baby toothbrush, as these have softer bristles which can be helpful for oral daily care for people with a painful mouth

If the person has difficulty swallowing, use non-foaming toothpaste

With dentures?

Remove dentures at night, and soak them in cleaning solution for the amount of time stated in the manufacturer's guidelines

Rinse dentures thoroughly before putting them back in the mouth

Brush dentures at least once daily using a toothbrush and running water

Rinse dentures thoroughly after meals

Check dentures for cracks, sharp edges and missing teeth every day

Check whether dentures still fit properly to avoid discomfort because weight loss can affect how dentures fit

Breathing and inability to swallow

As a person's body shuts down, it is normal that their breathing may become shallower with long pauses between their breaths. Sometimes this alternates with rapid breathing. Both are normal and not a sign of distress or suffocation. Inability to swallow is one of the problems that may be experienced within a few days or hours of dying.

Sometimes the person's breathing may become irregular and noisy. This is likely to be because they are not able to re-absorb or swallow the normal fluids in their throat, which can cause a rattling sound. Whilst you may find the sound unsettling, rest assured it does not distress your loved one.

Tiredness, sleep and consciousness

As time goes by, your loved one will become drowsy and will spend more time sleeping. Some people become completely unconscious for a period of time - this could be short, or as long as several days.

Changes in complexion and temperature

The person's skin may feel cold and change colour. Their hands, feet, ears and nose may feel cold to the touch due to reduced circulation.

Occasionally, a person's hands or other parts of the body may swell and their skin may also become mottled or uneven in colour. If the person's hands swell, please be assured that this is not usually painful or uncomfortable.

Confusion and Agitation

Sometimes the person may get confused and may not recognise familiar faces. They may hallucinate, and see or hear people or things that are not actually there. In the last few days, your loved one may appear more restless and agitated but there is medication to help them settle.

Loss of bodily functions

The person may lose control of their bladder or bowels. This happens because the muscles in these areas relax and don't work as well as they did. We can offer different ways to respond to this and maintain dignity. They may also have fewer bowel movements as they eat less, and their urine may get darker as they drink less.

Section 5

What to do when someone dies at home

This information is related to an expected death of person due to terminal illness.

[What to do after a death at home](#)

Phone your doctor

A doctor (or an appropriately qualified professional) will need to verify the death. This can be your local GP or if he/she is not available (for example if it is in the middle of the night), you could wait until the following morning or contact 111 and an out of hours GP could visit to verify the death.

Your local GP must certify the death. This means that the Medical Certificate of Cause of Death (Death certificate) will be completed and issued to you from the GP surgery.

The statutory implementation of medical examiner system will be coming to all NW London GP practices on 9 September 2024 (under legislation in the 2022 Health and Care Act). And this will change the Medical Certificate process.

1. Phone call from the medical examiner's office to the family

As soon as possible after the death (on average within 24 hours) the next of kin will receive a phone call from the medical examiner's service. This service provides an independent review of the cause of death and gives the next of kin time to ask questions.

(Medical examiners are senior medical doctors who provide independent scrutiny of the causes of death. They are trained in the legal and clinical elements of death certification processes. The medical examiner's service was rolled out nationally on 1 April 2023 to all community and GP services).

The medical examiner's office will be able to:

- confirm your loved one's cause of death
- discuss the care they received
- answer your questions, and concerns
- explain the wording on the death certificate agreed by the doctor and medical examiner.

If the cause of death is unknown, they will also be able to talk you through the referral process to the coroner (if required).

Following your call with the medical examiner's office the **medical certificate of cause of death** will then be electronically sent by the GP/doctor straight to the registrar in the borough the death was recorded. You will then be able to book an appointment to register the death.

You do not need to visit the GP surgery to collect the medical certificate of cause of death (from 9th September 2024)

[NEW: Medical examiner process :: North West London ICS \(nwlondonicb.nhs.uk\)](http://nwlondonicb.nhs.uk)

Phone your district nurse

If a district nurse has been involved in the care for your loved one, please contact them as soon as possible.

Unexpected death

If someone dies unexpectedly the police would need to be contacted and the death will be reported to a coroner. The coroner may order a post mortem examination to determine the cause of death and then issue the documents allowing the death to be registered.

The death may also be reported to the coroner if a death was expected but a doctor has not seen the patient in the last 28 days prior to their death or after their death.

Arranging equipment delivery and/or removal from home

Brent has commissioned a service through Nottingham Rehab Service (NRS) to provide community equipment. The Brent Integrated Community Equipment Service (BICES) provides equipment such as community beds, mattresses, pressure care devices, hoists, and slings etc.

Please contact the district nurses or GP or social workers to arrange for assessment and prescription of required equipment.

Removal of equipment from home:

If any equipment was provided by the hospice e.g. a bed or a commode, please contact the hospice team who cared for the person you love, to arrange for these items to be removed. The contact number to reach hospices is found on page 15.

You can also contact NRS on 0300 100 0253 for NHS/social care equipment collection/return provided by other services. You can help someone else who may need it, and help your local NHS and council save money and the environment.

There is also a dedicated mailbox that can offer additional help and advice that can be reached via the e-mail addresses as follows:

LA: communityequipment@brent.gov.uk

NHS: nhsnw.brentcommunityequipment@nhs.net

Take your time

You don't need to call a funeral director until you are ready. Gather the people who will want to say their final farewells. Sit with your loved one as long as you need to. When you're ready and the death has been verified then you could call the funeral director and they will come and take your loved one's body to the funeral home.

Section 6

Registering the death

After you have collected the Medical Certificate of Cause of Death from your GP surgery you can then officially register the death at your local registry office. From 9th September 2024 there is the new Medical Examiner. Within 24 hours after the death of your loved one you will receive a telephone call from the Medical Examiner and following this call the Medical certificate of death will be emailed directly to the Brent register.

There is a legal requirement that a death be registered within five working days. It is important to let the Register Office know if the funeral is to be held within 24 hours.

The person registering the death must be able to provide some basic details of the person who has died. You will need to take the Medical Certificate of Cause of Death with you.

Although it can be helpful to take the person's birth and marriage certificates, passport or NHS Medical Card, these are not essential.

Brent Register Office details

Brent Civic Centre, Engineers Way,
Wembley, HA9 0FJ
By appointment only.
Monday – Friday: 8.30am – 5pm
Saturday: 9am – 4pm Sunday: 9am – 1pm
Tel: 020 8937 1010

Information required by the Registry Office

- Date and place of death
- Full name
- Maiden name (if applicable)
- Date of Birth
- Place of birth (Town and County if born in the UK. Country if born outside of the UK)
- Their home address
- Their last full time occupation
- Details of surviving spouse or civil partner
 - Name
 - Date of Birth
 - Occupation
- Was the deceased receiving any state pension? Yes or No

The Registrar will give you the following:

- Green Form (Form 9). This gives you or the funeral director permission for the body to be buried or for an application for cremation to be made.
- Certificate of Registration of Death (Form BD8). This is for Social Security purposes only. You can notify Social Security of the death either by completing this one-page form or by calling them on the telephone number provided on the form.

Please note the Death Certificate requires payment.

It is advisable to purchase additional certified copies of the death certificate as they will be needed by banks, insurers, housing associations etc. People usually buy between 4 and 6 certificates depending on the number of institutions to be informed as photocopies cannot be used.

Arranging a funeral

A funeral can usually only take place after the death is registered. There are many things to think about and decide when arranging a funeral. The person may have left plans for the funeral they want, or you may need to arrange the funeral yourself. It can be a good idea to ask family and friends for help. Or you may want to pay for the services of a funeral director, who can take you through the whole process step-by-step.

Whilst planning a funeral, it can be useful to consider:

- waiting until you have the medical certificate of death certificate and (green certificate from the registrar for burial or cremation) before finalising any arrangements making any arrangements. Or after 9th September 2024 confirmation from the Medical Examiner.
- if the person has left instructions in their will or a letter about their wishes
- letting people know about the death and funeral details by organising an obituary in a newspaper or other.

[More information on arranging funerals on GOV.UK](#)

Contacting a funeral director

You can research options locally and online. It is advisable to contact more than one firm and ask for details of their charges and services before making your selection.

Another option is to call Your Funeral Choice on **01983 754 387** or visit www.yourfuneralchoice.com and enter your postcode to view a list of funeral directors in your area with details of how much they charge.

When you speak to a funeral director they will discuss the kind of funeral you want.

In the case of cremation, more forms are required from two doctors. One of them will be a doctor who treated your loved one during their illness. The second is an independent doctor not involved in the person's care. S/he will speak with the doctor who signed the Medical Certificate of Cause of Death, regarding the person's medical history.

Paying for the funeral

Where payment for a funeral is an issue, you may be entitled to help with the funeral costs through the Social Fund. However, any payment that they give is retrospective and will never cover the full cost. It is essential to consider this when arranging the funeral. Please visit www.gov.uk/funeral-payments for more details.

An organisation called Down to Earth (run by Quaker Social Action) can also provide practical support to people concerned about funeral costs. You can contact them on **020 8983 5050** or visit their website at www.quakersocialaction.org.uk

There is now a one-stop contact number at the Department for Work & Pensions for people to inform the DWP of a death (0345 6060 265 choose Option 2). This one-stop telephone service will cancel all DWP benefits.

They will also help you to establish if you are eligible for help towards funeral costs (a funeral grant), and advise you on your eligibility for any relevant bereavement benefits

Section 8 - [Legal and Financial for Palliative care for Brent \(medindex.co.uk\)](http://medindex.co.uk)

Benefits and changes to circumstances

Carers' Allowance

If you were receiving Carers' Allowance for caring for the person who died, this will continue for six weeks after their death.

Council Tax Benefit and Housing Benefit

Check that these are in your name. If these are not, then these may need to be reapplied for.

Child Benefit, Child Tax Credit or Working Tax Credit

If you are a parent and any of these benefits are in the name of the person who has died, the agencies will need to be informed:

- Child Benefit HMRC: **0300 200 3100**
- Tax Credits Job Centre **Plus: 0345 300 3900**

Please see more information about bereavement support on page 13.

Section 9 - Wills and legal matters

Probate (administration of an estate)

This is the legal process for the distribution of the deceased's estate (money, property etc.). You need to establish if the deceased had a Will. This may be found with their bank or solicitor, at home, with family or a friend, or if registered at the Principle Probate Registry **0207 421 8500/8509**.

When a Will is in place

The Will may include funeral wishes, wishes regarding the deceased person's estate and the name of the executor(s) or the person(s) legally entitled to deal with the estate. The executor(s) is (are) legally responsible for administering the estate according to the wishes in the Will. If the Will is with a solicitor, inform the solicitor of the death.

Named executors can administer the estate on their own. Information on how to do this can be found online at www.gov.uk, or they may prefer to get the help of a solicitor to carry this out.

When there is no Will in place

When someone dies without having made a Will, they are said to have died 'intestate', and different rules apply which can often be complicated. When this happens the law sets out who should deal with the person's affairs and who benefits.

Further information is available at www.gov.uk and www.ageuk.org.uk

Section 10

Looking after yourself (also see bereavement section)

Grief is physically and mentally exhausting.

- Rest when you need to. Try to eat something nourishing.
- Accept offers of help from others.
- Try to postpone making big decisions. It is better to wait until you can think more clearly. This may be about things such as moving house or disposing of possessions that remind you of the person that has died. You may regret these decisions if made too early on in your bereavement.
- No one can completely understand what another person's grief is like. It can often help to share how you are feeling with someone who has some understanding and is willing to give you a listening ear without judging you.
- Give yourself permission to express your feelings.
- Plan ahead. Anniversaries and birthdays may amplify your grief, try and have the support of others at these times

Section 11 - [Bereavement for Palliative care for Brent \(medindex.co.uk\)](http://medindex.co.uk)

Bereavement

We are sorry for your loss. Our goal is to assist you find the right support in the time and way that feels right for you and those around you. The information below will guide you on how to help yourself and others in this difficult situation. We have put together a list of national and local level information below

National Bereavement Services

- When someone dies in the UK, information about what needs to happen can be found here: www.gov.uk/after-a-death
- People who have been bereaved can call Cruse Bereavement Care for free on **0808 808 1677** or visit <https://www.cruse.org.uk/get-help>
- Child Bereavement UK offers support for families and professionals when a child dies or when a child grieves – tel **0800 02 88840** or <https://www.childbereavementuk.org/>
- Independent Age provides information on range of subjects including welfare, legal and finances – tel **0800 319 6789** or www.independentage.org/information/personal-life/when-someone-dies
- Marie Curie have information on a range of services including practical, legal and financial matters. Tel **0800 090 2309** or <https://www.mariecurie.org.uk/help/support>
- Bereavement Advice Centre: Monday - Friday: 9am - 5pm, Free helpline: **0800 634 9494** www.bereavementadvice.org
- Government Services: www.gov.uk
- Turn2us: www.turn2us.org.uk
- Samaritans - free 24/7 helpline: 116 123 www.samaritans.org or email jo@samaritans.org
- Muslim Bereavement Support Service – tel: **020 3468 7333** or email infor@mbss.org.uk. Supports Muslim women who are facing bereavement and/or are bereaved. They will speak with Muslim men and signpost them to appropriate bereavement support.
- Jewish Bereavement Counselling Service – tel: **020 8951 3881** or email enquiries@jbcs.org.uk
- The Compassionate Friends – tel 24-hour: **0345 123 2304** or email helpline@tcf.org.uk or www.tcf.org.uk. An organisation of bereaved parents and siblings dedicated to the support and care of other similarly bereaved family members.

Pan London Bereavement Services

- If you are bereaved and would like to speak with someone, you can call Cruse Bereavement Care for free on Tel 0808 808 1677 or visit www.cruse.org.uk
- At a Loss has a website with useful bereavement resources www.ataloss.org

Local Bereavement Services in Brent

- Any patient with a registered GP in Brent can access bereavement support through Improving Access to Psychological Therapies (IAPT), by self-referral at <https://talkingtherapies.cnwl.nhs.uk/brent> or via their GP
- The three hospices provide bereavement services (this is a charitable service)). Contact details included on page 11 of the guide.
- Brent Bereavement Service (Charitable) provides counselling, advice and information for bereaved people, their families and friends <https://www.bbsonline.org.uk/> or email info@bbsonline.org.uk
- Brent Council have a webpage with useful resources [End of life care | Brent Council](#)
- Brent Carer's Association support Brent Carers brentcarerscentre.org.uk
- Vanik Council UK is a charity organisation that provides pastoral, spiritual and End of Life Care for patients in their homes or care homes – mobile: **07775 523233** or visit www.vanikcouncil.uk

Section 12

Contacts Directory

This section will provide contact details about the local services and professionals who can help in the delivery and advice on End of Life Care.

Professionals or services	Evenings, Weekends and Bank Holidays
Service provider	24/7 telephone contact/email For patients, carers, healthcare professionals
St Luke's Hospice Supports a 24/7 telephone advice line, community specialist palliative care, in-patient care, outpatient and wellness centre, hospice at home and bereavement service. Available to the North of Brent.	0300 020 0224 nhsnwl.palliativehelpline@nhs.net
Pembridge Hospice (CLCH) Supports a 24/7 advice line, community specialist palliative care, wellness centre and bereavement service. Available to the south of Brent.	0208 102 5000 clcht.spa.referral@nhs.net
Other palliative providers or hospices supporting Brent	
St John's Hospice Supports in-patient, outpatients and wellness centre, hospice at home, lymphedema and bereavement service.	020 7806 4040
District Nurse The district nurses support adults in the community and who live in Brent or are registered with a Brent GP. This service is provided by the Central London Community Healthcare NHS Trust.	020 8102 3456

Table. 2. Contact details of hospices supporting residents in Brent

Locally based charities, community and faith based organisations play a huge role in supporting adults and relatives during important periods; locally based 'out of hours' services, advice and guidance are open to local residents. Find out about the range of practical support, advice and guidance available in Brent by email or telephone: support@cvsbrent.org.uk or 020 3011 1690.

The list of few faith group contacts in Brent are found in the table 3 below. It is advisable to contact the person's **own** local faith based organisation for support whenever required. Most Catholic Priests are usually only required for Confession/Reconciliation, Anointing of the Sick/Last Rites. Please note most Priests, Rabbi, Chaplain and other faith group support are 'volunteers', therefore we cannot guarantee their availability. If the telephone is not answered or goes straight into answer phone/voicemail, do not leave a message but either try again later or dial the next contact on the list.

Faith Groups within Brent		
Groups	Telephone Number	Area covered
Roman Catholic Churches (people are encouraged to contact their own local parish priest for advice and support)		
St Sebastian and St Pancras Church, Kingsbury Green	020 8204 2834	North Brent
St William of York R C Church, Stanmore	020 8954 1299	North Brent
St Joseph's Catholic Church, Harrow Weald	020 8427 1955	North Brent
Roman Catholic Parish of Harrow-on-the-Hill	020 8422 2513	North Brent
St Andrew's Church, Kingsbury	020 8205 7447	North Brent
St Pius X Roman Catholic Church	020 8969 6844	South Brent
Our Lady of the Holy Souls, Kensal New Town	020 8969 2660	South Brent
St. Francis of Assisi, Notting Hill	020 7727 7968	South Brent
Our Lady of Lourdes & St. Vincent de Paul, Harrow Road	020 7286 2170	South Brent
The Church of the Transfiguration, Kensal Rise	020 8964 4040/ 020 4542 3716	South Brent
Diocese of London, Church of England (people are encouraged to contact their local churches for advice and support)		
St Mary-the-Virgin, Kenton	020 3882 0553/ 020 8907 2914	North Brent
St Helen's Church, North Kensington	020 8968 7807	South Brent
St John Kensal Green	020 8969 2615	South Brent
Hampstead Parish Church	020 7794 5808	Hampstead
Other Churches		
Notting Hill Salvation Army Church	020 7725 5178	North Brent
Kensal Rise Baptist Tabernacle	07598 742 021	South Brent
Notting Hill Methodist Church	020 8902 1426/07401 345 203	West Brent
Church of the Latter Day Saints (Mormon) Hyde Park Chapel	020 7838 1920	South Brent
Jehovah's Witness Kingdom Hall	020 7792 0332	South Brent
Kensington Unitarians (Essex Church)	020 7221 6514	South Brent
Hindu		
Ashok Patel Hindu Chaplain	078 5805 4101	North Brent
Swaminarayan Temple Stanmore	078 3783 7843 (Nayan Joshi)	All Brent
London Sevashram Sangha	020 8743 9048	South Brent
Orthodox Christian		
Romanian - Grigore Pascu	078 0289 8705	North Brent
Serbian – Saint Sava Church	020 7727 8367	South Brent
Greek – St Sophia's Cathedral	020 7229 7260	South Brent
Russian – Cathedral of the Dormition and All Saints	020 7584 0096	South Brent
Jewish Community		
Mosaic Masorti Synagogue	Anthony Lazarus Magrill Generic Chaplain 078 0376 5656 Mobile no. is switched off for Shabbat (Fri night to Sat night), but for anything urgent please call landline 020 89549596.	All Brent
West London Synagogue	020 7723 4404	South Brent
Beit Klal Yisrael	07505 477 459	South Brent
New West End Synagogue – St. Petersburg Place	020 7229 2631	South Brent
Muslim		
Al Manaar The Muslim Cultural Heritage Centre (Acklam street Mosque)	020 8964 1496	South Brent

Faith Groups		
Groups	Telephone Number	Area covered
Bahai		
The Bahai Community of Kensington & Chelsea	020 7584 2566	South Brent
Buddhist		
West London Buddhist Centre	020 7727 9382	South Brent
Jain		
The Jain Centre	020 8200 0828	South Brent
Sikh		
Central Gurdwara (Khalsa Jatha) London	020 7603 2789	South Brent

Table. 3. Contact details of faith groups supporting patients

Section 13

Education and training

There are several available resources and training opportunities that may help you to feel more confident in caring for people at end of life. The training and useful information can help avoid crisis situations and reduce panic for residents, care staff/carers and family members. Regular courses are provided by local palliative care teams and hospices in Brent.

The email and 24/7 telephone contact on Section 13 for district nurses or community palliative providers are available for advice or additional support to residents who are either known or unknown to the service. There is also telephone support for other hospices supporting Brent.

Effective communication is of key importance at the end of life, hence some of the training resources below has links that will help you to improve communication when helping people in the community.

There is a freely available resource for patients and carers called HPAL <https://hpal.medindex.co.uk> The aim is to provide brief expert information on a range of palliative and end of life topics. There will be a link to this website for each content of the guide, and this [whole guide](#) can also be found electronically on the HPAL site.

There is also a [directory](#) of useful services - click on Services, click on Brent and there will a list of palliative, carer, bereavement, pharmacy plus useful national services.

- An e-Learning programme for the health and care workforce has been developed to support colleagues in looking after patients in the community. Participants will need to register on this link <https://www.e-lfh.org.uk/> in order to access various useful modules such as:
 - Supporting people to live and die well
 - Palliative care social work, supporting
 - Care planning at end of life and many others which will equip carers or social worker in looking after people in the community.
- Palliative Care Knowledge Zone includes a host of educational resources for carers such as:
 - Caring for someone in their last days and hours - [Caring for someone in their last days and hours \(mariecurie.org.uk\)](#)
 - Good Communication at end of life - [Good communication at end of life | Information for professionals \(mariecurie.org.uk\)](#)
 - Providing emotional care - [Providing emotional care | Information for healthcare professionals \(mariecurie.org.uk\)](#)
 - Recognising emergencies in palliative care - [Recognising emergencies in palliative care \(mariecurie.org.uk\)](#)

Carers who are supporting someone at home can access useful resources with video instructions [Resources - St Luke's Hospice \(stlukes-hospice.org\)](#)

- Rolling to the left
- Laying to the sitting
- Sitting to standing
- Saying Goodbye

There are a range of national workforce initiatives to improve the skills of people working in health and social care. In conjunction with Skills for Health and Skills for Care there has been

work undertaken to produce principles and competencies for workers who look after people at the end of their life. There are also communications skills training pilots and e-learning materials.

For further information, look on the workforce page of www.skillsforcare.org.uk

There is a freely available resource for patients and carers called HPAL <https://hpal.medindex.co.uk>. The aim is to provide brief expert information on a range of palliative and end of life topics. There will be a link to this website for each content of the guide, and this [whole guide](#) can also be found electronically on the HPAL site.

There is also a [directory](#) of useful services - click on Services, click on Brent and there will be a list of palliative, carer, bereavement, pharmacy plus useful national services.

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4. NHS Do not attempt cardiopulmonary resuscitation (DNACPR) decisions available at [Do not attempt cardiopulmonary resuscitation \(DNACPR\) decisions - NHS \(www.nhs.uk\)](http://www.nhs.uk)
5. St Luke's Hospice <https://www.stlukes-hospice.org/> [Accessed 31 May 2022]
6. St Luke's 'when death is near' - a guide for families, friends and carers
7. North West London End of Life Nutrition resource document
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9. National Institute for Health and Care Excellence (2021) Palliative care – oral. Available at <https://cks.nice.org.uk/topics/palliative-care-oral/>. [Accessed 05 Jul. 2022]
10. [Universal-Principles-for-Advance-Care-Planning-ACP.pdf \(england.nhs.uk\)](#)
11. [Planning Ahead: What matters most to you | Welcome \(advancecareplanning.org.uk\)](http://advancecareplanning.org.uk)
12. [Adult community-based specialist palliative care \(CSPC\) review :: North West London ICS \(nwlondonicb.nhs.uk\)](http://nwlondonicb.nhs.uk)

Appendix A

Brent Gateway Services

Carers Support Service

The Service provides a pathway for carers to access the support they need, and which is available to them.

The service is focused on providing a more equitable service and particularly target:

- Young carers
- Parent carers of a person with a disability

Carers of older people with a mental health issue e.g. Dementia or a functional/organic mental health condition

The carers service is community based primarily in the Brent Hubs and aims to reach out to what have traditionally been seen Hard to reach carers

The Carers Support Service will offer carers information and advice, support carers with care assessments and signpost to relevant services such as talking therapies, housing and benefit advice the service does not give this advice directly.

The Carers services holds engagement events and support sessions and will focus on developing peer support groups for carers.

To use this service, you should be a carer living in Brent or caring for someone in Brent

Young Carers

Raise awareness of young carers in Brent

Develop young carers champions

Organise peer support groups

Arrange respite activities

This service is available to young carers under 18 who are living in Brent or caring for someone in Brent. Call 07393 142 846 or email m.masanganise@nhs.net to request the referral form.

Carer's association

In addition to the information above, Brent Carer's Association support can be found on www.brentcarerscentre.org.uk/ or tel 020 3802 7070.



Adult Carers Referral Form

Brent Gateway Partnership provides support for Adult Carers with an emphasis on Parent Carers of a child with a disability, illness and Carers of older people with mental health issues e.g. Dementia or a functional/organic mental health condition (this also includes other disabilities/illnesses)

Services offered:

- Carer-specific information and advice service.
- Support carers to complete Carers Needs Assessment forms.
- Signpost to relevant services such as talking therapies, housing and benefit advice; our service does not give this advice directly.
- Support groups and carers training. Support sessions will focus on developing peer support groups for carers.
- Time banking scheme for carers.
- Social inclusion for isolated carers.

Criteria:

- Either the unpaid Carer must be a resident in Brent at the time of the referral
- Or the dependant or cared for is living in Brent.

Referral Line: 0203 948 0600

Email: info@brentgateway.org

Referral Information			
Date of Referral			
Referrer name:		Phone	
Job Title:			
Organisation name		Email	
Is the Carer aware of this referral? If not, please explain why?			
What is the reason for this referral?			
Is a Carers Needs Assessment required?			

Carer Information			
First Name		Last Name	
Date of Birth		Gender	
Interpreter Required?		Language Spoken?	
Client's Address		Mobile	
		Home Phone	
Post Code		Email Address	
Do you consent to Brent Gateway holding your information on a secure database?	YES / NO		
Equality & Diversity			
Ethnic Group		Religious Group	
Debt Identified?		Benefits in order?	YES / NO
Main Disability:			

Does someone also care for you?	If yes who cares for you?		
Overview of current situation (Caring role, who they care for?)	Please describe your caring role		
Where or how did you hear about our service?			
Dependent/Cared for Information			
First Name		Last Name	
Date of Birth		Gender	
Address Post Code If different to Carers address		Mobile	
Main Disability/ Diagnosis/need?		Home Phone	

Appendix C

Some examples of small snacks for people in their end of life

Small portions of food, which do not need a lot of chewing, may be easier to manage.

Suggestions:

- Mini tub of yogurt, fromage frais, dessert or custard (often sold in multipacks)
- Mini ice cream lolly or mini tub of ice cream
- Small pieces of prepared, soft fruit e.g. mango, melon, grapes, orange segments
- Favourite sweets or squares of chocolate
- Small pieces of scone with butter and jam or lemon curd
- Mini tub of cream cheese or cheese spread – these could be served with soft bread
- Quarter of a sandwich with a soft filling e.g. egg mayonnaise, tuna mayonnaise, pâté
- Cocktail sausages, mini sausage rolls, mini quiches or mini scotch eggs
- Squares of cheese
- A few 'soft' crisps such as Quavers or Wotsits

Nutritious drinks

Small cups or glasses may be easier to manage. If the person can only manage half a glass or cup, they may still find it easier to drink from a full cup or glass.

This can make swallowing easier because the person does not have to tip their head back as far.

Sips of citrus flavour drinks may help if the person has a dry mouth.

- Milkshakes
- Milky coffee
- Hot chocolate
- Malted milk drinks
- Smoothies
- Fizzy drinks or fruit squash (try to avoid sugar free, diet and no-added-sugar varieties)
- Fruit juice