End of Life Care: FAQs

Below is a set of Frequently Asked Questions written by the end of life care team from the Neighbourhood and Wellbeing Delivery Alliance (part of the Lambeth Together local care partnership). It was developed by the Herne Hill Group Practice Patient Participation Group and answered by local GPs. This provides detailed information to the general public around end of life care in Lambeth to help you understand your choices and think about how you might plan for that time for either yourself or a loved one.

The answers to many of the questions below involve knowing how the person (patient) would prefer to receive care and what preferences they may have. We have referred to an Advance Care Plan, and we encourage any adult of any age to consider thinking about this and communicating it so that Health and Care Professionals have good information to help them meet those preferences.

The end of a person's life is a difficult and upsetting time for everyone involved. It can lead to a number of uncomfortable and difficult decisions which often need to be made quickly and sometimes without warning. Whilst preparing for end of life care will never be easy, having these discussions ahead of time with your family and friends and making your wishes known can ease the process. Answering these questions can be difficult, there are many variables – remember sometimes a dying person may have different wishes to those of people close to them and in this case the wishes of the patient will be what guide health professionals who are caring for the patient.

Frequently Asked Questions

End of life medication

What end of life medication is available and who is able to give it?

- This is a broad question. The commonest types of medication are treatments for pain, nausea, anxiety/distress and excessive secretions (saliva etc). Often a Marie Curie nurse can be available to be in the home during the night at the very end and they can support with medication. There have been examples of relatives/carers being trained in giving this type of medication
- On a case-by-case basis, in the final 12-72 hours of life medication may be administered by either single injections or slow infusion through a very small needle under the skin. This medication is prescribed by a doctor and generally administered by a nurse. Most usually this is done by District Nurses (Community Nurses). 'Pal@home' service provide a night service to your loved one

Death at home

When is it appropriate for you to leave hospital and return home to die?

- Broadly, this is when you request to return home and when there is time to arrange this in a manner that ensures there is not a situation where death occurs in an ambulance without loved ones nearby or some other similar unwelcome event
- Coming home from hospital can be arranged much more easily if this is planned ahead and services at home are primed – which potentially can happen quite quickly

Will the GP visit you at home?

- It will vary from situation to situation. Different practices and individual GPs approach this differently – some GPs are very keen to be very involved and others would very much leave this to community specialist palliative care services
- Usually, the GP will issue a death certificate. In normal times to do this the GP should have seen the patient in the 2 weeks before death. Since Covid, this time has been extended and video calls can count

What palliative treatment (end of life medication) can be given at home?

- See answer above. There are other medications for more specific issues such as convulsions, headaches associated with brain tumour, bleeding or ulceration from particular tumours

- A palliative treatment is a treatment that is primarily aimed to bring relief rather than to cure or prolong life and most treatments that are available in hospital or a hospice are available at home
- One difficult area is that of fluid replacement – in the last few days of life a person may receive fluids from a ‘drip’ via a very fine needle under the skin
- A ‘good death’ is often associated with simplicity and not too much medical-related involvement. It can be difficult to accept that dying is a process where the body gradually stops performing certain functions, and part of palliation is to allow this to happen. Different body processes slow down and stop at different rates leading to a natural death

How easy is it to get help if you are distressed or suffering?

- It should be very easy. Ideally and usually family/carers will be given information about who can be contacted and when. Some support will be via the phone and other support will be in the form of someone who can visit. Usual avenues of support are GPs, community palliative care nurses (from a hospital or hospice), District Nurses, or other helplines
- Usually, consideration will be given to what problems are likely to arise in the following hours or days and plans made accordingly

What support can your relative(s) expect?

- Practical support (what do I do?) can come from paid carers, advice from nurses and doctors involved either in advance or at the time
- Another type of support is reassurance and information about what to expect – some of this can be from having conversations, some from websites (see page 7). Emotional support throughout the journey can come from family and friends as well as various professionals

When (if at all) should you be transferred to a hospital or hospice?

- This decision depends on how best to meet the needs and wishes of the dying person. Ideally some thought will have been given to this in advance.
- Request or wishes may be specified and shared in an advance care plan that you have created. However, if there is a plan for death to take place at home then sometimes there are not resources (in family or services) to allow this to happen and transfer will need to be arranged
- If you have an advance care plan stating death in hospice, the time of transfer will depend on how things are going at home and there can be a factor of bed availability at the hospice. When a person is clearly dying and they do not wish to be at home then transfer is probably appropriate
- If a person wishes to stay at home, as above, there may be a limitation on this if people are not available to provide care

Death in hospital

How are decisions to discontinue treatment made?

- For any treatment, consideration needs to be given such as; how helpful is it? What is it achieving? How distressing is it? What are the side effects?
- Some treatments are not medically appropriate (there is no realistic chance of them being effective) at a certain point, for example, cardio-pulmonary resuscitation (CPR) or mechanical ventilation

When are food / nutrition / water no longer offered / given?

- These would be offered for as long as they can be taken. A point comes in the process of death when more nutrition or fluid will not make a difference

Can relatives stay at the hospital all the time?

- In general, one relative would always be welcome to stay
- More than one relative is dependent on Covid-19 guidance and **on local factors** e.g., is there a side room available? How many people want to stay? What does the patient want? How comfortable can the relatives be made?

Death in a hospice

At what stage can you go to a hospice and how long can you stay there?

- This decision is influenced by how things are going at home. Generally, a hospice stay for the final stay would be 10-12 days (although respite is not offered)
- Remember you can also go into a hospice sometimes to bring symptoms under control before going home again to live better for a while longer

Do hospices take you with any condition?

- In principle yes – conditions may include heart failure, kidney disease, dementia as well as cancer

Are there any examples where you cannot go to a hospice e.g., having dementia?

- Not absolutely – whether dementia is the ‘main’ diagnosis or an additional one it is not a barrier to hospice care
- However, if you have dementia, it probably benefits you more if you are looked after at home

Do you have access to the same palliative treatment (end of life care medication) as that available in a hospital?

- Yes – arguably more

Death in a care or nursing home

What palliative treatment (end of life care medication) can be given in a care or nursing home?

- At least as much as at home

When (if at all) is it appropriate for you to be transferred to a hospital or a hospice?

- Generally, one would hope that a person dying in a nursing home (a place that is their home, where they live with trained nurses available) would stay there – generally there would be no benefit to being elsewhere
- A care home has less staff and no nursing staff and this is the person's home so really the principles are the same as those for a person in their own house or flat

How much communication / involvement should you and your relatives expect from the GP?

- This varies for a number of reasons. It is always reasonable to contact the GP and seek advice or help

Will Macmillan or Admiral Nurses visit the home?

- Nurses and / or GPs may visit homes routinely (but this is dependent on a number of factors)
- Other organisations may also regularly visit dependent on needs
- MacMillan do not provide any clinical support in community palliative care (in Lambeth) - they may advise on financial matters and they can provide grants to cancer patients under certain circumstances
- Palliative care is delivered by either St Christopher's Hospice or Guy's and St Thomas' Palliative Care Team in an expert advisory capacity rather than necessarily 'hands on'
- They may also give advice to care home/nursing home staff where needed – and will visit to give special expertise where needed or not available from staff
- The 'Pal@home' service has replaced the District Nursing night service in Lambeth

Religious and cultural considerations

How do health and social care staff ensure that your religious and cultural beliefs and practices (and those of your relatives) are respected in any of the above settings?

- An advance care plan sets out the wishes and requests of you and your family
- An advance care plan is available to you at any age and is free to complete. Please contact your GP practice for further information

- Staff often have an awareness of some general cultural practices, but further discussions with yourself and your relatives are important to ensure your beliefs and wishes are respected. Even though some generally preferred practices for people from different backgrounds, individuals may have particular wishes

Bereavement support

What support will be available before and after death, particularly when the death is particularly traumatic?

Hospice's, Macmillan, Marie Curie (and others) all have dedicated bereavement support:

- **St Christopher's Hospice:** https://www.stchristophers.org.uk/service/st-christophers-bereavement-service/
- **Macmillan:** https://www.macmillan.org.uk/cancer-information-and-support/supporting-someone/coping-with-bereavement
- **Trinity Hospice:** https://www.royaltrinityhospice.london/bereavement-support
- **Marie Curie:** https://www.mariecurie.org.uk/get-involved/day-of-reflection/grief-resources?gclid=CjwKCAiAxJSPBhAoEiwAeO_fP_5Y2XwuZEYCWBQ_jYzC2lQelB9WBpbOgfCz0I1yMbNlOPhuQ_XRehoCW90QAvD_BwE
- **Cruse** Contact your local branch | Cruse Bereavement Support
- **Robert Dimbleby Centre Guy's Hospital – for cancer patients treated at Guy's**
- Your GP practice
- Not everyone needs support – generally, staff looking after a dying person would give some follow up contact information to family and friends

Advance Care Plans

Health Services generally and in particular across Lambeth and Southwark are very keen that all local people have an opportunity to consider preferences and wishes they may have about how they are cared for. Especially in days or weeks leading up to the end of their life.

Local staff are progressively more likely to try to find ways to sensitively give local people opportunities to explain their wishes and to record them for future references. Always remembering that people may change their minds.

You can ask your GP for support in doing this or you can contact 'Compassion in Dying' a charity who want to help people with these matters.

How can you be sure that health and social care staff and relatives are aware of your Advance Care Plan?

- Advance care plans are shared across services and teams in the health system through a confidential web-based system called Urgent Care Plan
- Once created and uploaded, this electronic record can be viewed by your GP, local hospitals, the London Ambulance Service and Out of Hours services
- You can ask your GP to print out a copy of your Urgent Care Plan. If there are parts you have questions about or think should be updated it would be best to contact the person who has uploaded it to the UCP site. If it is difficult to contact this person you can approach your GP

Can an Advance Care Plan ever be challenged or overridden by health staff or relatives?

- An advance care plan is a plan – it does not set things in stone. You can change your mind at any time and update your advance care plan
- Some treatments you may ask for may not be available (may not be medically appropriate). Where you 'have capacity' (are able to make and communicate your preferences and wishes on a matter relating to your care), you can decline any treatment you wish even if health staff or relatives think it is a bad decision
- If you do not 'have capacity' you may have a legally binding 'advance directive' in place (e.g., to refuse CPR or a blood transfusion). An 'Advance Decision to Refuse Treatment' is best set up in advance when you are well. If your relative or friend has a Lasting Power of Attorney for Health, they person can make decisions on your behalf
- If you do not have a Lasting Power of Attorney, health and care professionals are required to make decisions 'in your best interests' but that decision should take into account any of your KNOWN preferences. Alternatively, information about preferences may come from your relatives
- Technically the preferences of your friends or family are not relevant – it is your preferences that are of interest
- If a decision is a medical one e.g., where CPR harms outweigh the benefits, then it will not be offered regardless of capacity and cannot be overridden. A second opinion may be offered in some situations if there is disagreement

What happens if the Advance Care Plan is unclear about something?

- Decision should be made by those caring for you in conjunction with you. If you do not have capacity, see above

For Further Information

- Let's Talk: Advance Care Planning | Guy's and St Thomas' NHS Foundation Trust
- Thinking about end-of-life care for you and your family | Healthwatch Lambeth

- Contact your GP
- Compassion in Dying
- Marie Curie - Planning your care in advance