

Frequently Asked Questions

Below are some of the questions that people receiving palliative care frequently ask:

What do we say to each other after a diagnosis?

Following a diagnosis everyone may have a different way of absorbing and coming to terms with the news. You may not know what to say to each other due to the immediate shock, and therefore communicate in superficial terms or simply avoid the issue and its implications as though things were as before. Attempts to retain a sense of 'normality' by denying the reality of what is happening may be helpful to begin with, but this response can usually only be sustained in the short-term. It is normal to experience a degree of coming and going of feelings, possibly alternating from numbness or emptiness to other times feeling quite extreme surges of emotions, like anger, sadness, guilt, etc, but everyone responds differently and there is no right or wrong way of responding or being. Serious and painful conversations should always be entered into carefully and periodically, with sufficient time left in between for everyone to step back in order to allow time to be absorb and reflect on the conversation afterwards.

How do I answer a child's question about what is going to happen?

It is important not to diminish the seriousness of the situation by giving partial or factually incorrect information. The truth will become apparent in time whatever you tell the child, so it is important to ensure that nothing you say will be contradicted later. You need to retain your child's trust so try and be honest with them at all times. A 'right time' might never present itself, so it's more important to get the information across so they know what is happening. This is better than leaving them to ask increasingly difficult questions, which become increasingly difficult to answer.

What is End of Life Care?

End of life care is an important part of palliative care, and usually refers to the care of a person during the last part of their life, from the point at which it has become clear that the person is in a progressive state of decline.

End of life care is usually a longer period than the time during which someone is considered to be "dying". In the UK it is mainly health care professionals who use the term end of life care, whereas patients and their families are more likely to refer to terminal illness and terminal care. The time at the end of life is different for each person, and each person has unique needs for information, for support and for care.

What is a living will?

A living will, advance directive or advance care planning are written statements in which you can record your decisions about which treatments you would like/would not like to have. This statement will help doctors and your family to know what your wishes are should you become too ill to tell them. A living will provides an opportunity to record any religious or cultural issues that are of important to you

What palliative care can be received in hospital?

Most palliative care in hospital is given by the nurses and doctors on the ward where you are staying. If you have issues that need more specialist input, your ward team can refer you to the hospital specialist palliative care service.

What is Hospice Care?

At home (not available in Redbridge), in day care and in the hospice, they care for the person who is facing end of life and for those who love them. Nearly a third of all people admitted to a hospice return home again. Hospice staff and volunteers work in multi-professional teams to provide care based on individual need and personal choice, striving to offer freedom from pain, dignity, peace and calm.

Do Hospice services apply in Redbridge?

In Redbridge the services provided by St Francis Hospice only include the inpatient unit and day hospice services.

Does everyone have to come to a Hospice for Care?

No, the majority are cared for in their own home by their family with support from their local doctor, district nurse and if within Redbridge, specialist advice will be provided and accessible from the Community Macmillan Team based at Manford Way Health Centre. Sometimes problems can be too complex and an admission is necessary to try and overcome these problems.

Why is an advance care plan important?

Advance care planning is the process a capable adult follows to ensure that their beliefs, values and wishes for future health care are known in the event that the adult is incapable of making health care decisions when the health care is required. When a capable adult does advance care planning, their close family or trusted friends and health care providers know the adult's wishes for health care treatment and can respect them in the event the adult is incapable of deciding for themselves when the care is needed.

Can my Advance Care Plan be changed or revoked?

Yes. You can change your Advance Care Plan at any time while you are still capable of making medical decisions for yourself. The best way to do this is by completing a new Plan and destroying the old one. Make sure you tell everyone who has a copy of a previous Plan that you have done this, and give them a copy of the new Plan.

What happens if a relative or carer disagrees with the use of the Liverpool Care Pathway (LCP)?

As with all clinical decisions in healthcare, the senior doctor and the multi-disciplinary team should reach consensus about what care is appropriate at this time. If disagreements occur between the members of the healthcare team or between the healthcare team and those close to the patient, then the clinical team should involve an independent advocate, and/or should seek advice from another senior colleague, and should also seek a second opinion and/or use local mediation services.

Good, comprehensive, clear communication is crucial and all decisions leading to a change in care delivery should be communicated to the patient where possible and deemed appropriate but **always** to the relative or carer. The views of all concerned must be listened to, considered and documented.

What if the patient improves can the LCP be discontinued?

Yes, the LCP can be discontinued following a review of the patient's condition by the multi-disciplinary team and in consultation with the patient, where possible and always with the relative or carer. The views of all concerned must be listened to, considered and documented.

Other End of Life Care factsheets which may be of interest:

Factsheet 1: Care in the last year of life	▶	Factsheet 6: Care after death	▶
Factsheet 2: Support in the last six months	▶	Factsheet 7: Frequently Asked Questions	▶
Factsheet 3: At every step of the journey	▶		
Factsheet 4: Approaching the final few weeks	▶		
Factsheet 5: Care in the last few days	▶		