

Remember:

Request that the patient is kept clean and comfortable at all times.

Inform a senior staff member that you will talk to the patient's own doctor, since he/she is likely to know them better. And you will inform the staff of any advice they offer.

Ask to be kept informed of any changes in your relative's condition (day or night) and provide your phone number; to ensure they contact you at all times.

Request that the patient sees and is examined by a doctor specialising in their condition.

If you become worried about the patient's progress seek an independent opinion. This may be regarding use of drugs, plans for care or other concerns.

Information

Drugs used when a patient is placed on the LCP can have a detrimental effect on their overall condition and may affect their ability to recover. Patients may demonstrate symptoms including:

Undue drowsiness: This can be due to a number of factors, but the first thing to check is whether the patient has been given a sedative, or medication such as morphine for any reason. You are entitled to make enquiries about these matters. If sedation or other medication has been given ask

"Why?" Keep on asking until you get an answer. You may need to speak to one of the doctors, and if need be speak to the Consultant. If you are still not happy about the situation, ask for a second medical opinion.

Pain control: If the patient seems to be in discomfort or pain, report this to the nurses and ask them to assess the situation. There may be a simple explanation, such as a need for the toilet, or the need to be turned in the bed, or the need for a drink or some food. Abdominal pain is sometimes due to severe constipation, which can be overlooked and can make the elderly unwell and confused. A urinary infection can also cause discomfort and is a risk for those with catheters. Sometimes patients are given morphine for reasons other than pain. It is also an effective medication to relieve coughing and shortness of breath. If the patient has been prescribed pain medication, check the drugs listed and find out why they have been used.

Some hospitals have been criticised for over using strong pain-killers, given via a syringe driver. This can be dangerous, but is valuable for patients who are terminally-ill whose pain cannot be controlled with simpler medication.

Questions and answers for patients and relatives to ask about the Liverpool Care Pathway

**What to do?
Who to ask?
What to ask?**

Information

Remember:

You must speak out for your friend or relative

Never be hesitant to ask questions or make suggestions on behalf of your relative or friend.

You should feel free to direct questions about the care that your friend or relative is receiving.

Be aware:

Is your friend or relative able to take anything by mouth?

Is it safe for the patient to eat, if so could you or another family member help with feeding?

Is there a 'Nil by mouth' notice by the bed? If so ask why?

How long has the notice been there, and why is it there?

How long will the order notice last?

Ask what they are doing about giving water?

If you suspect that the patient may have been placed on the LCP then request the LCP RELATIVE/CARER information leaflet.

Ask who has placed the patient on the LCP. As the LCP guidelines request that only senior members of staff make decisions about the patient?

When elderly or disabled people enter hospital as patients, they may be in a very vulnerable state. Friends and relatives may be needed to speak for them. It's possible that your friend or relative may be put on the Liverpool Care Pathway. This will affect the care the patient receives from doctors and nurses and will lead to your friend or relative dying.

With regards to **Food** it is not unusual to wait a while to see if a person regains the ability to swallow, if that is the problem, but while waiting, hydration should be provided. Most doctors advise that decisions about feeding should be taken sooner rather than later as malnourishment adds to the patient's problems. If swallowing is a problem, the patient should be expertly assessed and reassessed at least weekly. Sometimes oral feeding can be maintained using specially thickened feeds. The advice of a dietician is helpful.

If no food can safely be given orally, feeding can be achieved via a tube, passed into the stomach either via the nose and throat, or directly into the stomach. The latter, called a PEG for short, requires a small procedure under local anaesthetic and sedation. The advantages and disadvantages of this procedure should be discussed with all concerned. It carries a very small risk.

If the doctors advise PEG feeding, accept their advice, because without food a patient will inevitably die. If they do not raise this matter, do so yourself.

Remember:

Ask to see a copy of the document below and ask for an explanation of what is happening. Keep a note of any information they provide you.

Liverpool Care Pathway - For the Dying Patient Core Documentation - Version 12

Request that staff communicate everything to the patient and talk to them about what may happen.

Should they appear to be too poorly to talk with staff, then ask to be kept informed about treatment; as the next of kin or patient representative. This includes a request that you be present at any MDT (Multi Disciplinary Team Meetings).

Ask to see the fluid intake chart. If there is no chart, raise the question of other forms of hydration.

Can fluids be given orally if possible or intravenously (by drip or by anal tube) if this is considered more effective.

Request that they give the patient food if they are hungry and more importantly fluids at all times.

Ask for the fluids to be monitored so the patient is not physically overwhelmed by them.