

Received: 21.10.2008
Accepted: 28.10.2009

A – Study Design
B – Data Collection
C – Statistical Analysis
D – Data Interpretation
E – Manuscript Preparation
F – Literature Search
G – Funds Collection

CARE FOR DYING STROKE PATIENTS IN ENGLAND: THE LIVERPOOL CARE PATHWAY

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SUMMARY

The purpose of this paper is to introduce a new concept and tool in the care of patients after stroke who are in the final stage of their lives. This may resemble palliative care, but its main goal is to care for the dying patient for a short period of time, and not merely to reduce pain and suffering. This tool is called the Liverpool Care Pathway (Ellershaw, Wilkinson, 2003), and was developed a few years ago in the United Kingdom to support dying patients, their families and friends, and also to give directions for care to medical staff when the patient's death is imminent (Ellershaw & Murphy, 2005; LCP, 2007).

Key words: *diagnosis of the dying, integrated care pathway, palliative care*

INTRODUCTION

Although many people after stroke recover and gain varying levels of independence in order to live their lives after this event successfully and joyfully, some patients deteriorate and need more intensive palliative care. When the attending physicians notice changes in the patient's condition that indicate to them that the person is dying, they want to achieve the best quality of care for the end of life. To gain this goal they use a special framework, which has been introduced quite recently to British hospices, hospitals, and care homes, known as the Liverpool Care Pathway for the Dying Patient (LCP). The LCP is part of the Integrated Care Pathway (ICP), a tool used for the care of patients after stroke. It is not only a tool, however, but primarily a concept that embodies guidelines and best practice standards for looking after the individual patient (LCP, 2007). There are several slightly different forms of the LCP, which can be used in different environments surrounding the dying person, e.g. hospitals, hospices, nursing homes, and communities. The LCP was developed at the Royal Liverpool University Hospital by a specialist palliative care team based in the Marie Curie Palliative Care Institute in Liverpool, Great Britain (LCP, 2007). One of the main reasons for developing the plan was to transfer the hospice model of care into other care settings (Ellershaw, Wilkinson, 2003). This multi-professional document provides an evidence-based framework for end-of-life care.

There are some differences between palliative care and the LCP. The main goal of palliative care is to reduce the severity of disease symptoms, alleviating suffering and pain in order to improve the quality of life (Fallon, Hanks, 2006). It may be applied for a long time for a patient with certain conditions. LCP has been developed to help dying people at the end of their lives only, and also to support their families and relatives in this time. The focus on the patient's quality of life has increased intensively over the past twenty years. Over 50% of hospitals in the United Kingdom offer palliative care programmes. Quite recently the concept of a dedicated team, called a "palliative care team," has also appeared. Such a team is entirely concentrated on palliative treatment (Watson et al., 2005).

STRUCTURE AND CONTENT OF THE LIVERPOOL CARE PATHWAY

The first important question is, who has the authority to commence the LCP? The decision to put a patient on the LCP must be agreed to by the patient's consultant and discussed with the whole multi-disciplinary team (Ward, 2008a). The consequence of such a decision may be to stop any medication that is not helpful. It may be not possible to give the patient medication by mouth. It may not be appropriate to continue some tests, including blood tests, temperature and blood pressure monitoring. Members

of the patient's family may want to be involved in care at this time. The staff should consider maintaining the patient's comfort with the help of relatives, regarding position in bed, use of special mattress, and regular oral hygiene. It should be discussed with the family whether food and drink are wanted or needed. The LCP includes the need for staff to respect the patient's religious and spiritual needs and wishes at the time of death and after death. A wide range of information about the care plan is given to the family in leaflets and verbally by members of staff.

The decision as to which patient should go on the LCP is considered carefully, and several significant symptoms of deterioration are crucial. According to the procedure, a patient qualified for the LCP should meet at least two of the following four criteria:

- 1) is bed-ridden;
- 2) is semi-comatose;
- 3) is only able to take sips of fluids;
- 4) is no longer able to take tablets orally (LCP, 2007; Ward, 2008a).

The LCP consists of three main sections:

- 1) initial assessment;
- 2) ongoing care;
- 3) care after death.

Assessment of the patient's condition is documented by ticking the relevant boxes (Ward, 2008b). The characteristics of each will be presented separately.

Initial assessment

This section should be completed when the patient is commenced on the LCP. It includes an assessment of the patient's state in many spheres: physical, psychological, social, religious and spiritual. This section should be reviewed periodically to check whether the patient's state has changed compared to the previous, initial phase of the LCP (Addenbrooke's Hospital Integrated Care Pathway. Care of the dying pathway (LCP) – protocol, 2007).

"Physical condition" includes information about the patient's ability to swallow, nausea, constipation, confusion, agitation, restlessness, distress, catheterization, awareness or consciousness, respiratory tract secretions or dyspnoea, pain, oedema, itching, bleeding, and other similar symptoms.

"Psychological condition" includes the insight of patient and his family, as to the main directions of care and the reasons why the patient is commencing the LCP. At this stage insight into the condition is assessed. There are a few questions concerning the patient's and relatives' awareness of the diagnosis separately, as well as recognition of the fact of dying. Practical issues, such as the last will and testament, are also considered (Ward, 2008a).

Religious and spiritual support is assessed separately with the patient and members of the family. The religious tradition is identified, as well as spiritual and cultural needs for the duration of the LCP, at the time of impending

death, at the moment of death and afterwards. In some cases emergency marriage may be considered if necessary (Ellershaw, Wilkinson, 2003).

Another important goal of the LCP is to identify how the family are to be informed of patient's death: at any time, not at night time, while staying overnight in the hospital. When the dying patient is in the hospital, hospice or care home, his GP practice is also informed, and is aware of the patient's condition.

Initial assessment finishes with explaining and discussing the plan of care with the patient's relatives, and they should express their understanding of the information provided.

Ongoing assessment

This section refers to four hourly assessments of the current symptoms of the patient's condition (pain, agitation, respiratory tract secretions, nausea and vomiting, dyspnoea, other symptoms) and applied procedures (mouth care, micturition, medication). The assessment should be done at 400, 800, 1200, 1600, 2000, and 2400, and documented properly (LCP, 2007; Ward, 2008a). The goals are to increase the patient's comfort by making him pain free, not agitated, not feeling nauseous and vomiting, with mouth moist and clean, and urinary catheter applied if needed. Additionally, 12-hour assessments need to be done as well, regarding the patient's mobility and pressure area care, bowel care, insight support, religious needs, and care of the family. This should be documented at 800 and 2000 every day (LCP, 2007; Addenbrooke's Hospital Integrated Care Pathway. Care of the dying pathway (LCP) – protocol (2007).

Care after death

This section is supposed to be completed when patient has died. It includes verification/confirmation of death by qualified staff, either doctor or nurse. Relevant persons, such as the GP Practice, the Bereavement Care Service, and Social Services should be contacted as soon as possible. Necessary information should be communicated to the family and advice (leaflets) given to them.

DIAGNOSING THE DYING PATIENT

Diagnosing the dying is always difficult and complicated. There are many barriers to making the appropriate decision (Ellershaw & Wilkinson, 2003). It will always have an impact on the patient and his family. Identifying appropriate patients for the LCP is very important, although the decision is not made once and for all. If the patient improves, he can be removed from the LCP, and the whole previous treatment may be given again. The main concerns of the family include withdrawing and withholding treatment, fear of foreshortening life, and cultural and religious anxiety.

On the one hand, it is difficult to make a diagnosis of imminent because of certain barriers. On the other hand, there are several common signs and symptoms of the final stage of dying, so when they do occur, professionals recognize that the death of the particular patient is imminent. First of all, this may be the case when there is a day-to-day deterioration of strength, appetite and awareness. Other signs may also be observed, such as change in breathing pattern, low blood pressure, variable pulse, or decreased urine output (Ward, 2008b). Difficulties in swallowing medicine and loss of interest in food and drink may be another symptom of dying. When the patient is drowsy and manifests reduced cognition compared to his previous status (days, months), it may be worthwhile considering his deterioration in terms of dying.

There are also exceptions to this, such as sudden death without showing any of the common warning signs, or chronic illness with gradual deteriorations and acute episodes. It is worthwhile considering all of the points and putting the patient on the LCP if necessary. If there is improvement, the patient can come off the LCP; this decision may be reversible, appropriately to the patient's current state.

SYMPTOMS OF DYING TO BE OBSERVED

The most problematic signs for dying patients are those that need to be assessed currently (see section 2 of the LCP - Ongoing assessment; LCP, 2007). There are the following:

- pain;
- agitation and restlessness;
- respiratory tract secretions;
- nausea and vomiting;
- breathlessness (Ellershaw & Murphy, 2005; Ellershaw & Wilkinson, 2003).

The members of the medical staff may ascertain that the patient is in pain in several different ways: verbally (crying, telling), non-verbally (tense, grimacing when touched), physically (wounds, bruises, pressure sores on skin), internally (tumors, constipation).

The signs indicating that the patient is agitated and restless are similar to those which indicate pain. Because of that it may be difficult to distinguish between symptoms of pain and agitation. Due to differing treatments, the patient's condition should be considered carefully with the family and on the basis of a thorough examination. Moreover, the patient may experience pain and agitation simultaneously (Hospital Review of the Year, 2007; The Lewin Stroke and Rehabilitation Unit (*LSRU*),2007; Ward, 2008c).

Respiratory tract secretions may be identified by listening to the patient's breathing. Noise caused by secretion may be distressing to relatives (De Bellis et al., 1999). It should be explained to them. They may help the patients non-pharmacologically, e.g. by repositioning for drainage of secretions.

Vomiting may not be a new symptoms at this stage of the condition. The patient may want to turn away at the sight or smell of food. It may be necessary to protect them from smells by closing the doors or opening windows.

Breathlessness may be observed quite often in dying patients. Medical staff may help by applying pharmacological treatment (medications) or in a non-pharmacological way (using a fan, oxygen, repositioning).

Due to limited movement, there is a high risk of pressure ulcers and skin breakdown. The main aim in the LCP regarding this problem is to prevent further deterioration of existing sores and development of new ones. Patient should have an appropriate pressure relieving mattress (Ward, 2008c).

CONCLUSIONS

The main benefits of using the LCP is to give the patient an experience of a good death and to care for his dignity at the end of his life. The patient's family and friends can focus on the time they have left together, because they have confidence in the care being delivered. The LCP facilitates multi-professional communication, and the doctors and nurses are able to deliver the optimum care for the dying patient. This concept and tool is useful in diagnosing the dying person in different environments, mainly in hospitals, but also in hospices and nursing homes. It is helpful in documenting changes in the patient's condition. Because of its very strict plan of care, any improvement can be quickly noticed, and the LCP can be terminated if necessary.

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