



Treatment for the dying patient:

# The Liverpool Care pathway

## Key Concepts

- The Liverpool Care Pathway (LCP) is used to manage care in the last days and hours of a person's life, irrespective of diagnosis or setting
- The decision to place a patient on the LCP requires skilled judgement and is made once all reversible causes of a patient's condition have been eliminated
- The LCP promotes communication to explain the care strategy and to satisfy the spiritual and emotional needs of the patient and their family
- A secondary goal of the LCP is to expand knowledge relating to the process of dying
- Following training and registration, practices are able to use the LCP under the umbrella of registered DHBs, hospices, residential care facilities or hospitals
- Clinicians can be trained to use the LCP in under one hour
- The principles of the LCP are widely considered a model of excellence in caring for the dying and clinicians unable to access the LCP can still be guided by its principles

## Studying death and caring for the dying

New Zealand's population is ageing. People aged over 65 years are projected to make up over one quarter of New Zealand's population in the 2030s, compared to 12% in 2005.<sup>1</sup> Residential care facilities and general practices are increasingly required to provide hospice type care. However, research into dying is complicated and providing evidence based guidance for care in the final days of a person's life is difficult. It is unethical to provide terminally ill patients with potentially differing standards of care, and bereaved relatives' experiences can be traumatic, making data analysis difficult.<sup>2</sup> Compared to other areas, care for the dying has a relatively small literature base. The death of a "loved one" can be the most difficult period family and friends will encounter. The way a person dies lives on in the memories of those left behind. In the United Kingdom, only 16% of cancer deaths, and less than 5% of non-cancer deaths,\* occur in hospices. Most deaths occur in hospitals and residential care facilities (57%) and private homes (15%), therefore health professionals working in these settings also require training in end of life care.<sup>3</sup> In New Zealand, the Liverpool Care Pathway for the Dying Patient (LCP) has been selected by the Ministry of Health as the best means of providing quality, evidence-based, end-of-life care, and training to the people providing it.

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\*New Zealand statistics not available.

## What is the Liverpool Care Pathway?

A care pathway, also known as a care map, is an increasingly common tool used to standardise and manage the quality of healthcare. The concept began in the mid 1980s and has evolved to mean a multidisciplinary, evidence-based document, for a specific patient group, with a predictable outcome. Generally, a care pathway is a document held at the bedside that maps what treatment has been received and where treatment will likely lead. The Liverpool Care Pathway (LCP or the Pathway) was developed in the 1990s, as a collaboration between the Royal Liverpool University Hospital and Marie Curie Palliative Care Institute in Liverpool. The idea was to transfer the hospice model of excellence in care of the dying to other care settings. An advantage of the LCP over other palliative care pathways, is that it evolves as evidence changes and feeds back upon itself through self-auditing.<sup>4</sup> The LCP also has a strong focus on training and education.

### National LCP registrations

As of March 2011 (latest data):

- LCP projects are registered across 19 of the 20 DHBs
- 81% of inpatient hospices are registered to use LCP
- 40% of hospitals\* are registered to use LCP
- 28% of residential care facilities are registered to use LCP

\*As defined by New Zealand certified list of health care providers

In November 2008 the National LCP Office (New Zealand) was established at Arohanui Hospice (New Plymouth), New Zealand's first LCP collaborating centre, with funding from the Ministry of Health, and support from the LCP Central Office (United Kingdom). The National Office's goal is the promotion and co-ordination of sustainable implementation of the LCP across all DHBs in New Zealand.<sup>5</sup> In 2006 there were 12 sites in New Zealand registered to use LCP, as of March 2011 there were 278 (see sidebar).

### How do practices use LCP?

Registration is compulsory in order to use the Pathway, as the LCP document is copyrighted to ensure the "goals of care" remain intact. Registration is free and can be completed on-line with the advice and support of the National Office.

There are two registration options available for practices wishing to use the Pathway:

1. Register as a stand-alone LCP project.
2. Register as part of an existing project such as a residential care home, specialist hospital palliative care team, or hospice.

To register as a stand-alone project, in order to use the LCP in a patient's home, a practice would need to nominate a LCP facilitator to attend a single training day in Christchurch, Wellington or Auckland. Using a train-the-trainers model, the LCP facilitator then instructs the other practice staff. Education and training would also include other health care providers involved in patient care, e.g. district nursing teams, community pharmacists. Training can be completed in under one hour. There are currently no individual practices in New Zealand registered as stand-alone LCP projects.


A simpler option may be for practices to register as part of an existing project, e.g. a locally registered hospice. This would involve a previously trained facilitator spending a few hours with staff members who will be using the

Pathway. The practice would then be covered by the parent institution's registration. This second option is likely to be the most time and cost effective.

Like any tool, the Pathway is only as good as the people using it, therefore at least 80% of all staff using the Pathway, must be trained.<sup>4</sup>

The most successful example of LCP implementation in New Zealand is Mid-Central DHB, where the LCP can be used in the hospice, hospitals, residential care settings and in the community (i.e. patients' homes) across the entire DHB region under a single LCP project based from Arohanui Hospice. This means any GP operating in Mid-Central DHB, once trained, can place a patient on the Pathway. In the Mid-Central DHB, 87% of GPs have received Pathway training as part of this palliative care partnership.<sup>6</sup> It is the goal of the National Office to promote this level of primary care engagement across all DHBs within New Zealand.

For practices in DHBs other than Mid-Central, that wish to use the Pathway, it is advised that the National Office be contacted. National Office can provide information on previously registered hospices, residential care facilities, hospitals and also discuss registrations options with any interested parties.

 For further information, and online enrolment, visit the National LCP Office website at: [www.lcpnz.org.nz](http://www.lcpnz.org.nz)

### How does the LCP work?

The LCP starts once a patient's condition deteriorates and a multidisciplinary team agrees the patient is in the last days, or hours of their life. It is crucial that the team exercises expert judgement when making this decision.<sup>8</sup> The team, at a minimum, must include a doctor and a nurse. The team will have been previously trained in the LCP and through it will be linked to a specialist palliative care unit who are available to provide 24 hour advice. Following assessment, and consultation with the patient and relatives, the Pathway is initiated with regular assessments and a formal team review every three days for those patients still on

## Advance Care Planning

"Advanced care planning" is the term used for a voluntary dialogue a person may have with their caregivers regarding their illness, prognosis, or any other concerns they might have. Discussions are documented and notes can be used to look after a person's best interests if they lose the ability to make decisions themselves. For example, a patient may make an advance directive such as choosing not to be resuscitated in the case of heart failure.

Advanced care planning occurs before an expected deterioration in health status and generally well before the LCP is considered. In New Zealand there is no standardised format for performing care planning and no requirement to submit forms to a central agency. Advance Care planning does not replace the LCP, but rather it reinforces the need for good communication between the patient and their caregivers.<sup>7</sup>



the Pathway. Approximately 3% of patients will improve on the Pathway and the goals of care may need to be revised in some cases.<sup>8</sup> A patient may come off the Pathway at any time.

The LCP document provides comprehensive symptom control guidelines for the management of the five main end-of-life symptoms (pain, restlessness/agitation, respiratory tract secretions, nausea/vomiting, and dyspnoea) and takes into account local availability of medicines and clinical preference.

The LCP requires all stages of the care process to be documented. Documentation allows for auditing, benchmarking and for the continued evolution of care guidelines. The LCP National Office, in conjunction with the Ministry of Health, regularly collates information from LCP projects. Version 12 of the LCP document is currently in use. Ultimately it is expected this process will improve what is known about the process of dying.

### **What are the principles of the LCP?**

The decision to initiate the LCP is driven by the clinician and other members of the team. There are three parts to the Pathway:

1. Initial assessment
2. Ongoing assessment
3. Care after death

### **Initial Assessment**

The initial focus is communication, firstly with the patient, and secondly with family and friends. Any barriers to communication are removed, where possible, e.g. providing a translator, and discussions held relating to issues such as:

- Does the patient know they are dying?
- Do they have any wishes, feelings or beliefs they need to discuss?
- Are there people that need to be contacted?
- Does the patient have any specific spiritual requirements?

- Do they, or their whānau, have any cultural requirements?
- Have they considered organ donation, or burial versus cremation?

Taking into account the patient's individual requirements, a care plan is created with medicines prescribed preemptively on an as needed basis. Particular emphasis is placed on safe prescribing to neither hasten nor postpone death when alleviating the symptoms of:

- Pain
- Agitation/restlessness
- Respiratory tract secretions
- Nausea/vomiting
- Dyspnoea

Any equipment which may be required, such as a syringe driver, or oxygen support are assembled preemptively. The team, when constructing the care plan, also considers interventions such as hydration, clinically assisted nutrition, blood tests and IV antibiotics and whether or not a non-resuscitation order is in place. The Pathway is not prescriptive and is individualised in response to each patient's needs.

### **Ongoing assessment**

The focus is to ensure patient comfort. LCP symptom management algorithms are provided to manage the five common symptoms listed previously. The patient's condition is assessed and recorded in the Pathway document, at a minimum of every four hours (or at the time of a visit if in the patient's home). Assessments can be made by any member of the team within their scope of practice. The document contains reminders to assess specific aspects such as skin condition, continence and hygiene.

The Pathway recommends that food and fluid consumption should be maintained for as long as can be tolerated and that supply of artificial nutrition and hydration should be considered on a case by case basis.

The psychological and spiritual welfare of the patient is assisted through listening and responding where appropriate. The option of having karakia, or prayers, should be offered. The specialist palliative care unit is available at any stage in support of the patient and the bedside team. Attention is also paid to the bedside environment, in order to ensure that the patient can easily access anything they might need, and that family and friends can visit in comfort.

### Care after death

Following death, the body (tūpāpaku), is handled with respect to any previously expressed wishes. Policies are followed regarding personal possessions and any spiritual and cultural requirements, such as a blessing room are provided for the family.

It is explained to relatives what they need to do next, e.g. contacting a funeral director, and written documentation along with emotional support is given to assist in coping with the bereavement. If required, the need for a post-mortem is also discussed.

### Does the LCP work?

The LCP has been implemented to varying degrees in over 20 countries.<sup>9</sup> In the United Kingdom, the LCP has been identified as a preferred option, by the NHS, to provide high quality care and support during the last days of life, while ensuring staff caring for dying patients are properly trained.<sup>10,11</sup> However, adoption of the LCP did result in some initial media debate. A number of palliative care and geriatrics specialists were concerned that the LCP was advocating deep sedation and that dying patients would receive no fluid hydration.<sup>12</sup> The LCP does not promote deep sedation and the Pathway has since been revised (Version 12, December 2009), to include daily assessment of the need for clinical hydration and nutrition.<sup>8</sup>

Despite the increasing acceptance of LCP as a potential gold standard, the extent to which it improves the care and quality of life for dying patients has not yet been thoroughly investigated. The preliminary results of non-randomised,

qualitative and quantitative studies suggest that the LCP can significantly improve the quality of end of life care. A multi-centre study, conducted in the United Kingdom,<sup>13</sup> found that following the LCP introduction:

- The degree to which care during the dying phase was documented increased
- According to nurses and relatives, the burden of most symptoms was reduced
- The total symptom burden was significantly reduced

The first randomised study, currently underway in Italy,<sup>9</sup> is hoped to provide sound evidence as to the effectiveness of the LCP in improving care quality.

Patients should only start on the LCP when death is expected in the following few hours or days. Knowing death is imminent requires skilled judgement. Assuming the initial diagnosis is correct, it is highly unlikely that placing a patient on the LCP will reduce the standard of care they receive. The question remains, as to what extent the LCP benefit patients that are already receiving high quality end of life care, however, it can still provide a strong support framework.



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# Liverpool Care Pathway case studies

## Scenario 1

### Your patient, Bob Daniels:\*

- A retired, 73-year-old farmer
- Registered with your practice for 30 years, widowed several years ago
- End-stage heart failure secondary to ischaemic heart disease
- On maximum tolerated medicines for heart failure
- Currently an in-patient following admission for increasing breathlessness

**The prognosis:** The hospital registrar advises you that Bob's condition will continue to deteriorate and he is not expected to last more than a few days. The patient is fully aware that he is dying.

**The family:** His daughter, Karen, a registered nurse has arrived to be with her father. Bob wants to die at home. Karen agrees to assist, however, she is concerned that she may need specialist palliative support to manage her father's distress caused by his breathlessness.

**Your network:** Eighteen months previously you had a training session with a district nurse, who is the LCP facilitator in your region. Your practice, along with others in the region, has an existing relationship with the hospice. After consultation with the district nurse, both you and Karen are confident that quality care can be provided.

**What do you do?** You are sent a copy of the community LCP document from the hospice. With the district nurse and Karen, you construct a care plan with prescriptions for oxygen, anxiolytics and opiates to be used on an as required (prn) basis. The district nurse agrees to visit Bob daily and you will phone every morning and evening. At Bob's request, Karen contacts several of his friends and neighbours. The LCP document is held at the bedside allowing each member of the team to record visits and make notes. You also update Bob's medical record at the practice with brief notes from your phone calls.

**What happens?** After 48 hours Karen phones, clearly upset. She reports that Bob's condition has worsened. Later that morning, you visit and find Bob distressed and breathless with Karen not coping well. You rule out urinary retention and spiritual distress as guided by the Pathway, then choose to administer anxiolytics and phone the hospice for guidance on how best to counsel Karen. That evening Karen reports that her father appears much more comfortable. The following morning you are told that Bob died during the night.

**Conclusion:** In this example, it is unlikely that the LCP has significantly improved the quality of any clinical decisions that have been made. However, it has provided a strong support framework that has given the daughter the confidence to follow her father's final wishes. Through good communication, encouraged by the LCP, the final concerns of the patient have been addressed, allowing him to die in peace.

## Scenario 2

### Your patient Isla Coddington:\*

- A 77 year old woman with metastatic breast cancer
- Lives at a residential care facility
- Has been bed bound for the past month due to her deteriorating condition
- Anorexic and nauseous

**The prognosis:** Several weeks ago, Isla's oncologist advised her family that given her increasing symptoms and the advanced state of the cancer, her life expectancy was weeks or days.

**The family:** Isla's husband died several years ago and her two children live nearby. They visit regularly but are worried that their mother is suffering.

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\*Fictional names

**Your network:** The residential care facility has recently registered to use the LCP, however, you are not familiar with the details of the Pathway. After spending half an hour reviewing the LCP process and viewing the LCP document you are more confident.

**What do you do?** At a meeting with Isla's family and the charge nurse, you explain that their mother will be cared for according to the Pathway. This appears to alleviate their concerns. In conjunction with the charge nurse you create a care plan that includes cyclizine (50 mg sub-cutaneously every eight hours) for her nausea. As suggested by the LCP you pre-emptively prescribe morphine (2.5 mg, four hourly) sub-cutaneously for pain or dyspnoea should the patient require it, with instructions to increase the dose if necessary. You also prescribe an anxiolytic in case of agitation and an anticholinergic in case Isla develops respiratory tract secretions.

**What happens?** Two days later the charge nurse phones. Isla's situation has deteriorated, however, with the prescribed medication she appears comfortable and is still able to talk with her family.

After three days you meet with the charge nurse, carers and family as agreed in the care plan. The family mentions that Isla briefly complained of pain, however, this was quickly relieved by increasing the morphine dose. Upon reassessment you find that Isla is dehydrated and that this may be causing discomfort. After discussion with Isla's family you ask for a sub-cutaneous infusion of saline to be arranged. The next day you are told that Isla died during the night.

**Conclusion:** The principle benefit of the LCP was to assure family members that their mother would receive the best possible care. This allowed the family to focus their last days on their relationship with their mother. You were confident that the residential care nurses had clear guidance from the care plan and were not required to intervene. The pre-emptive prescribing of morphine allowed for pain control without delay and discomfort to the patient.

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