

Care pathways in palliative care

There is a huge national drive to encourage all care homes to implement ways of ensuring best practice in providing care for patients with life-limiting illnesses. In the UK, many care homes are using two of the most well-known tools, both of which have been accredited and recognised by the National Institute for Clinical Excellence (NICE). These are the Liverpool Care Pathway (LCP) and the Gold Standards Framework (GSF). There are other tools and pathways that are used in other areas, but as the LCP and the GSF are the most widely used and well known, I am going to focus on them. Where these pathways are implemented in the care homes that I visit, they work extremely well and give the carers confidence and support, as well as ensuring excellent care for the patients.

THE GOLD STANDARDS FRAMEWORK

The Gold Standards Framework, which categorises patients according to their stage of illness, has been around for quite a while in the general community. The patients' care is coordinated by their doctor and other healthcare professionals, such as the district nurse and the Macmillan nurse. The Gold Standards Framework has now been adapted for the care home setting, and this version is known as the Gold Standards Framework for Care Homes (GSFCH). The aim is to ensure that all patients in care homes receive the best palliative care possible as they approach the end of their lives.

The overall aims of the GSFCH programme are as follows:

- to improve the quality of care for patients who are nearing the end of their lives
- to improve coordination and collaboration with all caring professionals

- to reduce the number of patients who are transferred to hospital in the last stages of life.
The five goals of the GSFCH can be summarised as follows.
- The patient's symptoms are controlled.
- The patient is enabled to choose their preferred place of care in which to spend the last phase of their life.
- The patient feels safe and secure, with fewer crises.
- The carers feel supported, involved, empowered and satisfied.
- There is enhanced confidence and teamwork among the carers, and communication and collaboration with other professionals are maximised.

At the time of writing, approximately 40 care homes across Great Britain have received the Gold Standard Accreditation Award. Four of these homes are in my area of work, and a further two homes in my area are also very close to receiving this award. I feel extremely proud to be associated with them, as the award means that they are homes which provide a recognised, excellent standard of palliative care.

Currently, for a care home to undertake the GSFCH programme, they must register with the central team. Contact details can be found in the chapter on 'Further reading, useful websites and other resources' (*see* page 156). You can also ask your specialist palliative care nurse about the programme.

In order to achieve the Gold Standard Accreditation Award, there is work to be done by the participating care home. There is some additional paperwork involved, and participants are required to attend workshops. However, in my experience, the initial additional work and changes that need to be made are far outweighed by the benefits to everyone involved, especially the patients.

THE LIVERPOOL CARE PATHWAY

The Liverpool Care Pathway is a tool that can be used for all patients who are in their last days of life, irrespective of their primary disease or the cause of their imminent death. The LCP consists of a set of paperwork that replaces all other nursing care documentation and enables measurable outcomes of care. The aim of the pathway is to keep the patient comfortable by controlling their symptoms. It is important to remember that although a patient may be considered to be dying at the time of assessment for the LCP, the situation can change and that patient may 'recover.' This can happen in the elderly in particular, who can become very ill suddenly (for example, during an

infection), and then improve, so are no longer imminently dying. If this happens, the patient can be taken off the pathway.

The LCP is implemented by the following criteria.

The multi-professional team must have agreed that the patient is dying, and that two or more of the following criteria apply:

- the patient is bed bound
- they are semi-comatose
- they are only able to take sips of fluids
- they are no longer able to take tablets.

These criteria can be altered if the patient under consideration has different needs. For example, some elderly patients may be bed bound and have difficulty taking tablets and fluids, but they may not be imminently dying (*see* case study below).

When a patient is commenced on the LCP, the following are put in place.

- Medications are reviewed and all non-essential drugs are discontinued.
- Drugs for subcutaneous use are written up according to a set protocol.
- All inappropriate medical interventions, such as antibiotics, blood tests and intravenous fluids, are stopped.
- All inappropriate nursing interventions, such as washing and 2-hourly turning, are stopped.
- If it is needed, a syringe driver is set up within 4 hours of a doctor's order.
- The care plan is explained to and understood by the patient if possible, as well as the family and/or friends.
- Religious and/or spiritual needs are assessed with the patient and family.
- It is documented how the family or other contacts want to be informed of the patient's impending or actual death.
- The patient's family and/or friends are given information about facilities such as accommodation, car parking, access to refreshments, etc.

After death:

- the general practitioner is notified of the patient's death
- the patient is laid out according to protocol
- the family or another person who was close to the patient is given information on what happens after the death – for example, registering the death, collecting the patient's property, etc.
- any other advice and information, such as a bereavement leaflet, is offered to each of the bereaved individuals.

As you are reading this, some of you will no doubt be thinking 'Well, we do

all that when someone is dying.' What the LCP does is to ensure that 'all the boxes are ticked', and because of this, everyone should be providing the same standard of care and nothing should be missed.

There are two ways of implementing the LCP. The formal way is by registering with the central team, as is done for the GSF. Again, there is additional work to do and paperwork to complete. Alternatively, the LCP can be implemented informally by downloading the paperwork from the LCP website. However, you may need someone experienced in the LCP to go through the paperwork with you, until you become familiar with it. LCP contact details are given in the chapter on 'Further reading, useful websites and other resources' (*see* page 156).

CASE STUDY SUSAN – USING A CARE PATHWAY

(The following case study was kindly supplied by one of the care homes for which I provide input. This care home provided excellent support for Susan and her family, and I was not involved in her care.)

Susan was a 79-year-old woman who was admitted to hospital following a severe stroke. Because she had major difficulties with swallowing, the decision was taken to insert a feeding tube into her stomach. Susan was unable to be cared for in her own home, and was transferred to a care home with nursing staff. The use of the Gold Standards Framework and the Liverpool Care Pathway was well established in that home. The nurse who admitted her explained the GSF programme to Susan and her family, but felt that there was no need to mention the LCP at this stage. Susan's family were given a letter to take away that explained how the GSF would help with her care. Each week, Susan's key carer would discuss any changes with Susan's doctor, and these would be implemented quickly. Susan was completely dependent on two carers for all of her needs, and because she was more comfortable in bed, this is where she was nursed, using pressure-relieving aids and handling equipment. For the first month, Susan was quite stable and comfortable, but she then started to deteriorate. It was noted that she was becoming more sleepy and that she seemed to be less willing to be 'bothered' with her care. Within a few days she developed a chest infection. Susan had completed an advance care plan that had been signed by her doctor, and her wish was that she should not be given any treatment if it was felt that she was entering the end stage of her life. The opinion of all of the professionals involved was that Susan was dying, and that the sole aim of her care should now be to ensure her comfort. Her family

were in full agreement with this decision. The team of carers agreed that Susan was dying, and decided that it was time to use the Liverpool Care Pathway. However, the set criteria for using the LCP did not 'fit' in Susan's case. She had been bed bound since her admission, and because she was fed by tube, the criteria 'only able to take sips of fluids' and 'no longer able to take tablets' did not apply to her. Because she was increasingly sleepy, 'semi-comatose' was the only criterion that applied. However, because the care home staff were very experienced with the LCP, they set and agreed their own criteria as follows:

- Susan was semi-comatose.
- Without the feeding tube she would be unable to take tablets and fluids.
- She had a chest infection that she did not want to have treated, and which was likely to get worse.

After these criteria had been agreed, Susan's family were informed and involved in the process. Susan was too poorly to be involved in decision making, but had already made her wishes and funeral plans known. In accordance with the process, all unnecessary medication was stopped. However, because of the feeding tube, necessary liquid medicines could still be administered via this route, so there was no need to change the route of her painkillers to subcutaneous administration. The only subcutaneous medication prescribed in anticipation was hyoscine, to control secretions. All unnecessary medical and nursing interventions were stopped and Susan was checked regularly, according to the LCP paperwork, for any symptoms such as pain, agitation, respiratory tract secretions, nausea or vomiting. She was given regular mouth care, and the family also helped with this. The family stated that they wanted to be contacted at any time of the day or night if there was any change in Susan's condition, but in fact a family member was always present. Two days after commencing the LCP, the carers noticed that Susan's condition was changing. Her breathing was becoming laboured and her skin was tinged blue. They suggested to the family member present that Susan seemed to be entering the final few hours of her life. The rest of the family were alerted, and Susan died very peacefully soon afterwards with all her family around her. Susan's after death care was carried out in accordance with the LCP 'after death' guidelines. Her family were given the necessary information and helped to sort out what they needed to do. They were given a leaflet offering information on bereavement support and offered a telephone call from the care home in a few days to see how they were coping.