Supporting people who need Palliative and End of Life Care in the Community

Giving people a choice
Introduction

People who are terminally ill or at the end of their life need excellent nursing and medical care. They also need practical and emotional support for themselves and their family enabling them to be as comfortable as possible so that they can live well and die with dignity.

This booklet tells you about palliative and end of life care and who may be involved in giving a person care and support in the community.

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What is Palliative Care?

It is care or treatment that concentrates on reducing any unpleasant symptoms caused by an illness. The purpose of palliative care is to prevent or relieve any distress a person may be experiencing and to improve the quality of life for people facing serious, complex or life threatening illness. Palliative care seeks to view a patient as a whole person and considers all a person needs. It also aims to support the patient’s family and loved ones providing guidance, comfort and working with them to reduce the stress of caring.
Supporting people in making choices

It is very important to help people to make informed decisions about their care during their illness and to make choices about where they would ideally like to be cared for throughout their illness and at the end of their life. People with a serious illness are encouraged to talk about their wishes regarding care with their GP, district nurses or other professionals involved in their care. These wishes will be recorded as part of a plan of care so that everyone involved in a person's care is aware of what they want.
Who provides the Palliative and End of Life care?

Community Nursing Services

District nurses are nursing sisters who manage a community nursing team. Community nurses are staff nurses who support district nurses in caring for people in the community. These nurses are very experienced in caring for people who have a life limiting illness. They act as a person’s key worker during their illness and will assess what care and support a person and their family need. Working with the person’s GP and other professionals, they arrange for care to be put in place quickly, making sure that the person is supported as well as possible. A person’s GP, district nurse and the community nursing team will assess someone’s care on an ongoing basis. The district and community nurses ask for support from the following teams of professionals as and when it is needed.

Marie Curie Nursing Service

Marie Curie Nursing Service provide support throughout the last months of a person’s illness and at the end of life. Marie Curie qualified nurses and specially trained nurses and
healthcare assistants will visit a person’s house and provide hands-on nursing and personal care, helping a person to be as comfortable as possible, and providing emotional support. In addition to daytime support, Marie Curie healthcare assistants will, if needed, give support throughout the night. A trained Marie Curie Nurse is also on call during the night to give specialised support to people at home and to advise and assist the out of hours nursing teams in the community.

**Hospice at Home**

Hospice at Home is a team of trained nurses and healthcare assistants who specialise in palliative and end of life care.

The Hospice at Home team provide specialised nursing care in people’s own homes. This team provides care seven days a week from 08:00 till 22:00hrs. The nurses from the Hospice at Home team often support the district and community nurses and are an integral part of community services.

**Nurse Specialists in Palliative Care**

Macmillan/LOROS Community Matron Palliative Care (Macmillan), Nurse Specialists (Macmillan) and Nurse Specialists (LOROS) are nurses who provide advice, treatment and support for people with complex physical symptoms and distressing emotional reactions to their
illness. Their aim is to prevent and relieve suffering and to improve a person’s quality of life. They can help a person at any point during their illness. They offer various levels of support including telephone advice, single visit assessment and ongoing management. Regular visits to a person will probably not need to continue once their needs have been met.

LOROS, The Leicestershire and Rutland Hospice

LOROS is a local charity providing care and support for patient across Leicester City, Leicestershire and Rutland. It relies upon the voluntary support of local people and organisations. LOROS is a centre of expertise with nursing, medical and therapists who specialise in palliative care. LOROS’ services include: Inpatient Care, Care in the Home, Family Support Service, Day Therapy, Outpatient Care, a Telephone Advice Line, Counselling, Lymphoedema and Complementary Therapies. LOROS also has a very extensive education and research programme. The Hospice inpatient unit has 31 beds where care is provided for the physical, emotional, social and spiritual needs of each individual patient and support for their family and friends. The care environment recognises the particular needs of patients and their families.
Community Matrons & Long Term Condition Specialist Nurses

Community Matrons and Long Term Condition Specialist Nurses support people with long term conditions usually with an intricate mix of health and social care difficulties. They aim to provide a personalised, whole person approach to care, focusing on maintaining independence, dignity, comfort and quality of life.

An important part of their role is to recognise and identify those patients with chronic conditions who are approaching the end of life; to ensure that end of life issues are discussed and to make certain that individual’s needs for care and advanced wishes are documented in a care plan. As a consequence, helping patients to improve and maintain their dignity and care at the end stages of life.

Equipment

The Equipment Service is a very important part of our services. A nurse will assess what equipment a person requires for them to be able to be as comfortable as possible at home. This might include a special bed and mattress. There is also equipment that can be delivered that will help the nurses to give any medication that may be required in the most comfortable way possible.
End of Life Care at Home

Some people may have been unwell for some time and be receiving care in their own homes and wish to die in comfort in their own home. Other people may have had a sudden illness from which they would not recover and wish to remain at home to die or they may be discharged from hospital to spend their final days at home rather than in hospital.

When a person is coming towards the end of their life the community nurses will find out what care and support the person who is dying and their carers need. The nurse will arrange for those needs to be met as quickly as possible, in most cases within a matter of hours.
A package of care for a person at home could include:

- District Nurses
- Care from the Hospice at Home team
- Nurse Specialists
- Marie Curie Nursing Service
- LOROS family support
- Special equipment being delivered to the house to keep a person as comfortable as possible

It would be usual for a person to nursed using the Liverpool Care Pathway; this helps all the services involved in a patient’s care to work together with the person and their family. During this time, community nurses and a person’s GP would continue to be involved in their care.

You can gain further information regarding the Liverpool care Pathway from:
http://www.endoflifecare.nhs.uk/eolc/lcp.htm
Real life examples

David’s Experience

David’s mother, Gladys, was supported by her community nursing service. Eighty-seven year old Gladys lived at a residential home near Hinckley. She became poorly and her health began to deteriorate quite quickly. Her GP and the care home staff referred Gladys to her District Nurse.

Within an hour of the call, Sarah a local community nurse, visited Gladys to assess her healthcare needs. Sarah and Gladys discussed her wishes with her family, and Gladys decided that she did not want to go into hospital. Gladys was frail and her main concern was to be made as comfortable as possible.

Sarah immediately informed Gladys’s GP about her decision, and he visited and prescribed medication to control Gladys’s pain.

Sarah then arranged for a special bed to be brought into the home. Within a matter of hours, Gladys had an electric bed with an airwave mattress which meant that she did not have to bear the discomfort of being turned regularly to prevent pressure sores. Sarah visited Gladys three times a day to monitor her pain control and provide enhanced nursing care.
Gladys died where she wanted to be, with dignity. Her family were fully involved in her care.

Gladys’s son David was impressed with the service. He said, “I can’t thank the community nurses and staff at the home enough for the care they gave to mum. She was very frail at the end and it would have been awful if she’d had to be moved into hospital. She died where she wanted to be, surrounded by her family and friends.

“Sarah the nurse was great; she came in three or four times a day. Everyone worked as a team and it gave my sister and me peace of mind to know that mum was getting the very best care.”
Carol’s Experience

Carol’s husband, Dennis, an engineer and salesman from Charnwood, had terminal cancer.

Dennis had been in the oncology unit at the Leicester Royal Infirmary for about two weeks, when staff on the ward informed his wife, Carol, that he would be able to come home for his final days.

For Dennis to return home he would need equipment and medicine. The community nurses arranged for a profiling bed and syringe driver to be delivered. The ward had Dennis’s medication ready for collection and on the Friday afternoon, preparations began in earnest.
Carol asked if Dennis could come home the following Tuesday to allow her to make her preparations. At 8am that Tuesday morning, the bed and syringe driver were delivered, and Roz, the community nurse, arrived to help prepare the house for Dennis.

By lunchtime, everything was ready. Dennis was brought home and his own GP was there waiting for him, to complete the necessary paperwork with the nurse and Dennis’s nurse from LOROS.

Although there were a lot of people looking after Dennis, Carol says that it was not in any way intrusive: “I never felt taken over. It was more like a big family all working together. People would come in and do what they had to do with Dennis and talk to me, but there were also times when I was able to be on my own with Dennis. There were quiet times when I could take time out to eat and rest, but there was always someone at the end of the phone if I needed them.”

Carol was amazed by just how much the nursing teams did for Dennis. “I never had to supply or do anything. There was always someone there. I couldn’t believe how good the care was. They washed him, looked after him, checked his drugs and settled him down for the night. It meant that I could have quality time with Dennis. I could just sit with him, knitting, reading and playing his favourite music.”
Dennis died peacefully at home just before 6pm on the Wednesday – a day after he had come home. His wish had been made possible.

Roz says that this was mainly down to good communication and teamwork: “Everyone gave it their all to give Dennis what he wanted. It started with the oncology unit making the referral and carried on through all the teams and services involved, from the equipment side to Marie Curie and Hospice at Home. The community nursing team led the care and Dennis’s own GP was fully involved throughout.”
If you would like this information in another language or format, please contact the Patient Information Officer on 0116 295 0903

Visit our website: www.lcrchs.nhs.uk

Leicestershire County and Rutland Community Health Services is responsible for providing NHS services in the Leicestershire and Rutland area and is part of Leicestershire County and Rutland Primary Care Trust.

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