

# Better care every step of the way

Report on the quality of palliative and end of life care  
in care homes for adults and older people



## About this publication

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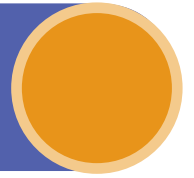
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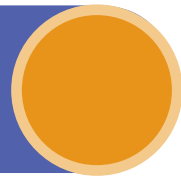
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... the care and conditions at the home were exemplary. While treatment, attention to physical care and high-quality surroundings are clearly important, it was the outstanding attitude of the staff which made the difference.

From diagnosis to death my mum only had two and a half weeks. During that time, thanks to the staff, my mum was able to stay in her room with her familiar pictures and objects around her, familiar staff and above all her family sitting in at anytime of the day or night, I was so grateful to be able to treasure these last weeks with mum and I was made to feel welcome and given so much support.



More people are living longer with life limiting, long term conditions. This has led to an increased need for good quality palliative and end of life care in Scotland's care homes.

The National Care Standards are very clear about how sensitively end of life care should be handled in care homes. The quality of care and support available must be high and take into account the needs of everyone involved. It is important that staff providing this vital care are well trained, have good communication skills and understand the needs of residents, relatives and carers.

In this report, we found that the quality of palliative and end of life care is good in many care homes. There are several examples of excellent care and we have received many letters of appreciation from relatives about the care of their loved ones. However, we found that the palliative care needs of residents in 43% of care homes for adults and older people are not always recognised or well supported by staff.

Staff in care homes must have increased knowledge, skills and support to ensure that residents, families and carers all receive the high quality care needed when people have life limiting conditions. Improved access to specialist palliative care for everyone who needs it is also vital. We will actively follow up the care homes where we have made recommendations and improvement is needed.

Whatever your interest in care, we hope you find this report useful and informative.

**Susan Brimelow**

Director of Healthcare Regulation  
Care Commission



# Terms we use in this report

This report is about **palliative and end of life care**. **Palliative care** is about ensuring a good quality of life for both residents and families at every stage of a life limiting illness, which can be from diagnosis onwards. One part of palliative care is care given towards the **end of life**, that is, care given in the last few months, days and hours of a person's life.

This area of care uses many specialist terms and, where possible, we explain these in the report. In this section we define terms that occur several times throughout the report.

## **General palliative care:**

This can be delivered by health and social care professionals, such as, care staff working in care homes, and is based on the palliative care principles, which include:

- focusing on people's quality of life, including controlling symptoms well
- a whole-person approach, which takes into account the person's life experience and current situation
- care that encompasses the person who receives care and those closest to them
- respect for the individual's own choices, for example, about how and where they wish to spend their final days
- emphasis on communicating openly and sensitively.

## **Life-limiting illness:**

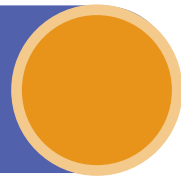
This term describes an illness where cure may not be possible, so care focuses on alleviating symptoms and ensuring a good quality of life for the individual.

## **Liverpool Care Pathway (LCP):**

This is a document that people from different healthcare professions use to improve the care of someone who is dying, used in the last days of a person's life. It includes guidelines, based on professional people's experience of this kind of care, and suggestions for caring for the dying person and their family. Those who use the document receive training in areas such as managing symptoms and communication skills, including breaking bad news. They also receive training in how to implement the LCP.

## **Palliative care approach:**

This is about caring for people as individuals, recognising that they may have needs which are physical, social, psychological or spiritual, or a combination of these. This approach can, and should be, adopted by anyone in a caring role in all care settings, including care homes.

**Palliative care link nurses:**

These are nurses who work in a general care setting, such as a care home and who develop a specific interest in palliative care. They share with their colleagues the knowledge they gain at specialist meetings, and are their contacts for palliative care information.

**Primary healthcare team:**

This includes health and social care staff who work in the community, such as, district nurses, general practitioners (GPs) and health visitors.

**Scottish Partnership for Palliative Care:**

This charitable body is the national umbrella and representative body for palliative care in Scotland. It seeks to promote, enhance, improve and extend palliative care services to people who suffer from life-threatening conditions, for the benefit of the individuals and their families. It contributes to national thinking about, and policies for, palliative care. It also promotes ways of improving care services at local level.

**Specialist palliative care:**

This is provided by health and social care professionals who have received specialist, accredited palliative care training. Many specialists work in palliative care teams and are often based in hospitals and hospices. They can be contacted for support, including advice and information, by staff in any care setting, including care homes.

They have looked after my Mum by providing a homely, warm and welcoming environment for many years and provided her with respect, dignity and love at a time when she was at her most vulnerable. They have always been very honest with me in regards to my Mum's condition and have always given me hope in very desperate times. In Mum's final month they did everything I asked and more.

# Summary, findings and recommendations

## About this report

In this report we aim to raise awareness of the need for good palliative and end of life care in all care homes. **Palliative care** is about ensuring a good quality of life for both residents and their families at every stage of a life limiting illness which can be from diagnosis onwards. One part of palliative care is care given towards the **end of life**, that is, care given in the last few months, days and hours of a person's life.

During our inspections of care homes between April 2007 and the end of March 2008 we paid special attention to palliative and end of life care. This report reflects what we found during 1,036 inspections and three investigations into complaints, about:

- whether staff in care homes have an understanding of what palliative and end of life care is
- how well they are delivering palliative and end of life care to residents and their families.

Scotland has a national action plan: 'Living and Dying Well', which sets out a plan for the delivery of high quality palliative and end of life care for everyone who needs it across all care settings in Scotland (Scottish Government, 2008). Scotland also has national practice statements for general palliative care in adult care homes called 'Making good care better', and this report considers how well care homes are implementing them. (Scottish Executive and the Scottish Partnership for Palliative Care, 2006).

## What we found

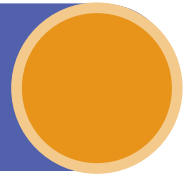
Our inspections showed that 587 (57%) of the care homes in our sample understood the importance of providing palliative and end of life care. We give examples of good practice throughout the report.

The good practice we found matches the document 'Making good care better', which sets out guidance on the quality of palliative and end of life care that homes should provide, and residents should expect to receive.

However we found many care homes had fallen short of best practice:

- 449 (43%) care home providers and staff do not recognise that they should be delivering palliative and end of life care to residents who have life limiting illnesses.
- 92 (9%) of care homes did not have a copy of the national practice statements, 'Making good care better'.
- 369 (36%) of care homes had not assessed their service to ensure they recognise and meet residents' palliative care needs.
- The majority (54%) of services have not trained and given their staff the educational support they need to deal with the sensitive issues surrounding death and dying, such as





how to cope with the emotional effects of living with a life limiting illness. Many care home staff told us how inadequate they felt when discussing sensitive issues about death and dying with residents. We made 120 recommendations about this.

- Only 44% of care homes have policies in place to guide staff on when and how to contact members of the primary healthcare team, such as, district nurses, general practitioners (GPs) or specialist palliative care services, such as, Macmillan and Marie Curie Nurses. We made 150 recommendations about this.

## **What should happen next**

### **We recommend that all care homes in Scotland should:**

- have a copy of 'Making good care better', assess their service against the national practice statements to ensure they give good palliative care well
- provide good palliative and end of life care for people with life limiting illnesses and understand how to do this well
- ensure staff have access to education on palliative and end of life care
- provide information to residents, families and carers on the kind of palliative and end of life care and support they can expect.

### **To make sure this happens we will:**

- follow up the care homes where improvement is needed
- work with care home providers and organisations, such as, health boards, local authorities and Scottish Government to promote palliative and end of life care to ensure that everyone in care homes who needs it gets it
- plan a further round of inspections on palliative and end of life care
- make sure care homes provide information to staff on how to access specialist palliative care services for support and advice
- make sure care homes develop palliative and end of life care policies.

### **We recommend Scottish Government:**

- updates the National Care Standards to inform people in care homes, both now and in the future, about how their palliative and end of life care needs should be met. This is an action in 'Living and Dying Well' (Scottish Government, 2008).

### **People who live in care homes, their families and carers need to:**

- be aware of what good quality palliative and end of life care is and read the guidance in 'Making good care better'
- discuss with care home staff what they have in place to meet residents' palliative and end of life care needs.

# Part 1: The background to this report

This part of the report sets out:

1. Who we are and how we regulate care services
2. What this report is about
3. What is palliative and end of life care?
4. Scotland's guidance on palliative and end of life care

## 1. Who we are and how we regulate care services

### About us:

The Care Commission is Scotland's national regulator of care services and was set up in 2002. We register and inspect almost 15,000 services that care for more than 320,000 people in all parts of Scotland.

Our work focuses on improving the quality of care for people in registered care services. These services include care homes for adults and children, care at home and housing support, childminders, daycare, foster care and adoption, private hospitals and voluntary hospices.

The Regulation of Care (Scotland) Act 2001 removed the legal differences between residential and nursing homes. All are classified as care homes. This means that people are free to move into and then stay in a care home for the rest of their lives if they so wish.

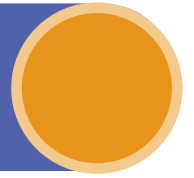
### How we regulate care services:

To assess how good a care service is, we look at a range of quality indicators, such as, quality of care and staffing. We consider all of these together, rather than in isolation. Our work is guided by the Regulation of Care (Scotland) Act 2001 and the National Care Standards (NCS) published by Scottish Ministers. These standards set out what people using care services in Scotland should expect.

We regulate care services by:

- registering them
- inspecting them
- investigating complaints
- enforcing standards of care.

During our work we collect a great deal of information about each service and we use this evidence to evaluate the quality of services. This report is based on information we gathered during inspections and complaint investigations.



As we inspect each service, we record information on the quality of services it provides. We ask the people using the service and their family and carers what they think about the service. We also talk in private to the staff of care homes to hear their views. We take into account the National Care Standards that apply to the service we are inspecting, and the requirements it needs to meet under the Regulation of Care (Scotland) Act 2001.

At the end of the inspection we tell staff what we have found by highlighting strengths and areas for development or improvement. We follow this up with a written report, which is publicly available on our website at [www.carecommission.com](http://www.carecommission.com)

We can take the following actions to improve the quality of care services:

**Recommendations:** If a service is not meeting a National Care Standard we can make a recommendation in our inspection report. These are measures we consider a service should take to improve standards of care. We can, and do, check to make sure that services act on recommendations.

**Requirements:** If a service is not complying with the regulations in or associated with the Regulation of Care (Scotland) Act 2001 we can make a requirement. This is a statement setting out what the service must legally do, within a timescale agreed with us. A requirement means the service has failed to meet the regulation to an extent that we are concerned about the impact this has on the people using the service.

**Enforcement action:** This is a legal power that allows us to vary or impose new conditions that services must meet to be registered with us. We can also serve a legal notice that requires services to make improvements within a timescale. We can, if necessary, close a service down if it does not demonstrate that it is improving in line with a requirement we have made. We have not taken enforcement action against a care home for the quality of their palliative and end of life care to their residents.

**Complaints:** Anyone can complain to us if they are unhappy about the quality of care a service is providing. We will investigate and inform the service provider and the person who made the complaint about the outcome.

## 2. What this report is about

This report considers palliative and end of life care in all of Scotland's care homes for adults and older people. We expect that all care homes will work towards achieving a palliative care approach that will enable the people who live in a care home to have all of their palliative and end of life care needs met.

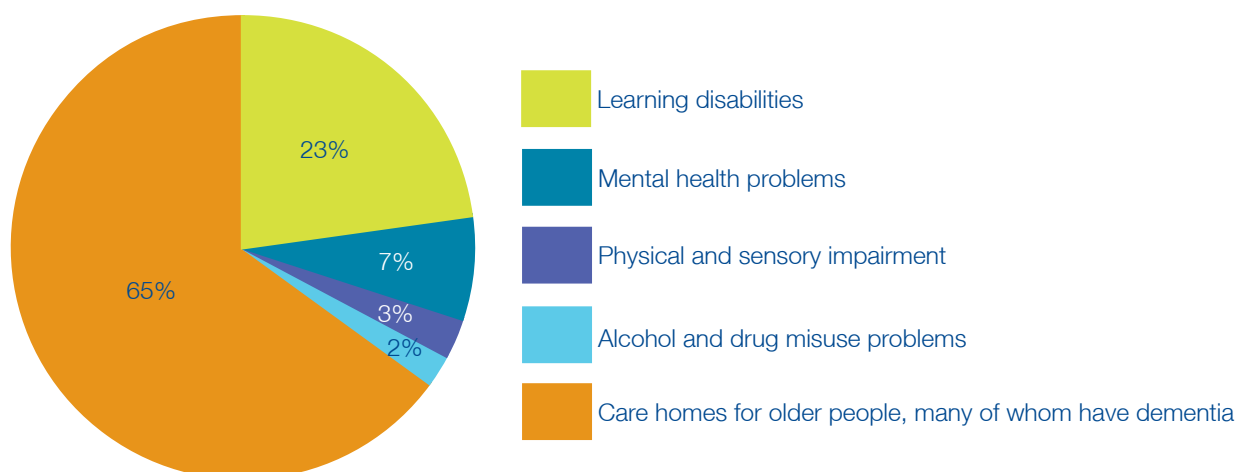
The report reflects what we found during 1,036 inspections from April 2007 to the end of March 2008, and three complaint investigations. By looking at the findings we were able to build up a picture of the quality of palliative and end of life care in the care homes we visited across Scotland.

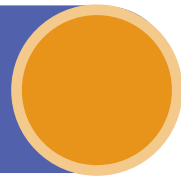
The table below shows the number and types of care homes included in this report.

### Care homes included in this report:

Care homes in which the people who use the service have:

Learning disabilities	242
Mental health problems	69
Physical and sensory impairment	34
Alcohol and drug misuse problems	17
<b>Sub-total</b>	<b>362</b>
Care homes for older people, many of whom have dementia	674
<b>Total</b>	<b>1,036</b>





### 3. What is palliative and end of life care?

Palliative and end of life care is an integral part of the care that health and social care professionals provide for people with an advanced, progressive or incurable condition (Scottish Government, 2008). The Scottish Government is committed to delivering high quality palliative care to everyone in Scotland who needs it (Better Health, Better Care: Action Plan, 2007).

According to the World Health Organisation (WHO), palliative care is an approach that improves the quality of life for people facing life limiting illness and their families. It helps to prevent and relieve suffering by identifying symptoms early and by treating pain and assessing other issues both physical and spiritual.

Palliative care, therefore:

- ‘provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care
- helps patients to live as actively as possible until death
- helps the family to cope during the patient’s illness and in bereavement
- uses a team approach to meet the needs of patients and their families, including bereavement counselling if families wish
- will enhance quality of life, and may also positively influence the course of illness
- applies early in the course of illness, along with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes the medical investigations needed to better understand and manage distressing clinical complications.’ (WHO, 2004)



## 4. Scotland's guidance on palliative and end of life care

Many care homes in Scotland are already providing good general palliative care, even though the term 'palliative care' may be unfamiliar to them.

### **Living and Dying Well:**

'Living and Dying Well' is a national plan to ensure that good palliative and end of life care is available for everyone who needs it across all care settings in Scotland (Scottish Government, 2008).

### **Making Good Care Better:**

In May 2006 the then Scottish Executive and the Scottish Partnership for Palliative Care published 'Making good care better'. This document set out what it refers to as national practice statements; that is, statements setting out the quality of palliative care that:

- residents should expect of care homes
- care home providers and managers should achieve to help them develop their services.

We highlighted 'Making good care better' when we met care home providers and their staff at meetings throughout Scotland. We also sought to make sure that 'Making good care better' was making a difference to palliative care in care homes.

We paid special attention to this aspect of care during our 2007-08 inspections alongside the National Care Standards for care homes for older people. These set out the standards of care that the Scottish Government expects care homes to achieve.

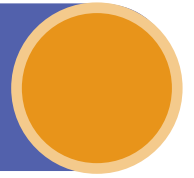
### **What the National Care Standards say:**

Two of these standards provide guidance relevant to the areas covered by this report and we took account of them during our inspections.

**Standard 19** is about support and care in dying and death. It states that people living in care homes can be confident that the home's staff will be sensitive and supportive during the difficult times when someone dies. It states:

'You are confident that any death in the care home will be handled with dignity, sensitivity and discretion.'

'If you lose someone close to you, you will be fully supported. You will have the opportunity to say goodbye or go to the funeral if you want. The staff will be able to help and support you.'



'You can say what you want to happen and who should be informed about your physical, personal and spiritual care in dying, death and funeral arrangements. You can be confident that your wishes will be carried out.'

'Staff will discuss your preferred place of death with you and those important to you. They will make every effort to achieve your wishes.'

'The staff will ensure that your death is as free of pain as possible. You will be able to choose whether or not you wish to have someone with you when you die and who that person should be. Staff will make every effort to ensure this happens.'

'There will be somewhere for those important to you to stay with you during your last few days and hours, if that is your wish and their wish.'

'When you die, your body will be treated with dignity, sensitivity and respect, in accordance with your expressed social, cultural and religious preferences.'

'The staff will make sure that your bereaved relatives, friends and carers can spend as much time with you after your death as they need to. They will support your relatives and friends through the formal processes relating to death, such as arrangements about belongings.'

**Standard 14** is about keeping well. It states that people who live in care homes should be confident that the care home staff will know their healthcare needs and meet them in a way that suits them best. Paragraph 8 states:

'You can expect staff to be aware of issues around the assessment and management of any symptoms you may have, including pain, and how to access specialist services.'

... no matter what grade of staff they were they worked great as a team and as I have said already the care my mother received was outstanding. The weekend my mother died the care and compassion shown to my mother and myself was 100%. The staff from the trained nurses to the care assistant and even the cook, who ensured that I ate whilst sitting with my mother, I will never forget these people.

# Part 2: What we found out about palliative and end of life care from our inspections

During our inspections we wanted to find out:

1. Were care homes providing palliative and end of life care for people who needed it?
2. Did care homes have a copy of 'Making good care better', the national practice statements on palliative care and, if they did, how were they using them?
3. Were staff aware of and did they understand the palliative care approach?
4. Had care homes access to palliative care specialists such as Macmillan or Marie Curie nurses?
5. Did staff have access to communication skills training relevant to palliative care?

This part of the report:

- details what we considered during our inspections
- explains what we found
- gives examples of good practice in palliative and end of life care from a sample of care homes in Scotland.

## **1. We looked at whether care homes were providing palliative and end of life care for people who have a life limiting illness.**

We wanted to find out:

- how many care homes were providing palliative care for residents with a life limiting illness
- whether staff knew about the national practice statements, which had been introduced a year previously.

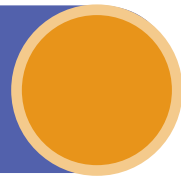
During our inspections from April 2007 to the end of March 2008 we asked 1,036 care homes to fill in our questionnaire on palliative care. This report gives a national picture of the quality of palliative and end of life care in care homes for adults and older people throughout Scotland.

A total of 587 care homes (57%) said they provided palliative and end of life care to people in their care.

We found that 43% of the care homes in our sample said they were not providing palliative care. We found, however, that not all staff understood the term 'palliative care' properly, some believing it to be solely the care given during the last days of someone's life. As a result, we made 39 recommendations to care home staff to provide palliative and end of life care for residents with life limiting illness.

We would expect all care homes in Scotland to be able to recognise and provide good palliative and end of life care for their residents when they need it. Residents should also have a personal plan that is based on their individual needs. This may be for residents requiring palliative care earlier in their illness as well as when they are dying.





## Examples of good practice in care homes for adults and older people:

### **Thorntoun Estate Nursing Home, Kilmarnock**

The manager of this Ayrshire care home had recently obtained accredited distance learning training packs on palliative care from Macmillan Cancer Support and plans were in place for staff to complete this training.

### **Morningside Park Care Home, Edinburgh**

This small care home looked after people with mental health problems. For residents in need of palliative and end of life care, staff were being encouraged to develop a person-centred approach; that is, taking account of the person's life experience and wishes.

### **Seaview House Nursing Home, Wick**

Information on residents' wishes concerning death and dying were recorded during admission in their personal plan. If needed, the support of district nurses, GPs and other health care professionals was provided within the familiar surroundings of the care home. Care home staff were committed to providing high standards of care and palliative care training was available.

- 2. We asked services if they had a copy of 'Making good care better', the national practice statements for general palliative care in adult care homes in Scotland. We also asked how they were using them to provide good palliative and end of life care.**

Of the 1,036 services who responded to us, 575 or 56% of care homes told us that they had a copy of the national practice statements.

There were 369 care homes (36%) who told us that the statements did not apply to their service. Staff said that their residents did not have palliative or end of life care needs. 92 care homes (9%) did not have a copy of 'Making good care better'.

All care homes for adults and older people should have a copy of 'Making good care better'. Staff should read the statements and understand how to give good palliative and end of life care well. Care homes must assess their own service against the national practice statements to ensure they recognise and meet residents' palliative care needs.

We made 88 recommendations to 77 services advising them to get a copy of the national practice statements and begin working towards implementing them.

### **Abercorn Nursing Home, Edinburgh**

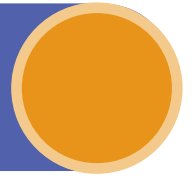
A senior staff member had received training in the Liverpool Care Pathway for care at the end of life. Other staff in the care home had education on palliative care at a local hospital, and there were plans to attend further study days at the Marie Curie Hospice. There was a thorough and extensive policy on palliative care to guide staff, which included details of how to contact palliative care specialists.

### **Ferry House, Dundee**

This small care home gave copies of the national practice statements 'Making good care better' to staff, residents, relatives and other visitors for their information. Staff had attended palliative care training and had put what they had learned into everyday care practice for residents.

### **St Joseph's Home for the Elderly, Edinburgh**

This care home had a copy of the national practice statements 'Making good care better', but not all staff knew its contents and how to access it. The manager set out to raise awareness of the statements. Most care staff have since attended palliative care training, which included learning about communication skills for sensitive issues.



### 3. We asked if staff in care homes were aware of and understood the palliative care approach to recognising and meeting a resident's palliative care needs.

Although her behaviour was still difficult to manage at times we were impressed with the patience and skill of staff in coping with this. Despite frequent assurance by the staff that they could cope, we continued for some time to fear that, as previously, a limit would be reached, and we would again be faced with finding another care home. We can only say that up until her recent death this stage never came. Indeed, we are convinced that the caring culture in the home ... significantly increased her capacity for enjoying life in her last years. Not only were staff good with residents but their open and helpful attitude to relatives contributed considerably to reducing their stress.

Just over half of services (532, or 51%) said their staff were aware of and understood the palliative care approach. However this figure increased to 82% of the services who said they provided palliative and end of life care.

146 care homes (14%) told us that they did not provide palliative and end of life care to their residents while 358 (or 35%) appeared not to recognise that they should be providing this important type of care. It is only fair to note, however, that some of these services had limited or no experience of residents with palliative care needs.

As a result of the above findings we made 149 recommendations to 147 care homes to ensure that staff have access to education and training to help them understand the palliative care approach.

All staff in care homes should have education on palliative and end of life care so that they have the confidence to meet residents' palliative care needs.

#### **Budhmor House Care Home, Portree, Skye**

Care home staff had an understanding of end of life care and saw the care they provided as being holistic, focusing on keeping residents comfortable and symptom free. Staff had access to Scottish Vocational Qualifications (SVQ) in communication skills training.

## Dean House, Kilmarnock

Staff had attended training courses on palliative care and the staff and manager believed strongly in providing high quality end of life care for residents. Staff worked closely and sensitively with families. Families were encouraged to spend as much time as possible with their relative and some chose to maintain contact with the care home after their loved one died. The manager has received many letters of appreciation.

‘Thank you for all the care and attention you gave to mum. It allowed her to live out her last years with dignity and in a comfortable and loving environment. We are very appreciative of everything you did for her.’

### 4. We also wanted to know if care homes had access to advice, information and support from members of the primary healthcare team and specialist palliative care services.

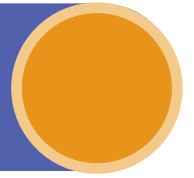


We found that 451 care homes (44%) had a policy in place for accessing specialist palliative care services if required. But the remaining 585 care homes (56%) did not think this was necessary; 17% said they had no policy for accessing specialist palliative care.

As a result of these findings, we made 150 recommendations to 146 services to put a policy in place to inform staff how to access advice, information and specialist palliative care services such as Macmillan and Marie Curie nurses.

The National Care Standards for older people state that staff should be aware of how to access specialist services (National Care Standard 14). It is important that care homes know who to contact for advice during the day, at night and at weekends to meet residents’ palliative and end of life care needs. All care homes in Scotland should have a policy for their staff on when and how to contact members of the primary healthcare

team, such as district nurses or GPs and how to access specialist palliative care advice, for example, from Macmillan or Marie Curie nurses.



### Summerlee House, Coatbridge

Staff were familiar with the palliative care approach and would feel confident in accessing specialist services. Staff recorded all involvement with palliative care specialists and most had received training in palliative and end of life care from colleagues who had formal training in the subject.

### Lomond Court Nursing Home, Glenrothes

Staff had access to a range of resources to help them deliver palliative care to residents, such as a Macmillan Cancer Support training pack, which 10 staff had completed within the care home. There was a Care of the Dying and Bereaved Policy which had procedures in place for obtaining specialist advice, community health care professionals and equipment.

Copies of 'Making good care better' were also available for staff to refer to for guidance.

### Riverside Healthcare Centre, Selkirk

Staff had recently attended palliative care training and found it very useful. The care home had identified a palliative care link nurse to provide in-house training and cascade information on palliative care to other staff members. Staff had established good links with the primary healthcare team, such as local health visitors, GPs, district nurses, and Macmillan nurses so that residents and their families could get more help if they needed it.

## 5. Education and training are vital to good palliative and end of life care. We asked if care home staff had access to communication skills training on sensitive issues such as personal and spiritual concerns.

480 care homes (46%) said staff had access to communication skills training to help them deal with sensitive, personal issues facing people with palliative care needs in care homes. The majority (54%) of care homes had not trained and given their staff the educational support they need.

As a result of our findings, we made 120 recommendations to 115 services about communication skills training for staff to help them meet sensitive, personal issues such as religious, spiritual and cultural needs in relation to death and dying.

In one care home for older people, staff said it was hard to talk to residents and their relatives about death and dying. We therefore recommended that staff should try to find out residents' and relatives' wishes about end of life care and death, and record what they say in residents' personal care plans. Staff should have guidance and education to help with this.

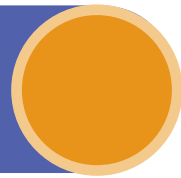
Education and training are vital to good palliative and end of life care and all care homes should ensure their staff have the knowledge, skills and confidence to care for residents.

### **Fa'side Lodge, Edinburgh**

This care home provided palliative care for residents along with GPs and other members of the primary healthcare team. Staff had access to a local service called 'crisis care' if they needed an additional staff member overnight to look after a resident with palliative care needs. The service is compiling a folder with information on palliative care to help guide staff.

### **Morrison House, Glasgow**

This care home were using the Liverpool Care Pathway. Health and social care professionals use this document to improve the care of someone who is dying in the last days of a person's life. Staff who use this document receive training in how to implement the Liverpool Care Pathway often referred to as an 'LCP'. This care home regularly involved residents and their families in reviews of their resident's end of life care.



### **Glenhelenbank Residential Home, Luncarty**

This Perthshire care home had adopted a palliative care approach to meeting the residents' care needs. They had received palliative care training during the previous year. This included communicating with residents and their families and understanding end of life care issues. The service was also planning in-house refresher training.

### **Windyedge Cottage Care Home, Forfar**

Staff had a caring insight into death and dying and how to promote good practice within the home. They recognised that the care home is a home for life for residents and try to ensure that if a resident wishes to stay at Windyedge until they die they are able to do so. Several staff had received education on palliative care and some also had Scottish Vocational Qualifications (SVQs) in communication skills and in coping with people who are distressed.



# Part 3: What we learned from complaints about palliative and end of life care

Anyone can complain to us about the quality of care a service is providing. We treat complaints very seriously and will investigate and inform the person who made the complaint about the outcome. This report looks at three complaints investigations we undertook and gives a picture of where palliative and end of life care needs to improve.

Complaints can be very upsetting for everyone. In care homes, they can involve the staff, the residents, and their family and carers.

It is very important to consider complaints, because they provide the opportunity to reflect on current practice and improve future care.

## **Complaint investigation 1:**

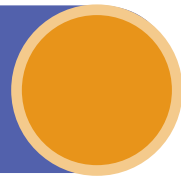
A family complained about palliative care and a lack of communication by staff about their relative's deteriorating condition.

When we investigated we found that, although staff did provide appropriate palliative care, there was a failure to keep the family informed about changes to their relative's deteriorating condition. We found that the care home had recorded some of the discussions that had taken place. But the record of communication with the relatives, which the home held, had not been kept up to date and did not accurately reflect important conversations that had taken place with the resident's family.

It is important that families are kept fully informed and well prepared when a resident is receiving palliative and end of life care. If a resident's condition deteriorates significantly, relatives and carers may well need more support, such as, helping them cope with the emotional upset or consider spiritual and religious matters. Care home staff should be aware of this and ensure that these needs are met.

We partially upheld the complaint. We made a recommendation that the service provide training to improve their staff communication skills with relatives, along with training in record-keeping and information sharing.





### **Complaint investigation 2:**

Concerned relatives complained that they felt they were not properly informed about the resident's deteriorating condition by care home staff.

We received a complaint about poor support for relatives during the last few hours of a resident's life in a care home. Families and carers need to have access to timely help and support when they need it.

We upheld the complaint and made two requirements that the care home:

- improve the staff's attitude and their response to families' needs
- put in place an effective call system so that relatives can get help from the care home staff when they need it.

### **Complaint investigation 3:**

Relatives complained that they felt care home staff were not addressing their relative's palliative care needs in relation to pain control. Following an investigation it was found that staff did not use a pain assessment tool to assess and monitor pain. Palliative care guidelines or a policy on pain and symptom management was not available for care home staff to follow.

It is very important that staff in care homes have access to assessment methods or tools used in palliative care and use them consistently. Controlling pain is an important part of palliative care.

We upheld this complaint. We made four requirements to this service; to develop a policy on pain control; to assess and review pain control for their residents on a regular basis; to improve care planning by stating how the residents needs will be met; and to provide training to ensure staff are able to manage residents' pain.

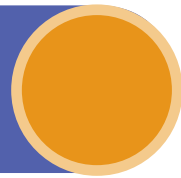
The final stages of my mother's life demanded a complicated range of medical and nursing interventions. Staff worked to ease my mother's pain, making her as comfortable as possible while also managing her diabetes and dementia.

I was most impressed by the teamwork demonstrated by staff at that time. My Mum's treatment and care had to be closely monitored and changed, sometimes by the hour. Communication across the staff team was excellent. My Mum's care was well coordinated and consistent.

The family too, benefited from this excellent practice. It didn't matter what time of day or night we visited, staff were able to update us on my Mum's care and condition. We were always made to feel welcome and treated with great sensitivity and respect, as was my Mum. I was also deeply appreciative of the fact that someone was with my Mum at her moment of death.

The loss of a loved parent is always a great sadness, but the burden of grief was alleviated by the knowledge that my Mum had received such excellent care.

# References



Marie Curie Palliative Care Institute Liverpool (2008), What is the LCP? - Patient & Carer Overview  
[www.mcpcil.org.uk](http://www.mcpcil.org.uk)

Scottish Executive (2001), Regulation of Care (Scotland) Act 2001, The Stationery Office Ltd  
[www.opsi.gov.uk/legislation](http://www.opsi.gov.uk/legislation)

Scottish Executive and the Scottish Partnership for Palliative Care (2006), Making good care better: National practice statements for general palliative care in adult care homes in Scotland  
[www.palliativecarescotland.org.uk/publications](http://www.palliativecarescotland.org.uk/publications)

Scottish Government (2007), Better Health, Better Care: Action Plan  
[www.scotland.gov.uk/publications](http://www.scotland.gov.uk/publications)

Scottish Government (2008), Living and Dying Well: A national action plan for palliative and end of life care in Scotland  
[www.scotland.gov.uk/publications](http://www.scotland.gov.uk/publications)

Scottish Government (revised edition 2007), National Care Standards: Care homes for older people  
[www.scotland.gov.uk/publications](http://www.scotland.gov.uk/publications)

World Health Organisation (2004), Definition of Palliative Care  
[www.who.int/en](http://www.who.int/en)

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