

We need to talk about Palliative Care

The Care Inspectorate

Introduction

The Care Inspectorate is the official body responsible for inspecting standards of care in Scotland. That means we regulate and inspect care services to make sure they meet the right standards. We also carry out joint inspections with other regulators to check how well different organisations in local areas are working to support adults and children. We help ensure social work, including criminal justice social work, meets high standards. We provide independent assurance and protection for people who use services, their families and carers and the wider public. In addition, we play a significant role in supporting improvements in the quality of services for people in Scotland.

We welcome the opportunity to respond to this call for evidence. We have also enclosed a case study, which we hope is useful to the committee. The case study outlines some of the challenges faced by a service in relation to palliative care provided to support a person with a learning disability in their home, illustrating some important points about how services can deal with these challenges effectively.

We would be delighted to provide further or oral evidence if the Committee would find this helpful.

Questions

1. What has been your experience in terms of access to palliative and end of life care?

The Care Inspectorate expects that the services we regulate work within the current National Care Standards, and current best practice such as the NHS Scotland guidance 'Caring for people in the last days and hours of life' (December 2014).

The National Care Standards are taken into account when registering any new service, when investigating complaints, on inspection and when carrying out enforcement activity.

As palliative care should be accessible to all children and adults, no matter where they reside, our expectation is that no service user or their family should be denied access to palliative and end of life care.

2. How could it be ensured that access to palliative and end of life care is equitable and available in all areas and for all types of terminal illnesses?

The National Care Standards are currently being revised and will adopt a human-rights based focus. It will be important to ensure that issues around palliative and end of life care feature appropriately across the new standards for all relevant care settings.

Integrated joint boards, as they start their work, can play an important role in ensuring that palliative care is provided in care settings through their strategic commissioning arrangements. The Care Inspectorate and Healthcare Improvement Scotland will work closely to provide scrutiny around strategic joint commissioning and the impact on outcomes for people in the coming years.

3. Can you identify any areas in terms of access to palliative and end of life care that should be focused on as priorities?

The Care Inspectorate is represented on the National Advisory Group for Palliative and End of Life Care. Work is underway to look at what data is currently available across the United Kingdom and what this is informing about priorities. There is also feedback from engagement road shows recently undertaken by Scottish Government which should provide some evidence based direction about future priorities from a stakeholder perspective. This will provide an evidence base for future work in this area.

4. When is the right time to begin discussing options for Palliative Care, who should be party to that discussion, who should initiate it and where should it take place?

We believe that options for palliative care should be considered by the medical or health team looking after the person and their family, either in the community or hospital setting.

NHS Scotland and Healthcare Improvement Scotland evidence based Scottish Palliative Care Guidelines (2014) states:

“A palliative care approach should be considered alongside active disease management from an early stage in the disease process. Palliative care focuses on the person, not the disease, and applies a holistic approach to meeting the physical, practical, functional, social, emotional and spiritual needs of patients and carers facing progressive illness and bereavement”.

Anticipatory care planning is therefore an important issue, and the prevalence of anticipatory care plans in care services is an indicator measured by the Care Inspectorate annually.

5. What works well in discussing palliative and end of life care and how is good practise communicated? Where do the challenges remain?

Inspection evidence

All our inspection reports are published in full on the Care Inspectorate website for services, carers and people who use services to read. All our inspections examine the quality of care and support provided, and in a care home for older people palliative care is integral to this assessment. On some inspections, we examine in more detail practice around caring for people with a life limiting condition, and have identified some examples of good practice.

Education about palliative and end of life care is important. We are aware from our inspection findings that many care homes are involved in setting up education programmes for their staff. For example, one large multi-site care home provider has developed an online learning programme for all their staff about end of life care. This education captures learning in workbooks and uses DVD, and group learning.

We have seen one example of a care home in Ayrshire which applied for integrated care funding to provide an enhanced end of life service. This initiative works well because there was a good working relationship established between Macmillan national leads, Ayrshire Hospice, and specialist palliative care nurses from Crosshouse Hospital. The important communication about when a person is nearing end of life is discussed openly with the person, staff at the care home, and people close to the person.

In another case we saw how extra staff had been put on night shift to support someone who was at the end stages of life, and supported the person's family who were able to be there with them at the end. The care home in question operated a multidisciplinary approach and worked in partnership with appropriate health care professionals to ensure that, with permission, all family members could take an active role in their relative's care. Staff offered good support to a family whose relative was receiving palliative care. Palliative care nurse specialists discussed with families and carers concerns or issues in relation to residents' palliative care needs, and the care service had offered to set up meetings between palliative care nurses and families.

We have also found examples of effective staff practice in care services, where staff were able to tell us how they would support someone that was dying, or relatives of someone dying and where the service provided accommodation for relatives who were supporting their dying loved ones to remain in the service in order to be close by, if that was their wish.

We are aware that a wide variety of services support people with palliative care, not just care homes for older people. Our scrutiny evidence around palliative care provided to children and young people is from a small number of specialist care at home services, including care at home services provided by Children's Hospice Association Scotland (CHAS). Our most recent inspection found the quality of care to be very good, and the quality of staffing and the quality of management and leadership to be excellent. Inspection reports are available on our website, www.careinspectorate.com.

Looked after children

The Care Inspectorate also has a statutory responsibility to review the deaths of children in the care of the local authority. In April 2013, we published a report into the deaths of looked after children in Scotland 2009-2011. (A further report is forthcoming, which will reflect those cases we have examined more recently).

In the published report, we reviewed the deaths of 8 looked after children with life-limited conditions, and the deaths of 7 looked after children with other

complex health issues, including complex health conditions, illness, and also sudden death. We found variable responses to planning for palliative and end of life care. Some local authorities work closely with colleagues in health, and with the Children's Hospice Association Scotland, to plan sensitively for the end of the child's life. In around half of all the reviews of the deaths of looked after children with a life limiting condition, we found high quality end of life care and planning.

The management of health in relation to palliative care of children and young people with life-limiting conditions was good but we rarely saw evidence of multi-agency care planning. This meant that the day-to-day carers as well as the child and family may not have been kept informed of changes in the child's condition. Exceptions to this were those children who were managed by hospice teams who had exemplary end of life care.

In children where acute deterioration was possible, there was evidence in some cases that the Children and Young People Acute Deterioration Management Form had been used. This important document promotes inter-agency communication and consensus decision-making involving the child and the family, where the child is approaching the end of life. There are guidance notes in conjunction with the full resuscitation planning policy for children and young people, to help with the completion of this document.

The report also noted that the use of anticipatory care planning at an earlier stage may increase communication about the child's and family needs and improve inter-agency working, although there may be circumstances when some children with chronic, longstanding illnesses die suddenly before clinicians have categorised them as being at the end of their life.

Sharing good practice

The Care Inspectorate has a number of mechanisms for sharing effective practice across care services. Specialist inspectors play a key role in this, engaging in professional dialogue and constructive challenge with staff and leaders in care services. The Care Inspectorate's online Hub provides a large number of resources, free, to support care services in the delivery of palliative care. Both Care News and The Hub provide vehicles for sharing case studies of effective practice in social care. The Care Inspectorate also retains health improvement advisors with specialist skills, including in palliative care, to build capacity in the sector and provide specialist advice.

In December 2010, the Social Work Inspection Agency produced a practice guide, in conjunction with Children's Hospice Association Scotland, called End of life care and planning for children and young people with life-limiting conditions. Since the Social Work Inspection Agency merged with other bodies to form the Care Inspectorate on 1 April 2011, we have continued to promote the effective practice contained within it

6. What is the role of anticipatory care plans in supporting Palliative Care discussions and how can their uptake be improved?

NHS Education for Scotland provides a webpage ‘Palliative care in practice’ that is promoted in social and health care settings. Anticipatory care plans can be helpful in allowing people to think ahead about how they want their care at end of life, or when their clinical condition deteriorates, to be delivered. Staff, however do require support to learn about these plans. It is important that anticipatory care plans are considered in all undergraduate education for nursing, allied health professionals and medical staff.

From our annual returns information and the services self- assessment of their service data has indicated that services are using more anticipatory care plans (ACPs), but there remains services who have not implemented ACPs hence why we support further education on anticipatory care planning. There may be very valid reasons why a person in a residential care home does not have an anticipatory care plan in place: for example, a resident may not be considered to be at or near end of life. This is particularly relevant in care homes for younger adults. In addition, anticipatory care plans require a person to have the capacity to give consent to the plan. This notwithstanding, we welcome the rise of the use of anticipatory planning and wish to re-emphasise the importance of effective joint working between health and social care colleagues in this area.

The table below shows the figures from the last three years, broken down by care homes for older people, and care homes for adults.

Percentage of service users who died that had an Anticipatory Care Plan.

Care home type	2012	2013	2014
Older people	38%	47%	62%
Other adults	20%	22%	27%
All care homes for adults and older people	37%	47%	61%

7. How should information about Palliative Care be made available to patients and their family during any initial discussions and how easily available is this information?

Palliative care is not carried out by the NHS alone; different levels of care may be carried out by a number of different people and services. Care will be offered in hospices, hospitals, in community settings such as general practitioners, and in patients’ own homes.

“Good life, good death, good grief”, an alliance of organisations and individuals co-ordinated by the Scottish Partnership for Palliative Care, produces leaflets, DVDs, and events around death and dying, which helps with changing the culture of allowing people to discuss such a topic.

NHS Inform also provide valuable information on palliative care and bereavement care. Charitable organisations, such as Macmillan and Marie

Curie, also provide important literature on living with long term incurable illness and palliative care. National awareness campaigns help to raise the profile of how support can be obtained.

Consideration should be given to the ensuring that teachers and other professionals working with children and young people are suitably equipped to support children and young people to have knowledge of death and dying and palliative care.

8. What training and support is provided to Health and Care staff on discussing Palliative Care with patients and families and are there any areas for improvement?

There are opportunities for staff to learn about palliative and end of life care, for example voluntary and NHS hospices provide education aimed at social and health care staff.

Care service providers can also access online learning courses, while many large service providers have their own education in place.

9. How do Health and Care organisations ensure that the discussions about palliative and end of life care are taking place at the right time?

The Care Inspectorate has provided education and development support to service providers on good practice about palliative care at their health education day events. At these events there is discussion about the need to deliver person centred care, which is ultimately about meeting those people's individual needs when they are requiring palliative and end of life care. We put all good practice on our knowledge and improvement website, hub.careinspectorate.com, for the public and service providers.

10. What are the challenges in recording and documenting Palliative Care priorities and how well are those priorities communicated between different health and care providers?

A future challenge will be the number of people being looked after in the community. It will be important that we have the right systems in place for the acute hospital sector to communicate with social care providers, and vice versa.

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Case study

General Information

People with Down's syndrome are living longer than ever before. Since the early 1980s life expectancy has doubled, most likely because of advances in medical treatment and improved living conditions. As they age, people with Down's syndrome have a greatly increased risk of developing dementia.

Staff who are looking after people with learning disabilities need to have access to education and training by people who know about supporting increasingly complex and multiple care needs.

Service/Provider

The Care Inspectorate has been involved in supporting a care service where a resident with learning disabilities wished to spend their last days in the service. The service has a small number of adults with learning disabilities living in a spacious bungalow with communal living areas, kitchen and bathroom, with each service user having their own bedroom. A staff room in the home facilitates sleepover cover.

Two residents had lived in the home for over 20 years; another resident had lived in the home for just over three years. There was a consistent staff team in the service with little staff turnover.

Background

Resident A was diagnosed with dementia by a consultant psychiatrist. Over the course of a two-year period staff noticed changes in resident A's care needs, becoming more forgetful, less happy and easily upset. Resident A's dementia was progressing and staff needed to be ready for sudden and profound changes.

The staff team was in contact with resident A's family and other external professionals to respond to what issues were appearing and to prepare everyone for the eventual decline in health. Equipment and training were put into place as needs changed with the help of community nurses and therapists. Discussions were held with the family about care being put into place as needs changed.

At the time, staff were confident in their ability to care for the resident at home and this was supported by the family. Resident A had expressed to staff and family the wish to be at home and had made funeral arrangements before becoming unwell.

The manager requested additional funding for a temporary increase in staff for resident A's care from the local authority, but the local authority preferred resident A to move to a nursing care home. The family and staff were adamant that this would not happen as it was felt that staff in the nursing care home, although trained for nursing care, would not necessarily understand resident A's needs relating to his learning disability, which was compounded by the onset of the dementia.

Resident A wanted to be at home happy and comfortable. The service ensured staff were available to provide the care resident A needed at home.

Care needs at end of life

Upon reflection, staff said they did not expect resident A's decline to be so quick. The GP said a decline may happen fast but nothing had prepared the staff for the almost daily changes in needs that resident A experienced. Staff were unprepared for the huge learning curve they suddenly found themselves in. They had to deal with not only their own emotions surrounding the decline of resident A's health, but also the emotions of the other service users and the families and friends involved in life at the service.

During the last six months of resident A's life family and friends were kept informed of resident A's condition and relationships were maintained. The staff phoned, emailed, and spoke in person to those in resident A's relationship circle on an almost daily basis.

Soon, staff found they had to support resident A more to get around the home. Declining mobility issues were compounded by resident A's learning difficulties, and this made for periods of confusion and outbursts as resident A's understanding of the world around him declined and changed.

When resident A could no longer get around, occupational therapists and physiotherapists advised on how best to keep resident A mobile. Staff received specialist equipment and training by the therapists. As staff noticed that resident A was having difficulty swallowing and appeared to be losing weight, staff contacted the Speech and Language Therapy service; a swallowing assessment was completed, and resident A's diet was changed so his nutrition could be maintained.

As resident A's mobility and eating issues continued to deteriorate staff noticed resident A's skin integrity was becoming impaired, largely due to his immobility and incontinence. A special bed and mattress provided for resident A's comfort.

Resident A's ability to tell staff what was wrong or how resident A was feeling declined rapidly and staff had to use other forms of communication to determine what was needed or wanted. Use of sign language and body language was a big factor in staff's ability to meet resident A's needs.

When resident A began to show signs of acute distress, staff thought the pain experienced by resident A was no longer being relieved by oral medicine and there were now difficulties with swallowing analgesia. The GP made a referral to Macmillan nurses in order to assess resident A's symptoms and end of life care.

Resident A was given medicine via a syringe pump to relieve pain and staff were instructed on how to monitor this. The community nurses came in daily to check on the effectiveness of the medicine and adjust the dosage if needed. This was based on reports from the staff about how well resident A was resting and if there appeared to be any further signs of pain.

Resident A died peacefully at home after over 20 years living in his adopted home. Staff quietly and discretely phoned the GP to inform of the death and the GP arrived before the other residents began their day.

The other residents went about their usual routines, attended their day centres or work, and were informed of resident's A's death when they came home. This gave staff time to contact families and arrange for the funeral home to attend.

Impact on other residents

Our inspection evidence identified that there had been little or no impact on the care provided to the other residents in the home during the period of resident A's palliative care. It is difficult to determine whether or not any behavioural issues displayed by service users during this time were due to the changes in the service required to provide palliative and end of life care to resident A. One parent of another service user felt that their son/daughter was often upset and required extra support from them for behavioural issues.

Service users were encouraged to visit resident A's room when resident A was no longer able to come out into other parts of the house. Staff said the other residents were very kind and would go in to visit and talk to resident A, telling resident A not to worry about chores or asking if resident A wanted anything when they went to the shops.

One parent of another service user was not happy that end of life care was being provided in the home presumably because this family member had concerns over her own relative's ability to understand and cope with all that was happening.

Key areas

Some of the issues faced by the staff team and provider, included:

- Ensuring there was enough support staff for the residents without dementia, releasing time for permanent staff in the home to meet to the person with dementia's end of life care needs
- The need for professional expertise, from example speech and language therapy, physiotherapy and occupational therapy and the community nursing team
- Responding to people's personal wishes – in this case supporting someone to stay in the home because it is their wish to do so
- Taking account of the information and support needs of relatives, and responding to their wishes and concerns
- The need for flexible and responsive financial systems that acknowledge the rapidly changing care needs of someone with dementia who has palliative care needs
- Education and training scheduled so that staff are ready before residents with dementia and a learning disability require palliative care

- Awareness of a person's changing needs and knowledge to have the skills to constantly reassess people who require palliative care
- Consideration of meeting an individual's need to stay in their preferred place of care and death a top priority

In the past, an easy option may be to place somebody in a care home and have a care package that takes into account of what they require - but this is not a person-centred approach. People with complex and multiple conditions have needs that are constantly changing and account should be taken of where the person wants to be. The services should be centered on the person.

These challenges were specific to this service but are indicative to think creatively about providing palliative care to people in a wide variety of care settings, including in services for people with learning disabilities who are at the end of life.

Improving outcomes for people

The support service staff and family acknowledge that without the support from the community learning disability nurses, Macmillan nurses, occupational therapist, physiotherapist, and community nurses, resident A's end of life care would have been less positive.

There had been consistent, practice-based education and training of the staff supporting resident A within this small service. This was a critical factor in diagnosing his dementia, and determining the type of care he needed to be given. Staff knew resident A very well and were able to pick up on the signs that something was not right early on.

The staff and manager were fully aware that complex care needs presented challenges to the staff team, which highlighted a need to change the current palliative care policy, particularly around anticipatory care planning and review some of the education and training needs for the provider.

One staff member has now developed a special interest in palliative care and will be visiting other services to talk to staff about the challenges the team faced and how quickly a resident can decline towards end of life.

It is envisaged that this will bring awareness to teams in order that they can be better prepared to support the people in their services who are getting older and living with a life limiting condition such as dementia and Down's syndrome.