

Death, dying and diabetes: The importance of providing condition-specific end-of-life care

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Article points

1. Calls for condition-specific guidance for end-of-life care have led to the development of UK diabetes-specific guidance.
2. This guidance provides a consistent, high-quality approach towards end-of-life diabetes care.
3. The diabetes-specific guidance reflects the importance of the need for competency-based education and offers a competency framework developed for all nurses working in diabetes with end-of-life patients.

Key words

- Diabetes
- End-of-life care

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Approximately 500 000 people die in England each year and of these, about 75 000 people will have diabetes. People with diabetes will have a unique set of care needs during the last year, months and days of life, so appropriate management of diabetes with agreed actions by individuals and their families is important. The Liverpool Care Pathway was developed over a decade ago and, although it was quickly adopted by many hospital trusts and community teams, it is now being withdrawn in the UK due to concerns over financial incentives associated with the pathway, as well as negative media coverage. The emphasis is now to develop condition-specific guidance and this article discusses the new consensus guidance for end-of-life care for people with diabetes.

Death and the care of the dying is an emotive subject that most people, including healthcare professionals, would prefer not to think about, never mind discuss. This subject has been the focus of a lot of media attention in recent times; as I write this article, the UK politicians are debating the assisted suicide bill and one of the arguments is that the care of the dying is suboptimal, with individuals experiencing prolonged suffering and pain.

The Liverpool Care Pathway (LCP) has been under scrutiny in the UK and is now being gradually withdrawn and there have been calls for more condition-specific guidance. Now, more than ever, it is time to consider the care provided for people at the most vulnerable time of their life.

This article focuses on the UK perspective while acknowledging that there are similar issues worldwide (IDF, 2013). It reviews the Liverpool Care Pathway and its demise in the UK and introduces consensus guidance on end-of-life care for people with diabetes.

Background

About 500 000 people die in England each year and of these about 75 000 people will have diabetes. Seventy percent of all deaths in England occur in people aged 70 years or above (Rowles et al, 2011). Most deaths follow a time of chronic illness, such as heart disease, cancer, and stroke. The majority of people (75%) say they would prefer to die at home but in 2011, it was estimated that only around 42% died in their usual place of residence and over half died in hospital (Department of Health, 2012).

Accurate death certification data on the incidence of diabetes as a contributory factor to death are not available; we know that life expectancy for people with diabetes is increasing, but many will die prematurely as a result of diabetes-related end organ failure (Rowles et al, 2011).

People with diabetes will have a unique set of care needs during the last year, months and days of life, so appropriate management of diabetes with agreed actions by individuals and their families is important (Diabetes UK, 2013a).

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1. The Liverpool Care Pathway was developed over a decade ago to improve the care of the dying; however, it has since proven controversial as concerns have been raised about financial incentives for hospital trusts that adopt the pathway.
2. An independent review into the pathway acknowledged that when the pathway was used in full consultation with patients and carers and operated by well-trained healthcare professionals, many carers reported that the care given was excellent; however, an audit revealed a number of complaints and 44 new recommendations were made.

Defining end of life

The term “end of life” is a phrase commonly used, but when should healthcare professionals start to think about planning for end-of-life care? The General Medical Council (2010) states that:

“People are approaching the end of life when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with advanced, progressive, incurable conditions; general frailty and co-existing conditions that mean they are expected to die within 12 months; existing conditions if they are at risk of dying from a sudden acute crisis in their condition, or life-threatening acute conditions caused by sudden catastrophic events.”

The influential work created by the Royal Liverpool University Hospital and the Marie Curie Palliative Care Institute, which resulted in the “Liverpool Care Pathway” (LCP), was developed over a decade ago and aimed to replicate quality care experienced by those expected to die within a few days in hospices. This generic pathway was considered innovative in its concept, and was quickly adopted by hospital trusts, primary care teams and community hospitals. It succeeded in opening up the conversation about death and dying and aimed to assist the dying to experience good quality, patient-centred care and a dignified pain-free death.

This work became controversial when concerns were raised that hospital trusts were receiving financial incentives according to the number of people cared for on the LCP. This, along with adverse media coverage and a public perception that it was

used to hasten death, resulted in an independent review of the LCP and it was subsequently withdrawn during 2014 from all healthcare services.

The Neuberger Report (Neuberger et al, 2013) acknowledged that when the LCP was used in full consultation with patients and carers and operated by well-trained and sensitive healthcare professionals, it worked well and many carers reported that the care given was excellent. A snapshot audit undertaken by the review panel of 16 hospital trusts (11% of all English trusts) revealed a total of 8655 complaints in 2011/12. A further investigation into specific complaints (255) found that only 3–7% (16) of all complaints related to the LCP (NHS Improving Quality, 2013). Common themes were revealed relating to the LCP complaints (*Box 1*).

These concerns mirrored the headlines in the UK media and other reports saying that some people should not have been considered as being “end of life” because they survived. In addition, further case reports of poor care from the Francis Report (Mid Staffordshire NHS Foundation Trust, 2013) resulted in the independent review (Neuberger et al 2013) making 44 new recommendations in the care of the dying. These included:

- That the term “pathway” should no longer be used as it led to fear among patients and relatives that somehow their death was inevitable and could be hastened.
- That all people receiving end-of-life care should have an agreed care plan (between the individual where possible, as well as carers and healthcare professionals). This should be supported by condition-specific good practice guidance.

Box 1. Common themes relating to 16 complaints about the Liverpool Care Pathway (NHS Improving Quality, 2013).

1. Specific issues surrounding nutrition and hydration, and use of artificial feeding. This can often relate to communication issues and understanding about aspects of care (for example, relative believes food and fluids were withdrawn, but actually the patient was receiving subcutaneous fluids).
2. Poor adherence to specific aspects of clinical care set out in the Liverpool Care Pathway (for example, overview of patient care or symptom management).
3. Review of care for patients whose care is supported by the Liverpool Care Pathway for a long time, or if a patient improves, and need for ongoing communication and involvement with families.
4. Communication throughout, including initiation of the Liverpool Care Pathway and ensuring families are aware, understand and are involved. There can be specific challenges where families are large and/or there are complex relationships, and/or relatives live far away.

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1. Until recently, there was little published evidence to demonstrate a preferred, or evidence-based approach to diabetes care at the end of life in the UK.
2. As a result, Diabetes UK commissioned a multidisciplinary working party to develop consensus recommendations on the care of diabetes during end of life.
3. The key purposes of these diabetes-specific documents are to offer a consistent and high-quality approach to end-of-life care in partnership with the person with diabetes and their family and carers.

- That there must be accurate documentation in the patient notes/records outlining the agreed end-of-life care plan.
- That all staff should receive initial and ongoing evidence- and competency-based training, which should encompass communication skills.
- The recognition that there are no precise methods of determining when a person is going to die. Therefore, the time frame for those not expected to live after one year needed to be defined and embedded into existing policies and programmes.
- That every person receiving end-of-life care should have a clearly identified and responsible clinician accountable for their care during normal working hours (both nurse and physician) and out-of-hours periods.
- All individuals who are able to eat and drink should be supported to do so. Failure to support people to eat and drink will be regarded as professional misconduct.
- Age discrimination would not be acceptable; if the individual lacks mental capacity, an independent advocate must be appointed.
- Financial incentives must cease in relation to any approach to care of the dying.
- The Government should set improved quality of care in the dying as a priority (Neuberger et al, 2013).

Other guidance in the UK is still in place such as: the Gold Standards Framework (2011), the *Amber Care Bundle* (Guy's and St Thomas' NHS Foundation Trust, 2012) and the *All Wales Integrated Care Priorities for the Last Days of Life* (available at: <http://wales.pallcare.info>). These are generic approaches to care and common to all is that the policies must be agreed by a multidisciplinary team, regardless of the care setting.

Diabetes and end-of-life care

Condition-specific guidance for end-of-life care, including that of diabetes, has until recently been sparse due to a lack of discussion in the literature. Many individuals and organisations had expressed concern about the lack of diabetes guidance (Kerr, 2009; Palliative care in Wales, 2010; Vandenhoute, 2010; Royal College of Nursing, 2013). Until recently, there was little in the way of published evidence to demonstrate a preferred, or evidence-based approach to diabetes care at the

end of life and there are no studies supporting or providing insight into glycaemic control, diabetes self-management, or use of particular glucose-lowering therapies (Vandenhoute, 2010).

As new guidance was needed, Diabetes UK commissioned a multidisciplinary working party through the Council of Health Care Professionals. This working party was led by Professor Alan Sinclair and Dr Jean MacLeod and aimed to develop consensus recommendations on the care of diabetes during end of life. This work was supported by the Association of British Clinical Diabetologists (ABCD; Rowles et al, 2011), the Institute of Diabetes For Older People (IDOP), and TREND-UK. It was reviewed and endorsed by key diabetes healthcare professional organisations, and more recently by NHS Improving Quality.

The following documents were developed:

1. *End of life diabetes care: Strategy document* (Diabetes UK, 2013a).
2. *Clinical care recommendations for diabetes and end of life* (Diabetes UK, 2013b).
3. Downloadable algorithms and flow charts (Diabetes UK, 2013c). These included:
 - Diabetes medication and end-of-life care.
 - Treatment of hypoglycaemia.
 - Steroid use (developed by MacLeod et al in 2012).

The LCP review (Neuberger et al, 2013) had emphasised that care should be individualised and planned with the focus centred on pain management and other distressing symptoms; providing psychological, social and spiritual support to patients; and supporting those close to the patient. The care of the person with diabetes adds other elements, including ensuring that staff have the knowledge to recognise when person may be entering an end-of-life stage and the confidence to manage diabetes medicines during this time in order to avoid unnecessary blood glucose monitoring, diabetes-related symptoms and metabolic emergencies such as hypoglycaemia, diabetic ketoacidosis or hyperglycaemic hyperosmolar state (*Box 2*).

The key purposes of these diabetes-specific documents are to offer a consistent and high-quality approach to end-of-life care in partnership with the person with diabetes and their family and carers (*Box 3*).

Box 2. Main principles in diabetes and end-of-life care (Diabetes UK, 2013b).

- Provision of a painless and symptom-free death.
- Tailor glucose-lowering therapy and minimise diabetes-related adverse treatment effects.
- Avoid metabolic de-compensation and diabetes-related emergencies:
 - frequent and unnecessary hypoglycaemia
 - diabetic ketoacidosis
 - hyperosmolar hyperglycaemic state
 - persistent symptomatic hyperglycaemia.
- Avoidance of foot complications in frail, bed-bound people with diabetes.
- Avoidance of symptomatic clinical dehydration.
- Provision of an appropriate level of intervention according to stage of illness, symptom profile, and respect for dignity.
- Supporting and maintaining the empowerment of the individual (in their diabetes self-management) and carers to the last possible stage.

Box 3. The key purposes of Diabetes UK clinical care recommendations (Diabetes UK, 2013b).

- Describe a consistent, high-quality approach towards end-of-life diabetes care provided by a series of quality standards.
- Inform the wider healthcare workforce about the key issues in end-of-life diabetes care that provides a platform for sensitive, appropriate and supportive care.
- Provide clarification of the main roles and responsibilities of healthcare workers, carers, and patients themselves in the end-of-life diabetes care.
- Highlight the awareness of newly identified training and educational needs for high-quality end-of-life diabetes care.
- To foster partnerships in end of life diabetes care, with established palliative care pathways, such as the Liverpool Care Pathway.

Stages of end of life

Written over a year before the LCP independent report, the diabetes specific guidance aligns to the Gold Standards Framework (2011) and identifies four stages of end of life. Specific time frames are colour coded for ease of use in the diabetes guidance and are in line with current recommendations depicted in the independent report (Neuberger et al, 2013):

- A. Blue: Individuals with life expectancy of 12 months.
- B. Green: Individuals with advanced disease and life expectancy of months.
- C. Yellow: Individuals whose condition is deteriorating and may have a life expectancy of weeks.

D. Red: Individuals who are in the last few days of life.

**Clinical recommendations
Glycaemic targets**

Treatment options for all diabetes therapies including insulin and non-insulin therapies are given and aligned to life expectancy; it is recommended that changes should be made where possible following full discussion with the individual, their family or the individual’s advocate. There is no stated HbA_{1c} target as there is no evidence to support a specific glycaemic target. Where capillary blood glucose targets are stated in the guidance, however, they aim to reduce hypoglycaemia and hyperglycaemia and their associated signs and symptoms:

- Aim 1 is that there are no glucose readings less than 6.0 mmol/L.
- Aim 2 is that there are no glucose readings more than 15.0 mmol/L.

Clear recommendations on how to tailor and individualise diabetes medication, including oral and injectable therapies (insulin or glucagon-like peptide-1 agonists), and blood glucose monitoring according to the needs and preferences of the individual and their clinical condition are given. This included specific guidance and algorithms relating to the following:

- Renal function is deteriorating.
- The individual uses an insulin pump.
- The management of intercurrent illness.
- The management of hypoglycaemia.
- Corticosteroid use (MacLeod et al, 2012).

Fluid and treatment withdrawal

Fluid withdrawal is not recommended unless it is the specific wish of the patient. The Neuberger Report is clear that fluids should not be withdrawn unless requested by the individual and that failure to support oral hydration and nutrition where still possible and desired would be regarded as professional misconduct (Neuberger et al, 2013). The review guidance does, however, include discussion about the withdrawal of any treatment and the acknowledgement that many factors may influence this process, including:

- The individual’s wishes. Remember, individuals will probably have been encouraged to take all their medication and keep to “tight” glycaemic targets

“The guidance allows for an individualised approach and so meets the requirements for matching individual patient needs and desires through the end-of-life stages.”

all of their diabetes life, so relaxing glycaemic control may present real challenges.

- Family concerns.
- The type of diabetes. For example in type 1 diabetes, it is recommended that insulin treatment should not be withdrawn but the number of blood glucose tests should be reduced in the last days.
- The presence of an “Advanced Directive”, which stipulates the wishes of the individual should they lack capacity to make health-related decisions in the future.

Training and competencies

A large part of the Neuberger Report focused on staff training and competencies. Staffing levels were discussed and the importance of regular evidence- and competency-based training was emphasised. The General Medical Council and the Nursing and Midwifery Council were challenged to ensure appropriate quality and revalidation. The diabetes-specific guidance reflects the importance of the need for competency-based education and offers a competency framework developed for all nurses working in diabetes with end-of-life patients (TREND-UK, 2011).

Summary

In the light of the Neuberger review and the recommendation that condition-specific guidance must be in place to support people during the last stages of life, the diabetes specific guidance is timely, but UK teams may need support to implement recommendations (Tapley and Needham, 2012). The concept of end-of-life care is emotive and often difficult to talk about. With recent reports highlighting cases where the individual and their family may not been dealt with sensitively, it is important that all healthcare professionals, including those who work in diabetes, have the communication and clinical skills to help the individual experience as “good a death” as possible.

The diabetes guidance was updated at the end of 2013 to ensure all the Neuberger recommendations were in place and has been endorsed by the NHS England Clinical Champion for end-of-life care; however, implementation may be challenging in individual hospital and community Trusts. The guidance allows for an individualised approach and so meets the requirements for matching individual

patient needs and desires through the end-of-life stages. The experience of the individual and their family will, however, ultimately prove the efficacy and value of the clinical care recommendation for people with diabetes. Dame Cicely Saunders, a pioneer in hospice care, has the last word when she says:

“You matter because you are you. You matter to the last moment of your life and we (healthcare professionals) will do all we can, not only to help you die peacefully, but also to live until you die.” ■

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