

End-of-life care: Anything but a pathway

June James

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Article points

1. All end-of-life care should be condition specific.
2. The use of the term “pathway” when referring to end-of-life care must be avoided.
3. All staff should and have ongoing training in the care of people in the last stages of life.
4. There is guidance on diabetes and end-of-life care that is in place and ready to use.

Key words

- End-of-life care
- Neuberger Report
- Older people

Benjamin Franklin wrote in a letter to Jean-Baptiste Leroy, in 1789, that: “In this world nothing can be said to be certain, except death and taxes.” As individuals in modern society we may be comfortable with talking about taxes, but the subject of death may be one that healthcare professionals are not so happy to address with patients. Every year, there are about 500 000 deaths in England alone and most of these follow a period of chronic illness such as heart disease, cancer or stroke. Seventy per cent of all deaths occur in people aged 70 years or more, while 58% of deaths occur in hospital, 18% at home, 17% in care homes, and 7% in other settings. Accurate death certification data where diabetes is a contributory factor are not available, but it is estimated that up to 75 000 people with diabetes die annually in England, and therefore the appropriate management of diabetes with agreed actions by individuals and their families is of great importance. People with diabetes have a unique set of care needs during the last year, months and days of life. Until now there has been little guidance on the specific needs of people with diabetes at this time.

“End of life” is a commonly used phrase, but what does it actually mean for healthcare professionals and clinicians, and when does the end-of-life phase begin? The General Medical Council (2010) states that: “Patients are ‘approaching the end of life’ when they are likely to die within the next 12 months. This includes patients 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.
- Life-threatening acute conditions caused by sudden catastrophic events.

Seminal work by the Royal Liverpool University Hospital and the Marie Curie Palliative Care Institute Liverpool resulted in the “Liverpool Care Pathway” (LCP; Neuberger, 2013). This was developed over 10 years ago with the aim of replicating quality care experienced by

dying people in hospices for hospital inpatients with a life expectancy of just a few days. This generic pathway was hailed as innovative in its concept, and it was quickly adopted by many hospital trusts, primary care teams and community hospitals. It very successfully opened up dialogues about death and dying, and promoted and aimed to assist dying individuals to experience high-quality patient-centred care and a dignified pain-free death.

The LCP work has in recent times become the subject of some controversy. Concerns were raised when trusts received financial incentives according to the number of people cared for on the LCP. This, combined with a public perception that it was used to hasten death, as well as adverse media coverage, has resulted in the LCP gradually being withdrawn in advance of 2014 from all healthcare services (Silverman, 2013).

The Neuberger Report, which reviewed the pathway, concluded that when the LCP was used and operated by well-trained and sensitive healthcare professionals in full consultation with dying people and carers it worked well, with many carers reporting that the care given

Author

June James is a Nurse Consultant – Diabetes, University Hospitals of Leicester NHS Trust, Leicester.

was excellent (Neuberger et al, 2013). However, concerns were raised that in some cases there was poor or scant communication, with little discussion between healthcare professionals and patients or carers. This combined with reports of fluids and food being withdrawn from those being cared for, that some patients should not have been considered as being at end of life because they survived, and cases of poor care from the Francis Report (Mid Staffordshire NHS Foundation Trust Public Health Enquiry, 2013). This led to 44 new recommendations for the care of the dying (Neuberger et al, 2013). These include the following:

- 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.
- All patients receiving end-of-life care should have an agreed care plan (involving the patient where possible, as well as carers and healthcare professionals). This should be supported by condition-specific good practice guidance.
- There must be accurate documentation outlining the agreed care plan.
- All staff should receive initial and ongoing evidence and competency-based training and education, which should include communication skills.
- It must be recognised that there are no precise methods of determining when an individual is going to die. Therefore, the time-frame for those not expected to live after 1 year needs to be defined and embedded into existing policies and programmes.
- Every person undergoing end-of-life care should have a clearly identified and responsible clinician accountable for his or her care during normal working hours (nurse and physician) and “out of hours” periods.
- All patients who are able to eat and drink should be supported to do so. Failure to comply with this 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.

Other guidance is still in place in the UK, including: the *Prognostic Indicator Guidance* (Gold Standards Framework Centre in End of Life Care, 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> [accessed 05.11.13]). These offer 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 of the care of people with diabetes at the end of their lives has until now proved a challenge as there has been a dearth of discussion or debate in the literature on this topic. Individuals had expressed concern on the lack of guidance (Kerr, 2009; Vandenhoute, 2010; Rowles et al, 2011; Royal College of Nursing, 2013). There was little in the way of published data to demonstrate a preferred, or evidence-based, approach to diabetes care at the end of life and no studies supporting or providing insight into glycaemic control and management, diabetes self-management, or use of particular glucose-lowering therapies (Diabetes UK, 2012a).

New consensus guidance was clearly needed, and so Diabetes UK’s Council of Healthcare Professionals commissioned a multidisciplinary working party led by Professor Alan Sinclair and Dr Jean MacLeod to develop consensus recommendations on the care of diabetes during end of life (Diabetes UK, 2012b). This work was supported by the Institute of Diabetes For Older People, the Association of British Clinical Diabetologists and TREND-UK (Training, Research and Education for Nurses on Diabetes – UK) and endorsed by key diabetes healthcare professional organisations.

This work resulted in the development of:

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- 1 *End of Life Diabetes Care: A Strategy Document* (Diabetes UK, 2012a).
 - 2 *End of Life Diabetes Care: Clinical Care Recommendations* (Diabetes UK 2012b).
 - 3 Downloadable algorithms and flow charts (Diabetes UK, 2012c), including:
 - *Diabetes medication and end of life care.*
 - *Steroid use* (developed by MacLeod et al, 2012).
 - *Treatment of hypoglycaemia.*

The Neuberger Report emphasises that individualised care should be planned, with the focus on: managing pain 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 dimensions to this in that healthcare professionals will need to be proactive in recognising the start of a terminal decline in health. In addition, there needs to be effective care planning in order to ensure the avoidance of unnecessary blood glucose monitoring, diabetes-related symptoms, and metabolic emergencies such as hypoglycaemia, diabetic ketoacidosis and hyperglycaemic hyperosmolar state (*Box 1*).

The key purpose of these diabetes-specific documents is to offer a consistent and high-quality approach to end-of-life care in partnership with the person with diabetes and the family and carers (*Box 2*).

Box 1. Main principles in diabetes and end of life care (Diabetes UK, 2012a ; adapted with permission).

- Provision of a painless and symptom-free death
- Tailor glucose-lowering therapy and minimise diabetes-related adverse treatment effects
- Avoid metabolic decompensation and diabetes-related emergencies:
 - Frequent and unnecessary hypoglycaemia
 - Diabetic ketoacidosis
 - Hyperosmolar hyperglycaemic state
 - Persistent symptomatic hyperglycaemia
- Avoidance of foot complications in frail, bed-bound elderly patients 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 patient (in their diabetes self-management) and carers to the last possible stage

Box 2. Key purposes (Diabetes UK, 2012a; adapted with permission).

The key purpose of the full guidance document is to:

- 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 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

Although over a year before the LCP review, the diabetes-specific guidance described four stages of end of life, which aligned to the “Gold Standard” recommendations. Timeframes are colour-coded for ease of use in the diabetes documentation and are in line with current recommendations depicted in the Neuberger Report (on page 14 of the document):

- A** Blue – individuals with a life expectancy of 12 months.
- B** Green – individuals with advanced disease and a life expectancy of months
- C** Yellow – individuals whose condition is deteriorating and who may have a life expectancy of weeks.
- D** Red – individuals who are in the last few days of life.

Clinical recommendations

Treatment options for insulin, non-insulin therapies and other diabetes-related medications are given and linked to life expectancy. These are aligned to the individual’s perceived life expectancy, and – where possible – based on full discussion with the patient and the family or the patient’s advocate. The glycaemic targets given are dependent on the stage of the illness and patient preference. There are no stated HbA_{1c} recommendations as there is no evidence to support a specific target. However, blood glucose targets are recommended in the guidance and aim to reduce the risk of hypoglycaemia and hyperglycaemia and their associated signs and symptoms:

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

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- Aim 2 is that there are no blood glucose readings higher than 15.0 mmol/L.

The guidance gives clear recommendation on how to tailor diabetes medication (including oral and injectable therapies) and blood glucose monitoring to the needs of the individual, and his or her clinical condition and preference. This included specific guidance and algorithms relating to the following:

- Deteriorating renal function.
- Insulin pump use.
- Steroid use (based on MacLeod et al, 2012).
- The management of intercurrent illness.
- The management of hypoglycaemia.

Fluid withdrawal is not recommended unless the individual requests this.

There should be discussion on the withdrawal of any treatment and an acknowledgement that many factors may influence this process, which include:

- The patient's wishes: remember that individuals will probably have been encouraged to take all their medication and keep to tight glycaemic targets throughout their life with diabetes, and so a relaxing of glycaemic control may present real challenges.
- Family concerns.
- The type of diabetes: in type 1 diabetes, for example, it is recommended that insulin treatment should not be withdrawn, but the number of blood glucose tests should be minimised in the last days.
- The presence of an advance directive.

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 emphasised. The General Medical Council and the Nursing and Midwifery Council were challenged to ensure an appropriate quality-driven approach and revalidation. The diabetes-specific guidance reflects the importance of this and offers a competency framework developed by TREND-UK for all nurses working in diabetes who see people in an end-of-life care setting (Diabetes UK, 2012b).

In light of the Neuberger Report and its recommendation that condition-specific guidance must be in place to support people during the last stages of life, the publication of diabetes-specific guidance is timely, but teams may need supporting in implementing recommendations (Tapley and Needham, 2012).

The concept of end-of-life care is one that is emotive and often difficult to talk about. With the development of advance directives and the deluge of recent reports focusing on cases where the patient and families may not have been dealt with sensitively, it is therefore important that healthcare professionals, including those who work in diabetes, have the communication and clinical skills to help the patient experience “as good a death” as possible. I will give Dame Cicely Saunders (a pioneer in hospice care) the last word (<https://www.stlukes-hospice.org.uk/our-care> [accessed 05.11.13]):

“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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