Matching individual patient needs and desires throughout end of life stages

June James, Nurse Consultant – Diabetes, University Hospitals of Leicester NHS Trust, Leicester Royal Infirmary, Leicester, UK

Correspondence to: June James, Nurse Consultant – Diabetes, University Hospitals of Leicester NHS Trust, Leicester Royal Infirmary, Infirmary Square, Leicester LE1 5WW, UK;
email: June.James@uhl-tr.nhs.uk

Received: 4 November 2013
Accepted in revised form: 5 December 2013

Summary

End of life care is a subject that many patients or health care professionals would prefer not to talk about. People with diabetes have a unique set of care needs during the last year, months and days of life, but until now there has been little guidance on their specific clinical requirements. Approximately half a million people die in England each year and around 75 000 of them will have diabetes. European statistics demonstrate important variations in mortality and the burden of disease related to diabetes with age standardised death rates per 100 000 ranging from 4.0 (Greece) to 17.9 (Portugal), and with higher levels ranging from 36.1 (Israel) to 46.8 (Armenia). It is important that health care professionals are equipped with the knowledge, skills and clear guidance in order to support patients, relatives and carers during what is often a difficult time for all.

This article gives a robust definition of the term 'end of life', discusses the demise of more generic United Kingdom guidance on the care of the dying, and presents a consensus approach to quality care for people who are nearing the end of their life. These recommendations were commissioned by Diabetes UK, developed by a multidisciplinary group of heath care professionals and endorsed by key diabetes organisations. The recommendations given can easily be adopted for use in other countries, and the documents and tools are freely available to all.

Eur Diabetes Nursing 2014; 11(1): 19–22

Key words

diabetes; end of life care; Liverpool Care Pathway; Neuberger report

Introduction

Each year, about half a million people die in England and most of these follow a time of chronic illness such as heart disease, cancer and stroke. Seventy percent of all deaths occur in people aged 70 years or more. Accurate death certification data on the incidence of diabetes as a contributory factor to death are not available,[1] but it is estimated that up to 75 000 people with diabetes die annually in England and so the appropriate diabetes management with agreed actions by individuals and their families are important.[2]

Statistics from Europe state that there are important variations in mortality and the burden of disease related to diabetes, with age standardised death rates per 100 000 ranging from 4.0 (Greece) to 17.9 (Portugal) – with higher levels ranging from 36.1 (Israel) to 46.8 (Armenia). It is also acknowledged that officially reported deaths from diabetes are likely to be an underestimate because of under-recording and poor coding of cause of death, particularly among older people.[3] People with diabetes have a unique and specific set of care needs during the last year, months and days of life. Until now there has been little guidance on the specific requirements of people with diabetes at this time.

End of life – definition

'End of life' is a phrase often used – but what does it actually mean for health care professionals and clinicians, and when does 'end of life' begin? The General Medical Council in the United Kingdom (UK)[4] 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.'

Important work by the Royal Liverpool University Hospital and the Marie Curie Palliative Care Institute resulted in the 'Liverpool Care Pathway' (LCP). This was developed over 10 years ago with the aim of replicating in hospital inpatients, with a life expectancy of just a few days, the quality care experienced by the dying in hospices.[5] This generic pathway was hailed as innovative in its concept, and was quickly adopted by UK hospital trusts, primary care teams and community hospitals. It very successfully opened up the discussion about death and dying, and promoted and aimed to assist the dying patients to experience quality patient-centred care and a dignified pain-free death. The LCP work has in recent times become very controversial;

concerns were raised when UK 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, and adverse media coverage has resulted in the LCP gradually being withdrawn by 2014 from all heath care services.

The Neuberger Report[6] reviewed the pathway and surmised that, when the LCP was used and operated by well-trained and sensitive health care professionals in full consultation with patients and carers, it worked well with many carers reporting that the care given was excellent. However, other concerns were raised that in some cases there was poor communication, with little discussion between health care professionals and patients or carers. This, along with reports that fluids and food were being withdrawn from loved ones, that some patients should not have been considered as being at end of life because they survived, and that the Francis Report[7] cited cases of poor care, resulted in the Neuberger group making 44 new recommendations in the care of the dying.[6] These include:

- 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 (patient where possible, carers and health care 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 that of communication skills.
- The recognition that there are no precise methods of determining when a patient is going to die. Therefore the timeframe for those not expected to live after one year needed 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 their 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 is not acceptable; if the patient 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 such as: the National Gold Standards Framework,[8] the Amber Care Bundle,[9] and the All Wales Integrated Care Priorities for the Last Days of Life.[10] These are also generic approaches to care, and common to all is that policies must be agreed by the patient, relatives or carers and 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 lack of discussion or debate in the literature on this topic. Individuals had expressed concern about the lack of diabetes guidance.[1,11–13] There have been few published evidence 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.[14]

New consensus guidance was clearly needed, so the Council of Healthcare Professionals, Diabetes UK, commissioned a multidisciplinary working party led by Prof Alan Sinclair and Dr Jean MacLeod to develop consensus recommendations on the care of diabetes during end of life.[14] This work was supported by IDOP (the Institute of Diabetes for Older People), ABCD (the Association of British Clinical Diabetologists), and TREND-UK (Training, Research and Education for Nurses in Diabetes), and endorsed by key diabetes heath care professional organisations.

This work resulted in the development of:

- 'End of life diabetes care: a strategy document.'[14]
- 'Clinical care recommendations for diabetes and end of life.'[15]
- Down-loadable algorithms and flow charts, including:
  - Diabetes medication and end of life care.
  - Treatment of hypoglycaemia.
  - Steroid use[16] (developed by MacLeod *et al.* in 2010[17]).

The Neuberger Report emphasises that individualised care must be planned. The focus should be 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 health care professionals will need to be pro-active in recognising the start

- The provision of a painless and symptom-free death
- To tailor glucose-lowering therapy and minimise diabetes-related adverse treatment effects
- To avoid metabolic de-compensation and diabetes-related emergencies such as frequent and unnecessary hypoglycaemia, diabetic ketoacidosis, hyperosmolar hyperglycaemic state, persistent symptomatic hyperglycaemia
- To avoid foot complications in frail, bed-bound patients with diabetes
- To avoid symptomatic clinical dehydration
- The provision of an appropriate level of intervention according to stage of illness, symptom profile, and respect for dignity
- To support and maintain the empowerment of the individual patient (in their diabetes self-management) and carers to the last possible stage

Box 1. Main principles in diabetes care and end of life care (Diabetes UK)[14]

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 health care 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 health care 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
- Foster partnerships in end of life diabetes care with established Palliative Care planning, such as the Amber Care Bundle

Box 2. Key purposes of the diabetes and end of life guidance (Diabetes UK)[14]

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 or 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 their family and carers (Box 2).

Stages of end of life

Although written over a year before the Liverpool Care Pathway review, the diabetes specific guidance described four stages of end of life which were aligned to the Gold Standard recommendations.[8] Timeframes are colour coded for ease of use in the diabetes documentation and are in line with current recommendations depicted on page 14 of the Neuberger Report:

A. Blue – individuals with life expectancy of 12 months.
B. Green – individuals with advanced disease and life expectancy of months.
C. Gold – 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

Treatment options for insulin, non-insulin therapies and other diabetes-related medications are given and aligned to life expectancy and, where possible, when full discussion with the patient, their family or the patient's advocate has taken place. Clinical 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, where blood glucose targets are recommended in the guidance, they aim to reduce the risk of hypoglycaemia and hyperglycaemia and their associated signs and symptoms:

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

The guidance gives clear recommendation on how to tailor diabetes medication including oral and injectable therapies (insulin/GLP1s) and blood glucose monitoring to the needs of the individual, their clinical condition and preference. This included specific guidance and algorithms where:
- Renal function is deteriorating.
- The individual uses an insulin pump.
- The management of intercurrent illness.
- The management of hypoglycaemia.
- Steroid use (MacLeod *et al.*[17]).

Fluid withdrawal is not recommended unless the patient requests this.

There is discussion around the withdrawal of any treatment and acknowledgement that many factors may influence this process to include:
- The patient's wishes: remember individuals will have probably been encouraged to take all their medication and keep to 'tight' glycaemic targets all of their diabetes life, so

relaxing of 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 amount of blood glucose tests should be minimalised in the last days.
- The presence of an Advanced 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 appropriate quality driven care 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 with end of life care patients.[18]

In the light of the Neuberger Report and recommendations 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 supporting in implementing recommendations.[19]

The concept of 'end of life' care is one that is emotive and often difficult to talk about. With the development of 'Advanced Directives' and recent reports focusing on cases where patients and families may not have been dealt with sensitively, it is important that health care professionals – including those who work in diabetes – have the communication and clinical skills to help the patient experience as 'good a death' as possible. The new guidance allows for an individualised approach and so meets the requirements for matching individual patient needs and desires through end of life stages.

Dame Cicely Saunders (pioneer in hospice care) will have the last word when she tells us:

'You matter because you are you. You matter to the last moment of your life and we [health care professionals] will do all we can, not only to help you die peacefully, but also to live until you die.'

KEY POINTS

- Condition specific guidance on end of life care is now recommended
- People with diabetes have a unique set of clinical needs during end of life care
- Insulin and non-insulin treatments and glycaemic targets need to be tailored to the individual and life expectancy

Acknowledgements

– Prof Alan Sinclair.
– Dr Jean MacLeod.
– Jill Hill.
– Elizabeth Kendrick.
– Prof Angus Forbes.
– Shehnaz Jamal.

Declaration of interests

There are no conflicts of interest declared.

References

1. Rowles S, *et al.*; on behalf of the Association of British Clinical Diabetologists(ABCD). Position statement on End of Life Care. www.diabetologists.org.uk/Shared_Documents/position_papers/ABCD_Position_Statement_On_Diabetes_and_End_of_Life_Care.pdf [accessed 9 July 2013].
2. Diabetes UK. *State of the Nation 2012*. www.diabetes.org.uk/state-of-the-nation-2012.
3. Jougla E, *et al.* Death certificate coding, practices related to diabetes in European countries. In *The European Observatory on Health Systems Policies Series. Caring for people with chronic conditions: A health system perspective*. Nolte E, Mckee M (eds). 2010. www.euro.who.int/__data/assets/pdf_file/0006/96468/E91878.pdf.
4. General Medical Council. *Treatment and care towards the end of life: good practice in decision-making*. 2010. www.gmc-uk.org/static/documents/content/End_of_life.pdf [accessed 10 July 2013].
5. Liverpool Care Pathway. www.mariecurie.org.uk/en-GB/Commissioners-and-referrers/Partnerships-and-innovations/liverpool-care-pathway/ [accessed 5 Nov 2013].
6. Neuberger J. *More care, less pathway: A Review of The Liverpool Care Pathway*. 2014. https://www.gov.uk/government/uploads/system/uploads/attachment_ data/file/212450/Liverpool_Care_Pathway.pdf [accessed 29 Sept 2013].
7. The Mid Staffordshire NHS Foundation Trust. 2013. Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry. www.midstaffspublicinquiry.com/sites/default/files/report/Executive%20summary.pdf [accessed 29 Sept 2013].
8. The National Gold Standards Framework Centre (GSF) in End of Life Care. 2006. www.goldstandardsframework.org.uk/cd-content/uploads/files/General%20Files/Prognostic%20Indicator%20Guidance%20October%202011.pdf [accessed 29 Sept 2013].
9. Guy's and St Thomas' NHS Foundation Trust. *The Amber Care Bundle: A guide for patients, their relatives and carers. 2012*. www.ambercarebundle.org [accessed 29 Sept 2013].
10. Palliative care in Wales. 2010. http://wales.pallcare.info/index.php?p=sections&sid=11 [accessed 29 Sept 2013].
11. Kerr D. Diabetes at the end of life. 2009. www.bgs.org.uk/Publications/powerpoints/spring09/kerr_diabetes.pdf [accessed 10 July 2013].
12. Royal College of Nursing. Diabetes – end of life care. 2013. www.rcn.org.uk/development/practice/diabetes/specific_contexts_and_populations/palliative_and_end_of_life_care [accessed 10 July 2013].
13. Vandenhaute V. Palliative care and type II diabetes: A need for new guidelines? *Am J Hosp Palliat Care* 2010;27:444–5.
14. Diabetes UK. End of Life Diabetes Care: a strategy document commissioned by Diabetes UK. 2012. www.diabetes.org.uk/upload/Position%20statements/End%20of%20Life%20Diabetes%20Care%20Stategy.pdf [accessed 29 Sept 2013].
15. Diabetes UK. *Diabetes and end of life care: clinical care recommendations*. 2012. www.diabetes.org.uk/upload/Position%20statements/End%20of%20Life%20Diabetes%20Care%20Clinical%20Recommendations.pdf [accessed 29 Sept 2013].
16. Diabetes UK. *End of Life diabetes care commissioned by Diabetes UK. Supplementary documents*. 2012. www.diabetes.org.uk/upload/Position%20statements/End-of-life-Supplement111113.pdf [accessed 29 Sept 2013].
17. MacLeod J, *et al.* Diabetes in Palliative Care Guidelines. 2012. www.hartlepool.nhs.uk/includes/documents/About_Us/Prescribing_Guidelines/Palliative_care_diabetes_guidelines_2010_FINAL.pdf [accessed 10 July 2013].
18. TREND-UK. *An Integrated Career and Competency Framework*, 3rd edn. www.trend-uk.org/documents/TREND_3rd.pdf [accessed 4 Nov 2013].
19. Tapley M, Needham E. Improving end of life care for people with diabetes. *Pract Diabetes* 2012;29:306–7a.