July 2012: in recognition that end of life diabetes care lacked quality standards, Diabetes UK commissioned ‘End of Life Diabetes Care: A Strategy Document’.1 After a review of the published literature, which identified that there was little published evidence to demonstrate a preferred or effective approach to diabetes care at the end of life, it arrived at core principles (see Box 1).

The Strategy then identified the key features of an end of life diabetes care pathway including its integration into the Liverpool Care Pathway of the Dying2 and the role of primary care, community diabetes teams, specialists and hospice care. Management goals and quality standards were also identified. It acknowledged that the lack of education and training in end of life care is a striking feature among those health care workers delivering diabetes care both in the hospital and community.3

April 2013 and onwards
In April 2013, Willow Wood Hospice4 joined with Tameside and Glossop Clinical Commissioning Group5 to organise a workshop to discuss the Strategy Document and ascertain the strengths and weaknesses of its guidance, and whether it was fit for purpose to help improve quality end of life care for our patients with diabetes. Twenty health care professionals representing the hospital, hospice and community teams met at Ashton Town Hall6 under the banner ‘A Celebration of All Things Palliative in Tameside and Glossop’.7 This provided a novel concept for specialists in diabetes to meet with palliative colleagues. As we had hoped, this enabled a considerable interchange of ideas. It has already reaped the benefit of initiating training sessions at the hospice from community diabetes nurses, and increased confidence among hospice staff to seek advice when patient need arises.

There was considerable praise in the workshop in recognition that the Strategy had been produced at this time. It emphasises the importance of multidisciplinary working and the key position of the diabetes team in providing advice as end of life approaches. It builds on the longstanding professional relationship that diabetes teams may have with the patient and their family while living with and managing diabetes for many years. The Strategy was examined by groups from each health care setting to discuss the relevance of its recommendations to the delivery of end of life care for patients living with diabetes in our locality.

In primary care, where many patients approaching the end of their lives are placed on the Gold Standards Register,8 monthly review meetings with the GP give an opportunity for diabetes care to be discussed within the context of the patient’s increasing frailty and changing scope of activities of daily living, energy requirements and dietary intake. It was identified that training might be offered to some GPs, especially as in some practices day-to-day management advice has been devolved to practice and district nurses, rather than being under the direct control of the doctor, contributing to a lack of confidence in diabetes management by the GP. There were particular concerns about the willingness of health care professionals from all backgrounds to address the communication issues inherent in discussing changing or stopping medication towards the end of life, especially as goals of therapy shift from rigid blood glucose measurement and control to a more flexible approach. The avoidance of unpleasant hypo- and hyperglycaemic episodes and providing comfort measures is more appropriate when life is expected to be short and the long-term sequelae of the metabolic and vascular consequences of diabetes are no longer relevant to the patient’s anticipated life expectancy.

Our community diabetes teams disagree with the Strategy Document’s recommendations about the timing of referral of a patient to specialist consultant care. The document identifies diabetologists (and we presumed these to be diabetes consultants) or diabetes health care teams as the providers of specialist care. In many parts of the UK, the splitting of service provision between hospitals and the community was thought to cause confusion and uncertainty about responsibility for management. Specialist skills should always be available in the community beside the patient especially when complex treatment decisions, such as commencing steroids or changing insulin regimens, including withdrawal of glucose lowering therapies, are being considered. These specialist skills should not be the preserve of hospital consultants, but, through training, many members of our multidisciplinary team can be equipped to manage what were previously identified as complex treatment issues.

Box 1. Core principles of the July 2012 Strategy Document1

- 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 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
While hospital admission may be required for diabetes-related emergencies such as hyperosmolar hyperglycaemia, in general, hospital admission should be avoided in those coming to the end of their lives as it may cause further anxiety, especially if the patient’s preferred place for end of life care is in their own homes.

Hospice staff agreed with the Strategy Document that referral of a patient for hospice inpatient admission should be considered when they have complex palliative needs such as pain and other symptoms, but we felt that hospice care was only appropriate when symptoms could not be adequately managed in the community. It was not thought that hospice admission was appropriate simply because ‘no nursing home is available’ (as suggested in the Strategy) as the specialist palliative skills in a hospice should remain available for those with complex needs, rather than the hospice being used to accommodate those for whom social care has not been provided in the community.

Hospices also provide ‘Day Hospice’ which can offer short episodes of care to address specific symptoms as well as psychological support to encourage patients to live to the full. This may also help patients gain the confidence to consider making advance care plans about where they might like to spend their last days if and when their condition impacts more on the quality of their lives and frailty supervenes. There was comment from our hospice team that further contribution from palliative care specialists to the diabetes Strategy might improve the description of how hospices may best serve patients during the different phases of their individual end of life trajectories.

**July 2013: ‘More care, less pathway’**

One year after publication of the Strategy, in the light of concerns raised in the media over many years, the Independent Review of the Liverpool Care Pathway (LCP) ‘More care, less pathway’, chaired by Baroness Julia Neuberger, made strong recommendations for changes in the practice of caring for the dying. While they reported that when the LCP was operated by ‘well trained, well resourced and sensitive clinical teams, it worked well’, they also said that some of the stories the panel had heard had much in common with the complaints that led to the Mid Staffordshire Public Enquiry. There were particular concerns about the situation in acute hospitals, and that: ‘Where care is already poor, the LCP is sometimes used as a tick-box exercise, and good care of the dying patient and their relatives or carers may be absent.’ When considering terminology, the Review recommends that the term ‘pathway’ should be avoided, and instead the term ‘end of life care plan’ is suggested.

So where does this leave ‘End of Life Diabetes Care: A Strategy Document’? Integration into the LCP is a key feature of the End of Life Diabetes Care Pathway, and now that the Review has made its recommendations, including avoidance of the term ‘pathway’, the Strategy Document will clearly require adjustment in language at the very least.

While the Review recommends that the LCP should be replaced ‘over the next six to 12 months by an end of life care plan for each patient, backed up by condition-specific good practice guidance’, is there sufficient emphasis within the End of Life Diabetes Care Strategy to ensure individualisation of patient care and avoidance of tick-box approaches? When caring for people with diabetes there may already be tendencies, perhaps over a lifetime of treatment, to manage numbers – the blood glucose, the HbA1c etc – rather than seeing these, and any desired outcomes of treatment, within the holistic personal psychological and emotional landscape in which we individually live. Perhaps the Review itself could be criticised for recommending a care plan backed up by ‘condition specific guidance’ – surely this should be ‘patient specific guidance’ with the illness playing second fiddle to the advance care plans of those who may be about to die.

**Now: no tick-boxes, but patient-centred care?**

‘More care, less pathway’ states that formal independent prospective testing of the LCP has not yet been carried out after nearly 10 years of its dissemination which is ‘a major cause of concern’. This is despite the Department of Health publishing generic quality care standards in the End of Life Strategy of 2008.13 The diabetes Strategy identifies that end of life is a complex period of health care and that management of diabetes varies significantly between individuals, and at different phases in a person’s progression to death. It also emphasises that the end of life trajectory is varied, with some experiencing ‘a rapid, curvilinear decline while others may experience a more gradual decline with intermittent periods of improved health’. Even variation of patient experience, whether they are at home, hospital or hospice, is also stated.

Here lies the rub – while the Review has criticised a lack of individualisation of care in the LCP and a tendency to tick-box approaches, sadly the diabetes Strategy contains even larger boxes which categorise treatment approaches based on predicted life expectancy despite recognition that the art of prognostication is always a fine judgement when caring for people coming to the end of their lives, including patients with diabetes and multiple comorbidities. We wonder if this may lead to a cohort-based approach to care rather than the individualisation which it strives to achieve.

Management towards the end of life necessitates seeing past the diabetes and allowing the natural death of a person who is coming to the end of a life living with diabetes. They and their family should be offered the support they wish for, whether they are in their own homes, care homes or hospital, with appropriate person-centred care.

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**Declaration of interests**

There are no conflicts of interest declared.

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