

Palliative care and diabetes: Making the most of the end of life

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In clinical practice, many people with diabetes also have other co-morbidities. The challenge for clinicians, and for their patients, is to jointly manage all aspects of their care as well as possible. This article focuses on the management of palliative care and diabetes, and the priorities of diabetes care at this stage of life. Glycaemic targets and control, treatment regimens and the avoidance of acute complications are discussed, as well as the organisation of services in terms of the quality of diabetes care and the systems that deliver it. Finally, case studies are used to demonstrate the difference in quality of care between proactive and reactive organisation.

The verb palliate, according to the Collins dictionary, means to lessen the severity of (something), without curing it. This definition hints at the breadth of palliative care, as there are many examples in clinical practice of conditions that cannot be cured but can be made less severe. Prime examples include long-term conditions, such as diabetes, heart failure and motor neurone disease, as well as the commonly associated condition of cancer. However, in clinical practice, an important decision to be made is when care becomes palliative, rather than active, and this can obviously vary depending on the individual. Clearly, good communication between the person with the condition, his or her family, and clinicians is paramount, which requires planning and time to do safely and well. It also requires inclusion and collaboration with other non-diabetes clinicians, who may have been the initial team managing care, and who require diabetes

specialist advice for the effective management and coordination of diabetes care.

Organisation of diabetes services

People with diabetes, at every stage of their journey, may travel unknowingly across organisational boundaries between primary, secondary, tertiary and intermediate care. Help is thus needed to navigate these systems, and fundamental to this navigation is the clarity of clinical responsibilities in order for patients to be seen at the right time, by the right person, in the right place. Diabetes has a long history of service redesign, linking with other services and specialities in primary, secondary and tertiary care. With these experiences, diabetes services should be able to respond to the needs of the person requiring palliative care. However, to ensure this happens, the coordination of services is paramount, along with the clarity of care pathways. This has been recommended by NHS Diabetes in its document on commissioning

Article points

1. In clinical practice, the decision for whether a person with diabetes should undergo palliative care is important and one that is highly dependent on the individual.
2. Numerous components of palliative care, including glycaemic control, treatment regimens and acute complications, are discussed.
3. The author describes two case studies, which demonstrate the need for early referral, education and discussion of diabetes outcomes, and service design for palliative care.

Key words

- Collaboration
- Organisation
- Palliative care
- Quality of life

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Page points

1. The coordination of services is paramount, as recommended by NHS Diabetes (2010) and Hughes-Hallett (2011).
2. Diabetes and palliative care services need to coordinate and collaborate in order to improve the quality of life for people with diabetes and their families.
3. The author obtained funding to employ an additional DSN, who provided the necessary support and training in the local hospice to improve diabetes care.

diabetes and end-of-life care services, and the palliative care funding review (NHS Diabetes, 2010; Hughes-Hallett et al, 2011).

Commissioning diabetes end-of-life care services

NHS Diabetes has outlined the key features of good diabetes end-of-life care and provides a high-level intervention map to describe clinical and administrative interventions for the most effective and efficient care from admission to discharge (or death) from the service. This is not intended to be a care pathway or clinical protocol, but to simply describe how “diabetes without walls” should operate across different sectors in health care (NHS Diabetes, 2010).

The aim of the document was to bring together all the key standards of quality and policy relating to diabetes and end-of-life care. It includes a standard service specification template for diabetes end-of-life care services that requires a flow diagram of the patient’s journey. Importantly, it also requires ownership and accountability, with a definition of who provides the service, how it is provided, the hours of operation, and the training and experience required. What will be provided is another requirement, which also includes referral criteria, as well as an identified co-ordinator of care.

Palliative care funding review

The palliative care funding review commenced in July 2011, with the intention of unpicking the current confusing system, where it is difficult to obtain care, support or choice (Hughes-Hallett et al, 2011). The overall aim was to create a fair and transparent funding system, deliver better outcomes for people with diabetes and provide better value for the NHS. It recommends that every clinical commissioning group maintains an end-of-life locality register. It acknowledges that many people are admitted to hospital to die. The Quality, Innovation, Productivity and Prevention (QIPP) programme has estimated that it costs as much as £3000 per hospital death, suggesting that approximately £180 million of hospital costs could be saved if a better alternative is used (Hughes-Hallett et al, 2011). Hospital admissions in the last year of life for adults cost

the NHS a total of approximately £1.3 billion (Hughes-Hallett et al, 2011). In addition to the huge financial implications, it is simply not the best place to die. This funding review reinforces both the NHS Diabetes commissioning document and clinical experience, demonstrating the necessity for coordinated diabetes and palliative care services, in order to improve the overall experience for people with diabetes and their families.

Local experience and rationale for change

Within diabetes and palliative care services, there have been numerous examples reported of poor care, management and delayed referrals, indicating an urgent need for review and improvement. It has been recognised that earlier specialist intervention is needed for people with diabetes, whether they are at home, in the hospice or in the hospital, and networks are needed to enable this to happen. Fundamental to these networks and service improvements is the closer liaison and shared learning between palliative care teams, surgical teams, medical teams and the diabetes specialist teams. For instance, the author successfully obtained funding from the primary care trust to employ an additional DSN, who provided support and training in the local hospice as one of her responsibilities. It was believed that via the education of the hospice staff, the quality of life for the people with diabetes could be improved.

Clinical priorities for diabetes management and care

Clearly, it is important that the diabetes service is organised to enable communication and joint management, but the ability of the clinicians to assess and plan care, based on evidence and specialist skills, is equally important. End-of-life care is assumed for a terminal diagnosis of cancer, but this can also apply to stroke, heart failure, renal disease or unrelated co-morbidities. Irrespective of the reason for end-of-life care, clinical discussions should focus on the needs and wants of the person with the condition, as well as the nature of the condition itself. Current and potential symptoms and side effects also need to be included in discussions

to provide a comprehensive care plan that is agreed and communicated to carers. This is where inter- or intra-professional liaison is key.

Glycaemic targets and control

Adapting targets to the current situation and prognosis for the person with diabetes is imperative, for which HbA_{1c} treating to target is now considered irrelevant. However, checking blood glucose levels can be useful in identifying trends initially and confirming the effects of treatment changes, so should be used when appropriate. Both renal and liver function are likely to deteriorate so diabetes medication should be reviewed regularly, and stopped and changed as appropriate, in order to reduce risk of side effects.

Reviewing treatment regimens

Treatment should also be reviewed when there is any change in dietary intake, as this will also affect blood glucose levels and increase the risk of acute complications, such as diabetic ketoacidosis, hyperosmolar hyperglycaemic state or hypoglycaemia. Changes in dietary intake may be attributed to a lack of appetite, difficulty swallowing or chewing, nausea or vomiting, or changes in conscious level or pain. Enteral feeding and steroids will also affect blood glucose levels, prompting treatment monitoring and review.

In addition, treatment changes are influenced by the wants of the person with diabetes and the resources available, which will vary depending on whether treatment is in the setting of a hospital, home or hospice. However, all contraindicated drugs for renal and liver complications should be stopped and replaced with safer alternatives. Sometimes starting insulin treatment is considered appropriate, particularly basal as a background or bolus used when eating (or both), which allows flexibility. The primary aim is to relieve the person's symptoms, and improve his or her comfort and safety.

Preventing acute complications

Diabetic ketoacidosis can be a fatal consequence of type 1 diabetes, owing to insufficient levels of insulin. This can be avoided by continuing

insulin treatment for people with type 1 diabetes, even when their appetite is poor, using reduced doses or an adapted regimen. Blood glucose and ketone monitoring ensures safety and symptom relief, yet also enables the intake of favourite foods and fluids to be encouraged. If hyperglycaemia persists, it is worth reviewing treatment and diet concordance, adjusting treatment according to safety, and considering whether treatments, such as steroids, to improve appetite are necessary. The same process should be applied when there is evidence of hypoglycaemia, as it can sometimes be attributed to a reduction in food intake or variations in the timing of food intake. If the person is being treated with insulin, the injection technique should be reviewed and the food choices possibly relaxed to reduce the risk of hypoglycaemia. Hypoglycaemia treatment should be available and used promptly.

Cases from clinical practice

This article discusses two cases, which serve to illustrate the difference that planned, organised care can make to patient and family experience versus reactive care.

Case study 1

Julia was diagnosed with cancer of the pancreas and underwent insulin treatment. She managed well, reduced her HbA_{1c} levels to 60 mmol/mol (7.6%) and went back to part-time work. It was observed that she was supported by her husband and daughter, but was not regularly followed up by a DSN or specialist team and was seen infrequently in practice, generally only when she felt unwell. Julia was admitted to a surgical admissions unit with abdominal obstruction. She was dehydrated (despite treatment with intravenous fluids *in situ*), cachexic and hyperglycaemic (her blood glucose was 22–28 mmol/L over the past 3 days) She was semi-conscious and in pain, and her insulin treatment was halted the day following admission. She was under the care of the palliative care team alone; the diabetes team had not been involved in her care and an inpatient DSN found Julia by chance.

Immediately, the DSN re-started her insulin treatment to reduce her hyperglycaemia and

Page points

1. It is important to review and adapt glycaemic targets according to the current situation and prognosis of the individual.
2. Treatment regimens should be reviewed regularly, particularly if there are any changes in dietary intake.
3. The appropriate treatments should be available for the prevention of acute complications.

“As with the aspiration to provide people with diabetes a good quality of life, there should also be a focus on the aspiration to provide a quality of death.”

symptoms (she was on a basal–bolus regimen), and blood glucose monitoring was increased as was the level of insulin dosage accordingly. This was identified as a clinical incident after which there was a multidisciplinary discussion, amongst the ward, palliative care and surgical teams, regarding the need to continue with insulin even in the terminal phase, and the need for early DSN involvement. It was clarified that using insulin was required to resolve the symptoms, rather than achieving tight control. The need for the diabetes and palliative care specialist nursing teams to work more closely together was identified.

Julia appeared to become more energetic and less sleep-deprived as her blood glucose levels improved. Her basal–bolus regimen accompanied her to the local hospice, where there was communication between the hospice team and diabetes specialist team to adjust her doses, and she died peacefully with her family. The author notes that had she not been found by chance, this would perhaps have been an unlikely outcome.

Case study 2

Contrasting with Julia, Anthony’s story demonstrates what can be achieved with early intervention and planning. Anthony was referred to the diabetes specialist team from the medical day case unit where he was about to start chemotherapy for lymphoma. He had been diagnosed with type 2 diabetes for 15 years and was taking metformin (2 g) once daily and gliclazide (160 mg) twice daily. He had severe side effects from the chemotherapy, including nausea and vomiting. Steroids increased his blood glucose levels, and his mouth was sore owing to ulcers and oral thrush, making it

difficult and painful to eat or take tablets. He was observed to lose his appetite and become exhausted. His treatment was changed to a basal insulin with a bolus insulin when eating or when his blood glucose was >10 mmol/L. He also had injectable anti-emetics and his oral thrush was successfully treated.

Anthony gained remission and had two more chemotherapy treatments, returning to oral treatments in between courses. Six months later, he relapsed and the treatment options were limited, after which followed the route of palliative care rather than active care. As he felt weak and tired, and unable to take tablets again, he returned to his basal–bolus insulin regimen. He lived alone and was admitted to the local hospice with access to the diabetes specialist team for advice.

Conclusion

Such cases highlight the need for the clinical skills of DSNs in many settings and demonstrate a number of key points to consider (see *Box 1*). It is clear that with planning and collaboration, adequate diabetes expertise can be provided when and where needed. As with the aspiration to provide people with diabetes a good quality of life, there should also be a focus on the aspiration to provide a quality of death. ■

Hughes-Hallett T, Craft A, Davies C (2011) *Palliative Care Funding Review: Funding the Right Care and Support for Everyone*. NHS National End of Life Care Programme, Leicester. Available at: <http://bit.ly/Q1MOGU> (accessed 06.09.12)

NHS Diabetes (2010) *Commissioning Diabetes and End of Life Care Services*. NHS Diabetes, Leicester. Available at: <http://bit.ly/RoykNc> (accessed 06.09.12)

Box 1. Key points demonstrated by Case studies 1 and 2.

- Early referral enables planning, ongoing contact and review with diabetes specialist teams.
- Education and discussion of diabetes outcomes, particularly symptom relief and patient safety, is vital with non-diabetes clinicians.
- Service design around this part of a person’s life with diabetes is important, and enables collaboration and improved patient experience and safety.