



ABCD position statement on diabetes and end of life care

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Introduction

Approximately half a million people die in the United Kingdom each year, of whom more than three-quarters are aged 75 years and over. Calculations based on the prevalence of diabetes indicate that 6–9% of those dying will have diabetes. In ethnic minority groups the prevalence will be significantly higher and in all groups the majority will have type 2 diabetes. Accurate data on the incidence of diabetes as a contributory factor to death are not available due to the vagaries of death certification.

Excellent end of life care (EOLC) strategies such as the Liverpool Care Pathway for the Dying Patient are already in routine use. The aim of this position statement is to augment such EOLC tools with guidance specifically related to people with diabetes, their families and carers. Outside the scope of this statement are issues relating to the use of advance directives (although patient autonomy and choice are paramount at all times), preferred models of palliative care services to support patients with diabetes, and referral criteria for hospice care.

Historically, the diabetes community has pioneered a patient-centred approach to care but the care of the dying patient with diabetes has been neglected and needs to be incorporated into our practice. Sensitive and timely sharing of information around the potential impact that diabetes can have both on quality and quantity of life is important, and open discussion with user groups will be of major importance so that dying

patients can be truly empowered in their decision making.

The multidisciplinary diabetes team (MDT) will need to be proactive in recognising the onset of a patient's terminal decline in health, and liaising with the appropriate EOLC services. Conversely, those providing EOLC should ensure that the diabetes team is aware of the patient so that specialist guidance on the management of diabetes can be provided. EOLC services are focused on high quality end of life care, symptom management and the provision of psychosocial support with an agreed set of criteria to identify those who require urgent palliative care support worker responses in different situations, e.g. unresolved pain, rapid discharge from hospital or care breakdown at home.

Glycaemic control at the end of life

When palliative care is instituted there are several elements of particular relevance to those with diabetes. Unnecessary tests such as frequent blood glucose monitoring and complex insulin regimens are burdensome and should be avoided. An intervention required during relative health may not be indicated for the dying, with the caveat that patient preference is always of overriding importance.

Patients, families and carers will often have spent many years striving for tight glycaemic control in an attempt to reduce the risk of long-term complications. They may find it difficult to understand that, when the end of life is imminent, maintenance of strict euglycaemia can be detrimental

to quality of life and the avoidance of long-term complications becomes an irrelevant goal. Both patients and carers may require sensitive counselling from members of the MDT to explain the shift in glycaemic goals.

Nevertheless, it is important to maintain adequate control to enhance comfort by preventing hyperglycaemia-induced thirst, dehydration, confusion, drowsiness and symptomatic hypoglycaemia. Many elements presenting at the end of life predispose to alteration of glycaemic control; hyperglycaemia may result from, for example:

- The stress response to severe illness.
- Disturbance in glucose metabolism caused by certain malignant tumours.
- Use of steroids for symptom relief.
- Co-existent infection.

The insulin requirement may be reduced, with the consequent risk of hypoglycaemia as a result of, for example:

- Weight loss.
- Anorexia leading to malnourishment.
- Renal and/or hepatic failure.

Oral hypoglycaemic agents may no longer be required and the involvement of an experienced dietitian can be invaluable for those with poor food intake.

Dying with diabetes

In many instances, diabetes is a comorbidity in patients with a terminal illness such as cancer. Treatment regimens should be tailored to each individual by those with appropriate skills, in consultation with the patient

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and their carers. Certain diabetes-related symptoms/complications may be exacerbated in those with terminal illness, for example:

- Pain (combination of neuropathic and bone pain).
- Constipation (combination of autonomic neuropathy and opiate-induced effects).
- Fatigue (effects of hyperglycaemia and malignancy).

Recommendations

The aim should be to avoid symptomatic hyper- and hypoglycaemia with a minimum of blood glucose monitoring. A target range for blood glucose of 5–15mmol/L is appropriate and detailed treatment algorithms are best avoided. Early involvement of the specialist diabetes team for individualised advice is advocated.

Type 1 diabetes

This is a disease of absolute insulin deficiency; therefore insulin withdrawal is likely to lead to death. Unless a patient is entering the final phase of life (embarking on the EOLC pathway) we would recommend the continuation of insulin with the regimen simplified wherever possible unless the patient specifies otherwise. Suggested options are:

- Twice-daily fixed mixture.
- Twice-daily isophane insulin.
- Once-daily long-acting analogue.

If a mentally competent patient requests withdrawal of their insulin, this should be respected. Blood glucose monitoring should be kept to a minimum (once or twice daily).

Type 2 diabetes

Insulin-treated patients with type 2 diabetes without symptomatic hyperglycaemia may be able to discontinue insulin. Should the individual become symptomatic, a simple insulin regimen can be reintroduced such as once-daily long-acting insulin analogue or twice-daily isophane.

Tablet-treated patients may also be able to discontinue treatment as a reduction in food and fluid intake leads to lower blood glucose levels and may increase the risk of hypoglycaemia. Blood glucose monitoring should not be performed in these patients unless there are plans

to adjust treatment based on the blood glucose results or it is the patient's preference.

Patients with diabetes taking corticosteroids

High dose steroids may be prescribed for symptom relief. Depending on the frequency of dosage, patients may experience a rise in blood glucose 2–3 hours after steroids are given, returning to baseline levels about 12 hours later. A single injection of isophane insulin given with the steroids is often sufficient to avoid symptomatic hyperglycaemia. Involvement of the specialist diabetes team is recommended if more complicated insulin regimens are required.

Dying from diabetes

Although life expectancy for people with diabetes is increasing, many will die prematurely as a result of diabetes-related end organ failure. The subject of proximity of death is rarely broached with individuals suffering severe complications of diabetes, thus denying them the chance to express their wishes for end of life care. Identifying individuals who are entering their last 6–12 months of life is difficult both medically and emotionally, and health care workers need to examine the reasons why they may shy away from these emotional encounters. There are some well recognised generic indicators of poor prognosis of which those working closely with patients with diabetes should be aware so that appropriate discussion and care planning can be initiated. These include the presence of:

- Multiple co-morbidities.
- Non-intentional weight loss of >10% over six months.
- General physical decline.
- Serum albumin <25g/L.
- Dependence in most activities of daily living.

Diabetes-specific modes of death

This position statement does not cover the specific modalities of death that occur with an increased frequency in those with diabetes because, by definition, they cannot be anticipated and therefore an EOLC strategy is not appropriate. However,

knowledge of their existence may help those dealing with the bereaved in the aftermath of the death of a patient with diabetes. Both 'Dead in Bed' syndrome and sudden in-utero fetal death, although rare, are more common in people with diabetes; the exact aetiology in both cases has yet to be established.

Conclusion

As the population of the UK ages and the incidence of diabetes rises, more individuals will be reaching the end of their life with co-existent diabetes. In the words of Prof J Saunders, diabetologist and ethicist: 'Dying patients should receive care that offers comfort, dignity and freedom from distressing symptoms as far as these are possible.' That includes those with diabetes for whom the aim should be to keep the blood glucose within a range which will avoid symptoms while reducing invasive tests, such as blood glucose monitoring, to a minimum. This position statement offers some guidance for the management of diabetes during the end stages of life and hopes to trigger discussion within the multidisciplinary diabetes teams relating to their role in EOLC. The MDT should engage with user groups and primary and secondary care colleagues to enhance the provision of end of life care for patients with diabetes for whom we are both carers and advocates.

Conflict of interest statement

There are no conflicts of interest.

Key references

Websites

Readers can go to the following websites and retrieve information on end of life care in diabetes:

- www.diabetes.org.uk.
- www.diabetes.nhs.uk/commissioning.

Publications

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