

Why we can't leave end-of-life discussions too late



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Diabetes UK (2018) *End of life diabetes care: Clinical care recommendations*. Diabetes UK, London. Available at: <https://is.gd/bqUCPP> (accessed 10.04.18)

Dunning T (2018) Palliative and end-of-life care: Essential aspects of holistic diabetes care. *Journal of Diabetes Nursing* 22: JDN015

The *Journal of Diabetes Nursing* article by Trisha Dunning (2018) demonstrates the relevance of end-of-life care to people with diabetes, given their increased mortality and morbidity compared to the population without diabetes. Trisha aptly describes the diabetes journey as following an expected chronic disease pathway, and thus raises important issues. She points out that lifespan will be generally shorter, and because of this – and despite acute episodes – there must still be opportunities found to discuss what the person wants to happen to them before they die.

Leaving the discussion until the person is deteriorating prior to death is obviously too late. Earlier, proactive discussions are important because the person and their family have more time, and so are less pressured into decisions. The person may also feel more capable of making informed decisions at this point, and thereby feel greater control over their care. Their family can feel confident that they fully understand and support the individual's wishes. So what is the reality in our current practice?

Clinicians in general do not always discuss end-of-life care proactively; even when able to do so, patients do not always bring this up and some may be so acutely unwell that it is not possible to have a conversation. Yet this is exactly the time when the person's wishes, if known, can be acted upon and form part of his or her care plan. This has been my experience working in the acute hospital setting; lack of personal wishes mean that futile attempts at resuscitation can be made, distressing families and everyone involved. On reflection, this is not what most of us would want for ourselves or our families, yet it could be avoided if opportunities were taken to proactively discuss an end-of-life plan.

I had a positive experience when a family member was admitted to our hospital with exacerbation of her heart failure. She was elderly (92 years old) and adamant that she had had a good life and did not want to be resuscitated if her heart stopped. She wanted treatment to make her comfortable but not

lengthen her life. She was reassured that her wishes were documented and had been communicated to both her clinicians and her family. She died peacefully in our hospital 3 weeks later, with all her wishes followed and free from pain. We were confident of what she wanted, so acted accordingly, even when she could not act for herself. As a result, we all have positive memories of her life. Without prior discussion with her, we would have been uncertain of what we should do, and both clinicians and family members would have been robbed of peace of mind.

This is what clinicians deny families if we do not discuss an end-of-life plan as soon as is appropriate. We are very fortunate to have some excellent guidance in the recently updated consensus statement, *End-of-life diabetes care* (Diabetes UK, 2018). This document guides us in the best treatment options and changes as people progress along the disease pathway. This is most useful for us to share with non-diabetes clinicians, as it explains the rationale for withdrawing treatment, reducing monitoring and not initiating insulin, with the aim of reducing osmotic symptoms, reducing the risk of hypoglycaemia or diabetic ketoacidosis, and improving quality of life. These issues must be discussed with our patients and their families at the earliest possibility, as it is possible that our actions could be misinterpreted as a reduction in good care, or simply not caring at all.

Trisha Dunning's research informed her article and the consensus statement, and both emphasise the importance of including end-of-life planning as part of the care journey for the person with diabetes and his or her family. Trisha aptly finishes her article with a quote from Dame Cicely Saunders:

"The way people die remains in the memory of those who live on."

It certainly does. This is something we should all remember when it comes to caring for a person with diabetes at the end of life. ■