

We must support rather than stifle the expert patient

People with diabetes who require insulin have a long tradition of being actively involved in their treatment and are in effect the expert patient. These individuals have had to work hard to develop their self-care management strategies and achieve that ever-elusive “target” glycaemic control; they can never escape their diabetes! The savvy patient has usually undertaken hours of structured education, had opportunities for self-experimentation, performed many internet searches and is probably very knowledgeable about technology.

Healthcare propaganda states people should take responsibility for their own health. So why do professionals and our healthcare systems stifle our well-informed patients? The problem seems to “rear its ugly head” when official policy is not flexible enough to allow self-care, yet it allows healthcare professionals who are not experts to meddle with the savvy patient’s diabetes. Staff members typically believe that they know best and take a paternal approach to the patient, in effect taking over. On admission to hospital the assumption is made that the patient has consented to professionals taking over all aspects of his or her care. The savvy patient must therefore defend his or her case for self-care. Those who show clinical knowledge often experience disbelief or even opposition from the professionals. The best that can be hoped for may be a visit from the diabetes team, who can advocate for them.

Policies usually dictate that staff are in control and patients cannot have independent access to their own insulin, calculate insulin doses or use their own blood glucose monitors. The fact that the expert patient makes these decisions on a daily basis using their equipment does not matter. Rather ironic given that in diabetes clinics and during phone consultations, complex decisions are made using information provided by the patient.

Patient safety is the argument for the non-diabetes specialist taking control. The implications are that

staff members act in the patient’s best interests. If I was being cynical, I would suggest the driver is the prevention of litigation rather than safety. Inappropriate changes in treatment are often made, which cause stress and potentially harm the patient. Not surprisingly, therefore, individuals with diabetes have a longer average hospital stay than people without the condition.

Conflict between policy and practice

Many hospitals claim to allow patients to manage their own diabetes whilst an inpatient; however, the reality is often different. Assessments and complex time-consuming forms need to be completed. All rather ironic given that the savvy patient usually knows more about their own diabetes and its management than the member of staff designated to assess them!

Consideration and collaboration are key. I am not so naïve as to believe that all patients can take responsibility for all aspects of their diabetes, and of course there will be times when even the savviest patient needs to surrender his or her self-care to the clinicians. In these situations, diabetes management is regimented, with the administration of fixed doses of insulin. If the savvy patient’s knowledge and experience were considered in a more structured way, however, a different type of care system could evolve where outcomes could be improved. Patients who want to be autonomous should be supported to do so, and individuals who need more support would benefit from redirection of resources.

The answer is simple. Start trusting patients. Allow the savvy patient to routinely take responsibility for his or her own healthcare without interference, remind hospital officials that policy is not supported by common law and devise policy that reflects the NHS banter of working in partnership with patients. The outcomes will be so much better if both sides collaborate. ■



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