

Enabling informed choice: Replace paper-based records?



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The *National Service Framework for Diabetes: Delivery Strategy* (Department of Health [DoH], 2003b) exhorted us to provide people with diabetes with more information in the shape of personal diabetes records (commonly referred to as 'patient-held records'). These, it said, should comprise an agreed care plan, with information on treatment, test results and agreed management goals (note: goals agreed with the person with diabetes, not agreed new General Medical Services contract indicators), as well as a record of review dates, identified needs and named contacts. You may have these in place. If you do, and well done you, they will probably be in paper format.

Yet 'users' (that's people with diabetes to you and me) at a recent Transforming Chronic Care Programme (see www.tccp.nhs.uk [accessed 15.06.2006] for more information) meeting I attended could not see the benefit of holding copies of their own investigations and care plans. Most felt this information was needed by health professionals, not themselves. Many were against the idea of personal records, citing accidental loss of the record and possible breach of confidentiality should it be read by someone else if it were in paper form. They didn't see them as self-education items.

Empowerment became the goal of patient care some years ago. We can encourage 'empowerment', for example through the use of such personal records, only if individuals are willing to participate in the process and only if systems are in place to address their concerns.

Care provision must change

We should be becoming increasingly aware that we cannot afford to continue to provide diabetes care in the same way as in the past. The number of people with diabetes is rising sharply, people with diabetes are living longer and they are requiring more services. Have you noticed a matching rise in healthcare resources? Or an increase in the amount of our time devoted to diabetes care?

We see each person with diabetes for around 3 hours per year, if that. We need to involve people with diabetes in their own care because, quite frankly, we cannot afford to do it for them. And nor should we. In my opinion, telling someone what to do is not productive, never has been, and never will be.

However, we do need to make those 3 hours count. We need to engage people with diabetes in making informed decisions about their care. We need to educate. We need to provide the tools for them to do the job.

We're not alone in finding changes to traditional health care challenging. I recently heard this quote from a person with diabetes:

'I don't think the new GP's very good. He kept asking me what I wanted to do. He's supposed to tell me.'

A powerful tool

Personal diabetes records provide structure to diabetes management through care-planning, patient engagement and education. Both health professionals and people with diabetes stand to benefit from increased knowledge and skills if personal records are used effectively and aid communication between the patient, the primary care team and specialist services. Diabetes UK could find very few models that had been evaluated but, in common with the DoH, provided an adaptable template (DoH, 2003a; Diabetes UK, 2003). Both were in paper format.

This year saw the requirement for primary care trusts to provide structured education for people with diabetes (DoH, 2005). Although group work forms the backbone of the guidance we should be considering the many who cannot, or will not, participate in this form of education. We need to help people with diabetes to look after themselves.

The personal diabetes record can be a powerful tool. It encourages informed choice. It, and the education to put it to effective use, should be available to all who can use it. But how we lose the disliked paper element of the plan seems more difficult to achieve... ■

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