

Seamless diabetes care – but between whom?

Gill Freeman

ARTICLE POINTS

1 A seamless service between primary and secondary care has been recommended for many years as the key to improved diabetes services.

2 In 2000, the Audit Commission identified measures that would aid integration of services, including facilitators, shared records and guidelines.

3 Eight years on, these measures have still not been adopted nationally, although the number of facilitators is increasing.

4 Current government initiatives stress the need to empower patients to take greater responsibility for their own care.

5 It is suggested that the 'new' shared care should be between patient and health professional, rather than between primary and secondary care.

KEY WORDS

- Seamless care
- Patient empowerment
- Peer counselling
- Patient-held records
- The expert patient

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Introduction

In 1996, Professor George Alberti stated, in response to the White Paper *Choice and Opportunity – Primary Care: The Future*: 'There are finally opportunities for a seamless service between primary and secondary sectors, something that the BDA has worked hard for. If used properly, these will benefit people with diabetes' (Irving, 1996). And even before this, the *St Vincent Joint Task Force for Diabetes Report (DoH/BDA, 1995)* said: 'We regard the improvement of working relationships between primary care and hospital services as an essential key to the betterment of diabetes services.' This article discusses whether these opportunities have been realised, 8 years on. Is seamless care beyond the capacity of the health service?

The quality of diabetes care varies greatly from area to area. In 2000, the Audit Commission's report *Testing Times: A Review of Diabetes Services in England and Wales* found that different measures could be taken to make care more integrated, with approaches such as employment of facilitators and liaison nurses, shared record systems and the development and implementation of guidelines.

Unfortunately, these measures have not been adopted nationally, although the number of diabetes facilitators has increased in recent years in response to government initiatives. The majority of these facilitators are actively involved in, and dedicated to, many projects aimed at enhancing seamless care. The Audit Commission concluded that care is often poorly coordinated.

The NHS 10-year programme of reforms to bring the NHS into the 21st century (Department of Health, 2000) aimed to provide equal access to high quality seamless and integrated care.

The current system of shared care in diabetes services will change substantially as a result of the *National Service Framework (NSF) for Diabetes: Delivery Plan* (Department of Health, 2003) and the new GP contract. Are these innovations going to be more successful than their predecessors?

Devolvement of routine diabetes care to the primary sector (as recommended by the NSF for Diabetes) and the worldwide increase in prevalence and diagnosis of diabetes will seriously overload primary care unless adequate resources are provided.

If previous systems have failed to produce seamless care, what can we do? There is only one group of people who know as much, if not more, about managing their own condition than health professionals, and that is the patients. Perhaps the 'new' shared care should be between patients and health professionals rather than between primary and secondary care?

There are not many conditions where individuals have control over day-to-day programmes of care, but diabetes is one of them. Rodgers (2000) believes that:

'True partnership with patients may be the single most effective way of reducing future complications of diabetes.'

People with diabetes have contact with a health professional for 3 hours a year on average, but spend 8757 hours (365 days) self-managing their condition (Deakin, 2003). The person with diabetes should be seen as a valuable member of the care team, whose knowledge and invaluable experiences may be passed on and learned from (Freeman, 1999).

The NHS Plan (Department of Health, 2000) recommends the provision of information to support self-care:

‘Patient empowerment is the cornerstone of the plan.’
(Diabetes Update, 2000)

A shared care plan is agreed between the person with diabetes and the health professional, to enable that person to take control of his or her own condition. It:

‘...offers people active involvement in deciding, agreeing and owning how their diabetes will be managed’
(Diabetes Update, 2000).

It also recommends new structures to promote this, such as the Patient Advocacy and Liaison Services (PALS). The NSF for Diabetes (Department of Health, 2001b, 2003) has gone one stage further, encouraging partnership between professionals and the person with diabetes.

Hughes (2003) feels that within the NSF:

‘...there is a welcome shift from the medical model of care to empowerment’.

It is becoming increasingly obvious that the key to effective management of diabetes must rest with the patient who lives with this condition 24 hours a day.

The Commission for Patient and Public Involvement in Health (CPPIH) has been set up within the NHS to support patient groups who influence services. For many years, members of Local Diabetes Services Advisory Groups (LDSAGs) have included service users, and this will continue and hopefully develop further with the advent of Managed Diabetes Networks.

Empowerment

So, how are we to achieve seamless care with the person with diabetes? Hill (2003) believes that empowerment in the context of diabetes means ensuring that people with diabetes have sufficient knowledge, skills and understanding to make an informed choice about the management of their diabetes and are responsible for the consequences of their decisions. This takes the concept of self-management and partnership with health professionals to a

higher level. Acquiring this knowledge is an enormous task for the person with diabetes, when one considers the influence that this complex condition has on the human body. It means not only managing the condition and making lifestyle changes, but also developing the confidence and motivation to begin this process.

Skinner and Cradock (2000) provide evidence in their article to suggest that empowerment works well within the care of patients with diabetes, but Rodgers and Walker (2002) feel that many professionals are loathe to change the way they deliver information to the person with diabetes and deny that most patients want to be empowered.

The expert patient

The idea of developing an expert patient programme was first mooted in the 1999 White Paper *Saving Lives: Our Healthier Nation* (Department of Health, 1999). This was followed by a more formal commitment in *The NHS Plan* (Department of Health, 2000), when a task force was set up to design and deliver the programme.

User-led, self-management programmes are not new. They have been developed over the last 20 years, mainly in America, but we already have them in the UK for people with chronic diseases such as arthritis, manic depression and multiple sclerosis.

Research studies of these programmes have produced evidence to support reduced severity of symptoms, significant decrease in pain, improved life control and activity, and improved resourcefulness and life satisfaction, as well as an improvement in the quality of the doctor–patient relationship.

The recommendations of the report *The Expert Patient: A New Approach to Chronic Disease Management for the 21st Century* (Department of Health, 2000a) states that:

‘Expert patient programmes are based on developing the confidence and motivation of patients to use their own skills and knowledge to take effective control over life with a chronic illness.’

Peer counselling

Peer counselling courses in diabetes have been very successful in several parts of the UK. These courses have been set up with

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2 Research has shown that empowerment works well within the care of patients with diabetes.

3 However, many professionals are loathe to change the way they deliver information to the person with diabetes and deny that most patients want to be empowered.

4 *The Expert Patient* report (DoH, 2000a) recommends making patient expertise ‘a central component in the delivery of care to people with chronic disease...’

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1 Peer counselling courses in diabetes have been very successful in several parts of the UK.

2 They aim to enable self-management of diabetes, to teach people with diabetes to pass on their knowledge to fellow patients, and to support patient involvement in local organisations.

3 Health professionals have to accept that patients often learn more from other people with diabetes than from them.

4 A comprehensive, user-friendly patient-held record is crucial to the success of seamless care between patients and health professionals.

5 It remains to be seen whether this 'new' shared care model will be successful; it may be that not all patients, or even all professionals, will want to be part of it.

the following aims:

- To enable self-management of diabetes
- To teach people with diabetes to pass on their knowledge to fellow patients
- To support patient involvement in local organisations for diabetes.

One of their functions is to provide support for healthcare professionals in the provision of diabetes care. The Isle of Wight runs a very successful in-depth course. Participants on the course attend sessions for 18 weeks and are taught by a multi-professional care team. They are rigorously assessed at the end of the course and several have gone on to teach on subsequent courses (Wilson, 2003). The successful peer counsellors are now taking referrals from healthcare professionals.

Other successful support initiatives include the Buddy Network scheme in Scotland, the Diabetes Peer Support programme in Wales, and the 3D (Diabetes, Diagnosis, Discussion) in England.

As professionals, we have to accept that patients often learn more from other people with diabetes than from us, and that we are sometimes loathe to acknowledge this (Rodgers and Walker, 2003).

Patient-held records

To aid the process of seamless care between patients and health professionals, it is essential to have a comprehensive, user-friendly patient-held record. Duplication of information and investigations and conflicting advice lead to patient confusion. It is important that the patient feels that the record belongs to him or her; for this to happen the patient must be empowered to enter his or her own information.

In North Bedfordshire, one such record has been in use for 6 years as part of their Diabetes Care Scheme. Pledger (2003) believes that the record allows patients involvement in, and ownership of, their care plan, but the commitment necessary for this to succeed has been enormous.

Conclusion

So, does the original meaning of seamless care still exist? The old integrated primary and secondary care model is likely to fade in the face of recent government guidelines.

As health professionals, have we made too many assumptions on behalf of the patient? There is evidence to show that the projects discussed do improve diabetes care, but do all patients want to be part of this? And if not, how can we help? Do all health professionals want to be part of this shift – are we ready for it and will we succeed? Only time will tell. ■

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