



Blind leading the blind

J Head*

Introduction

It is accepted that people with diabetes can reduce the risks of long-term complications of diabetes if they have been taught total self-management of their diabetes.^{1,2} The health care professional has a responsibility to provide the information and learning environment which these people need to empower them to take charge of their own care.³⁻⁵ They need to be able to understand the relationship between their blood glucose readings, activity levels and food intake.^{4,5} With a sound knowledge of these three aspects of diabetes care, they will be able to adapt their therapy or activity in order to avoid extremes of blood glucose.

Empowerment

Most people with diabetes are able to carry out self-care on a level that suits them and their lifestyle. However, there may be those who choose not to take on this management role. Health professionals will need to be sure that these people have been empowered to make that choice, and have not simply been left out of the education loop because of apparently insurmountable barriers to self-care. Those

Abstract

Self blood glucose monitoring is an important tool to help people with diabetes manage their own diabetes. There may be barriers to carrying out the technique, including severe visual impairment. This article describes a solution to this problem using available modern technology. Copyright © 2004 FEND.
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Key words

diabetes mellitus; visual impairment; blood glucose monitoring; reducing the risks

with any degree of visual impairment are such people.

Visual impairment and diabetes

Diabetes is a common cause of visual impairment and blindness in the working age population.⁶ Findings consistent from study to study, make it possible to suggest that, after 15 years of diabetes, approximately 2% of people become blind, while about 10% develop severe visual handicap.⁷ However incidence worldwide is difficult to assess as the various studies available use different definitions of blindness.⁸ At the 2003 meeting of the European Association for the Study of Diabetic Eye Complications it was reported that diabetic retinopathy causes 11% of blindness in western countries.⁹ Many of these people will have previously managed their own care, but subsequently have had to rely on others when their sight fails. Some, who have impaired vision prior to diagnosis, may never have been fully engaged in the education process because adequate equipment was, and still is, not available. A study in the USA indicated that of the 17 meters studied 4 had voice output, but it was also noted that these meters are larger than ordinary meters which may make them less portable. They emphasised the need for more input into the manufacture of these

meters.¹⁰ Meters with voice synthesisers are not available in the UK despite the fact that diabetes nurses have repeatedly asked the meter companies to produce one.

Technology

All meter companies provide software to record and retrieve results and a download cable to link the meter to the computer. There may be a cost with some of them, and this may vary across Europe. The relevant company representatives, or the websites, will be able to help nurses outside the UK.

Computer skills

Rehabilitation and training of the visually impaired now include teaching computer skills using a voice synthesiser to speak the actions of the keyboard and to read the screen. Countries will differ as to what is available. Details for the UK are available from the Royal National Institute for the Blind (RNIB).

The problem

In this article I would like to share the experience of one person who wished to manage his own diabetes but needed to overcome issues of severe disability.

In July 2003 I received a phone call – nothing unusual in that, *but* it has changed my life. The conversation went along the lines of the following account (the caller's name

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has been changed to protect privacy).

Caller: My name is Mike and I was diagnosed with type 2 diabetes three months ago when I was admitted to hospital with an enormous carbuncle on my back and very high blood sugars. On discharge from hospital, the district nursing team visited daily to re-dress the wound and check my blood sugar. The infection is now healed and visits are reducing. My general practitioner does not agree with nursing visits 'just' to do blood tests. I am expected to walk down to the surgery at the appropriate times to have the levels checked. I work full time and this would be impossible to fit into my day.

Having been advised, by the consultant physician, to check blood sugars – fasting and two hours after my main meal, twice a week – I need a meter which can be downloaded to my computer so that I can test myself.

JH: I'm sure I can help – there are many meters on the market that download to computers. We need to get together to discuss this.

Caller: By the way I am blind.

JH: How much do you see?

Caller: Nothing – I have been blind since birth, as has my wife. What I need is a way of taking a blood sugar, downloading it to my computer and letting my voice synthesiser read it to me.

JH [realising that this is no ordinary individual on the end of the phone]: I know of meters with download software which is simple to use, and I am about to take delivery of some new meters (Ascensia Breeze) that may be of use. [Luckily, the Ascensia Breeze was being launched in the UK around the time he rang.] However, I have to stress that there is an issue with making contact between the blood and the strip, as the strip works like a drinking straw and the



Figure 1. The meter opens with a catch at the sensor end

tip has to be in the blood sample to sip in the blood. This is vital for the measurement to take place.

Caller: I would like to have a go. I do not wish to have inferior care because I cannot check my blood sugars.

From the beginning of the conversation it became obvious that Mike was not pleased with assumptions being made about what he could or could not manage. Following a long chat on the phone, involving much laughter, we agreed to make plans to meet. I enjoy a challenge and Mike was prepared to try anything in order to be independent. I put him in touch with the Bayer helpline to acquire the software and find out more about the meter from the Internet. I half expected a call from the helpline asking me what I thought I was up to!

A number of meters, from different companies, are provided free of charge to Diabetes Nursing Teams in the UK. As I had not taken on such a challenge previously, I felt more confident working with the Bayer software (WinGlucofacts) which I had used in my previous post when working with children. When I received my supply of

Ascensia Breeze and tried the meter for myself, I felt positive that I could teach him a technique to locate the strip and blood – time would tell. The meter is robustly built and the shape easy to hold. I made sure that I understood the instructions and carried out numerous tests before meeting Mike – firstly to feel confident, and secondly to have some results to download.

Initial visit

I was greeted like a long lost friend by Mike, his wife Vera and their two very friendly retired guide dogs.

Being a software manager in his working life, Mike had already downloaded the WinGlucofacts software (Bayer) and was trying to make sense of it. He had also found details on the web about the Ascensia Breeze (www.ascensia.com). Unfortunately, as the instruction book is written for sighted people, the pictures made little sense to him – not easy when you have absolutely no idea what it is all about!

Education issues

There were major issues to overcome – the first being the educational challenge for me. I had not



experienced teaching blood glucose monitoring to a totally unsighted person who had no previous knowledge of diabetes, and only the hospital experience of blood glucose monitoring. I would need to explain to Mike how to test, what to do with the results and how to record them, and then present them to the health professionals for discussion about his management.

As with any person learning blood glucose monitoring, assessment of psychomotor, intellectual and emotional ability is vital. Teaching a skill usually involves explaining then demonstrating the skill. The learner then practises the procedure until they are competent to manage alone. When vision is impaired or lacking, the demonstration needs to be adapted.

Demonstrating use of the meter

This took probably the best part of an hour and proved to be the most important part of our learning process.

I guided Mike around the meter and the lancing device, explaining all the parts, opening and closing the relevant sections with his hands and mine together on the meter (in the same manner as that shown in Figure 1). Each action needed to be explained, carried out together, and refined in order to be absolutely foolproof each time. Then Mike repeated the process until he felt confident and I could see that his technique was correct. We would have made interesting viewing! Having already downloaded the instructions onto his screen, he was able to recognise all the parts as we went through it all. Mike wanted to be sure that each movement was repeated exactly. He needed to be confident that he would be able to complete the procedure when alone. Having spent his life 'seeing' with his fingertips, this was amazing to observe.



Figure 2. The meter aligned to a finger – the Ascensia Breeze has an indentation at the point where the sensor protrudes from the meter

Making a record of results

During this time Mike successfully downloaded old results from my meter and was able to read them. He had no perception of what a record diary was like so I had to try and describe the screen for him to be able to locate results. I also handed him an actual record log so that he could understand how sighted people record results. He then realised that the individual and health professionals use this to look for trends and patterns. He was pleased that he would have the opportunity to know his levels and be able to discuss them, with me, over the phone.

Getting the blood to the strip

From the start there was going to be the problem of aligning the tip of the sensor and the blood sample. This issue is the major one for any person with visual impairment attempting to test.⁷ Unfortunately, the number of incorrect attempts can dissuade the user from persevering with the process. Mike developed a system by instinctively puncturing his fingers in the same place (on the upper surface with his thumb upwards, always oppo-

site the bottom of the nail) and using the finger below to locate the strip. Luckily, he is not doing more than four tests a week – except on the two weeks before clinic, if he is unwell, or if he has unusual results which he cannot explain. Many more and he would run out of places – he favours his left hand. The Ascensia Breeze has an indentation at the point where the sensor protrudes from the meter. Using this, he locates the sensor and then lines up his 'punctured' finger with the tip (Figure 2). By carrying this out repeatedly with control solution, he became adept.

To quote Mike, 'It's to do with intuitive knowledge of self ... you do not have to see your right ear in order to scratch it if it itches.'

Practice, practice and more practice

This section of the training was particularly difficult for me. I had to 'sit on my hands and keep my mouth shut'. I had to observe only, and let Mike make all the moves without any help while he mastered them. It was a privilege to watch.



Awaiting the result

Patience was needed until the meter beeped. Mike then downloaded the result and his voice synthesiser told him the result. He quickly learned that the beep was shorter and sooner if there was an error. He had success at his first try.

Time commitment

The first visit and training session took nearly four hours and we were both exhausted.

If such a venture is being planned, the allocation of time needs to be clearly arranged in advance. Although subsequent visits were shorter in time, I needed to see Mike twice a week, when testing, to review his technique and teach more about the self-management of his diabetes. Total contact time was about 12 hours over eight visits.

Impaired vision

We all have patients with impaired vision and many of us have been asked for talking blood glucose meters for these people.⁷ There are not many available and cost may be an issue in some countries. In the UK, there is no talking meter available with strips on National Health Service prescription – one would have to be purchased privately. People with impaired vision have to rely on sighted persons around them to help with the process, check the result and keep records. Those without a sighted partner have had to rely on health professional, hospital and surgery visits to find out their blood glucose levels. This is not suitable for those who work and live independently and wish to adjust their medication for optimum control.

Modern meters

The advent of meters which no longer require calibration, and those which have strips inside the meter, has made blood glucose monitoring much easier to teach as there are fewer steps to learn. The person with limited sight may be able to read the larger displays, but that is no use to the unsighted person.

The blood glucose monitoring equipment and software used in this challenge is freely available to all Diabetes Nurses in the UK from Bayer Diagnostics representatives. It was a happy coincidence that this meter became available at a time when Mike needed it, the aspects of the Ascensia Breeze that made it suitable for Mike are listed in Table 1.

Conclusions

Mastering self blood glucose monitoring using the available modern technology was an enormous learning exercise for both of us and an extremely rewarding one for me.

This is only one way of overcoming the issues around monitoring for visually impaired people with diabetes. With modern screening and medications, long-term complications should be delayed or at least detected early so that treatment can be commenced. As people are living longer, we may be seeing an increase in visual impairment. If we are to continue to encourage self-management with blood glucose monitoring, we need some solutions before the problems become worse. Maybe this is one way forward for those who have access to the technology. We still need solutions for those who do not.

Patient partnership

By working with someone like Mike, who has never let his lack of vision be a barrier to life, I have learned not to see visual loss as a

No calibration	No need to try and match numbers
Integral test sensors – easy to load	Meter opens with catch at the sensor end of the meter (Figure 1) Sensors in a disc of 10 ready to load Each disc of sensors drops into the meter
Positive set up action – pull/push	Handle is easy to locate/positive action
Indentation at point of sensor extrusion	Easy to check that sensor is extruded
Lancing device easy to set – pull/push	Same action as meter Lancet loading tricky – needs practice
Clear bleep signals	Need to learn which is which
Download cable can be left in when in use	No need to disconnect if not needed every day
Easy to use software	Downloadable from website Diary can be printed off or sent by e-mail Local policy will apply re e-mail
Easily ejected sensor	Drops out into contaminated sharps bin with a press of a button

Table 1. Aspects of the Ascensia Breeze that made it suitable for Mike



Key points

- People who are empowered to use blood glucose monitoring as a self-management tool may be able to reduce the risks of long-term complications
- Diabetes is the most common cause of blindness or visual impairment in people of working age
- Visual impairment need not be a barrier to carrying out blood glucose monitoring
- One solution may be a meter which can be downloaded and a computer with screen reader and voice synthesiser

barrier to anything. The way in which Mike taught himself to manage the meter, and the actions he used in order to manipulate the equipment have been invaluable for me when teaching other people. The names he uses for the parts have gone into legend and become usual vocabulary. The names he used for me, as we attempted to communicate, will remain our secret!

Spreading the word

Mike has presented his demonstration to a group of community nurses who were, like me, amazed. He is planning to write a short article for his company colleagues and has been helpful in talking to other

patients. I have already used my knowledge of the technology required to help others in the same situation, both in my own practice and for others.

Last word to Mike

Mike explains the value he puts on being able to do this. 'Whilst I am sure that improvements in techniques can be made, this ... leaves me in no doubt that a totally blind person [can] manage blood glucose levels, leading to a liberating experience and an improved quality of life.'

Conflict of interest statement

Subsequent to completing this project the author has been invited to contribute to a focus group for Bayer Diagnostics and other companies in diabetes care.

References

1. DCCT. Diabetes Control and Complications Trial Research Group. The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus. *New Engl J Med* 1993; **329**: 977-986.
2. UK Prospective Diabetes Study (UKPDS) Group. Intensive blood glucose control with sulphonylureas or insulin compared with conventional treatment and risk of complications in patients with type 2 diabetes. (UKPDS 33). *Lancet* 1998;

- 352**: 837-853.
3. National Service Framework for Diabetes: Delivery Strategy. Department of Health, London 2002.
4. European Diabetes Policy Group. A desktop guide to type 1 (insulin dependent) diabetes mellitus. European Diabetes Policy Group 1998. *Diabetic Med* 1998; **16**(3): 253-266.
5. European Diabetes Policy Group. A desktop guide to type 2 diabetes mellitus. European Diabetes Policy Group 1999. *Diabetic Med* 1999; **16**(3): 716-730.
6. Frank RN. Medical Progress: Diabetic Retinopathy. *N Engl J Med* 2004; **350**(1): 48-58.
7. Allwinkle J. Blood glucose monitoring for visually impaired people with diabetes. *J Diabetes Nursing* 2002; **6**(5): 157-159.
8. Comack TGM *et al.* Incidence of blindness due to diabetic eye disease in Fife 1990-9. *Br J Ophthalmology* 2001; **85**: 354-356.
9. European Association for the study of Diabetic Eye Complications subgroup of EASD. Conference reports www.diabeticretinopathy.org
10. Uslan MM *et al* Accessibility of blood glucose monitoring systems for blind and visually impaired people. *Diabetes Technol Ther* 2003; **5**: 439-448

Contact addresses

Bayer Diagnostics. <http://www.ascensia.com>; <http://www.bayer.co.uk>
 Royal National Institute for the Blind. Factsheet: Speech Output Systems. <http://www.rnib.org.uk>

Dates for Diary

7-9 October 2004 Choice: does it really exist in diabetes care? Leverkusen, Germany. Hosted by Bayer Diagnostics. **Contact:** Lee-Anne Haye, Events Manager, SB Communications, tel: +44 (0)20 7627 1510; Fax: +44 (0)20 7627 1570

9-10 September 2005 FEND 10th Annual Conference. Athens Hilton

Hotel, Athens, Greece. **Contact:** Conference registrar, Sari Rodriguez tel: +358 3 379 1589; fax: +358 50 408 7021; email: Rodriquez@kolumbus.fi

10-15 September 2005 41st Annual meeting of European Association for the Study of Diabetes (EASD), Athens, Greece. **Contact:** EASD secretariat email: [annual-](mailto:annual-meeting@easd.org)

[meeting@easd.org](mailto:annual-meeting@easd.org). Website: www.easd.org

3-7 December 2006 19th International Diabetes Federation World Diabetes Congress, The Cape Town International Convention Centre, Convention Square, 1 Lower Long Street, Cape Town 8001, South Africa. Website: www.capetownconvention.com