"Living a healthy life": An education, monitoring and screening programme for adults with learning disabilities

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Article points

1. People who have learning disabilities can have difficulty making lifestyle choices, which can lead to an increased risk of diabetes.
2. The "Living a healthy life" programme provides information about diabetes and healthy living education to groups of adults with learning disabilities in Enfield.
3. Additionally, annual screening of random blood glucose levels is offered to people with learning disabilities in Enfield to identify diabetes and instigate referral for diagnosis and management.

Key words

- Diabetes education
- Learning disabilities
- "Living a healthy life" programme
- Screening for diabetes

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It is widely recognised that people who have learning disabilities are more likely to have poorer access to health services, and as a result of health inequalities are more likely to develop major health problems (Department of Health, 2008). Obesity is one of the common health problems faced by adults with learning disabilities and may also increase the risk of the development of diabetes (NHS Information Centre, 2010). There are examples of excellent practice in diabetes for people with learning disabilities around the country, yet there is still much work to be done to ensure equal access to care. This article outlines the Enfield "Living a healthy life" project, which provides information about diabetes and healthy living education to groups of adults with learning disabilities in order to prevent the potential development of diabetes. This project also incorporates an annual screening programme for people with learning disabilities using random blood glucose levels at regular health assessments.

Diabetes is a complex condition that affects approximately 2.9 million people living in the UK; it is estimated that there are around 850 000 people living with diabetes who are currently undiagnosed (Diabetes UK, 2012). People who have mental health issues and learning disabilities are more likely to develop major health problems and can be more prone to the development of diabetes (Disability Rights Commission, 2006).

People with learning disabilities have numerous challenges to overcome on a daily basis. They may be faced with problems relating to poor memory, difficulty with communication and lack of understanding or insight. Making correct lifestyle choices to avoid the development of diabetes can be extremely difficult.

Prevalence of diabetes among people with learning disabilities

Statistics and data on adults with learning disabilities have varied considerably over the past decade. An example of this is that in "*Valuing People*" (Department of Health, 2001), it is stated that "producing precise information on the number of people with learning disabilities in the population is difficult"; the document goes on to estimate that there were 1.2 million people living in the UK with mild or moderate learning disabilities and 145 000 living with severe or profound learning disabilities.

Additionally, MENCAP (2012) recognises that there are a lack of data in this population:

> *"There is a lack of comprehensive data available on the exact prevalence of learning disability, and further research is desperately needed."*

In 2009, Diabetes UK reported that 9 million people in the UK had learning disabilities, with an estimated 270 000 of these having type 2 diabetes (Diabetes UK, 2009).

However, in his report on *Health Inequalities and People with Learning Disabilities*, Emerson (2011) stated:

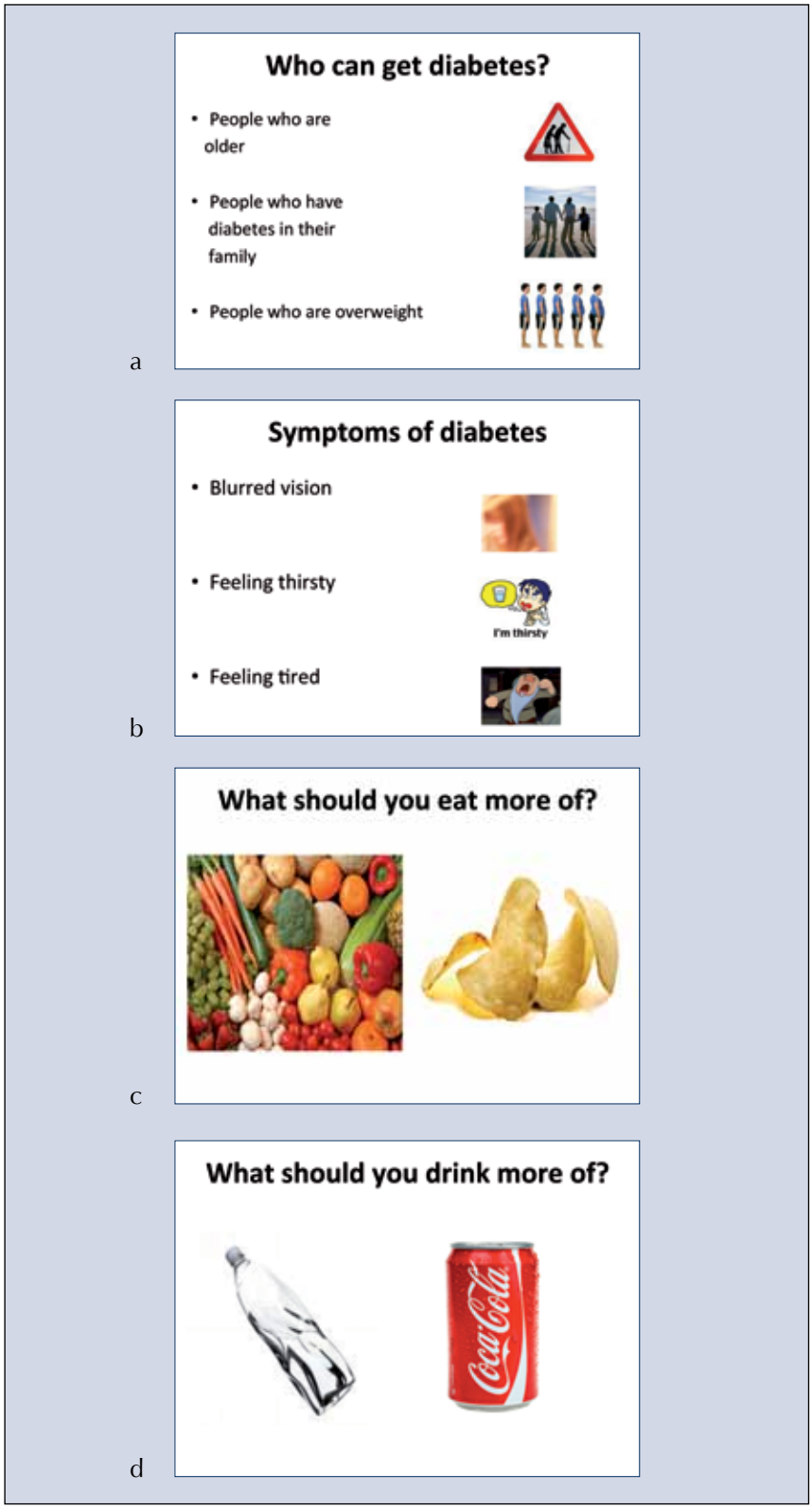

Figure 1. Slides from the authors' presentation for the "Living a healthy life" programme; the programme is delivered to adults with learning disabilities to improve their understanding of diabetes and healthy living.

"We are not aware of any UK-based data on the prevalence of diabetes among people with learning difficulties".

As we are not able to determine the number of people living with learning disabilities, let alone the number of people with both learning disabilities and diabetes, in the UK at the current time, commissioning diabetes services for this group will be extremely difficult and there is the possibility that it could be overlooked.

In October 2005, the Enfield diabetes redesign project commenced (Hicks and McAuley, 2006). The philosophy underpinning this project was to ensure that all people, regardless of background, socioeconomic status or postcode, had access to high-quality diabetes management as and when required. Part of this work was to raise the profile of diabetes to groups of people that were regarded as "hard to reach", as well as those who were considered to have an increased risk of diabetes.

We were approached by Deanna Rogers, who was Cancerlife Project Manager at the time, to take part in a joint programme for adults with learning disabilities. The programme was developed in partnership with One-to-One (Enfield), Enfield Disability Action, and Enfield Integrated Learning Disabilities Services. A diabetes facilitator from one of our local trusts had initially agreed to help with an education and screening programme for this group; however, at the start of the diabetes redesign project it was believed that work in this area was to become part of the new Enfield diabetes nursing team's portfolio. The programme, entitled "*Living a healthy life*", provides information to adults with learning disabilities in Enfield.

"Living a healthy life" programme

In order to prevent the potential development of diabetes and highlight those at risk of diabetes, the "*Living a healthy life*" programme comprises one teaching session on diabetes and healthy living, and two blood glucose screening sessions that take place at health "drop-ins" at two sites in Enfield each year.

Diabetes and healthy living education

The purpose of the teaching session is to cover:

- What is diabetes?
- Who is at risk?

"We were aware that if the talk was delivered in an inappropriate way for the target audience, we would not only appear insensitive to the needs of the group but, more significantly, would also not get an important message across and would lose their attention."

- Signs and symptoms of diabetes.
- Healthy eating.
- Importance of exercise.

At the time we were approached to do these sessions, both members of the diabetes nursing team lacked experience and expertise on how to present information to groups of adults with learning disabilities; we deliberated over what we should say and how we should present the information. We were aware that if the talk was delivered in an inappropriate way for the target audience, we would not only appear insensitive to the needs of the group but, more significantly, would also not get an important message across and would lose their attention.

In "Delivering diabetes care to people with intellectual disability", Rey-Conde and Lennox (2007) advise:

> *"Communication can be improved if healthcare providers adjust their approach to interacting with people in their care. The following advice to healthcare providers has proved effective when working with people with intellectual disability:*
> - *Avoid jargon and adopt language that is familiar to the person.*
> - *Use clear and direct speech.*
> - *Use age-appropriate style and vocabulary.*
> - *Use real and familiar examples to explain concepts.*
> - *Expect a response – wait at least 10 s.*
> - *Use body language, signs, gestures, facial expressions and demonstrations."*

With this in mind, we felt that our presentations had to include the following principles:

- Be respectful.
- Be factual.
- Be appropriate for the target audience and easy to understand (in plain English).
- Be interactive.
- Be fun.

The education sessions take place to groups of 15–20 participants. An example of how our presentations reflect our own ideas as well as the principles laid down by Rey Conde and Lennox (2007) can be seen in our slides depicted in *Figures 1a*, *b*, *c* and *d*. We made an effort to use clear and concise language alongside pictures that are associated with the messages conveyed. *Figures 1c* and *d* illustrate healthy and unhealthy choices; the group are asked to say which food or drink is a better, healthier choice. We then explain in an easy-to-understand way why this is the case. These

Figure 2. Before performing a random blood glucose test, people with learning disabilities are shown the blood-testing equipment and talked through the procedure.

interactive slides always prove to generate interest within the group, and enable participants to share their ideas and experiences with us.

Once these formal presentations are over, the next part of the programme is by far the most poignant and relevant. We invite a participant to come forward and tell his or her story to the group. One participant who attended the fledgling programme in 2005 was diagnosed with type 2 diabetes after a random blood glucose reading of 17.1 mmol/L. This man described his journey with diabetes to the group, and he was keen as well as proud to tell of his experiences. This part of the programme is always the most impactful, as it demonstrates to the group the importance of adhering to a healthier lifestyle.

In order to reiterate healthy food choices, we play the "higher and lower" game. This game is based on the sugar game that is found in the DESMOND (Diabetes Education and Self-Management for Ongoing and Diagnosed) training package (DESMOND Collaborative, 2008). Various foodstuffs and drinks, such as diet drinks and full-sugar alternatives, jelly, jam and biscuits, are set out on a table with sugar cubes. The group participants are invited to volunteer to come forward to place the amount of sugar they believe a food type may contain alongside it. Once they have decided the amount, the rest of the group then shout out whether they believe that the number of sugar cubes is "higher" or "lower" (in homage to Bruce Forsyth's "*Play Your Cards Right"* television programme). The correct answer is then given and we explain in more detail why this is the case. This part of the programme is the liveliest and generates a huge amount of interest from the group.

We believe that important information about healthy food choices is demonstrated in a way that the group enjoy, but more importantly understand.

Blood glucose screening sessions

As any healthcare situation can provoke higher levels of anxiety in people with learning disabilities (Royal College of Nursing, 2010), we believe that it is essential to ensure that the service users who attend the screening sessions are fully informed and prepared about the processes involved in testing their blood glucose levels.

Before attendance on the day, our colleagues who act as community support workers and carers remind participants about the screening sessions. This information is reiterated again on arrival at the health drop-in site. Before screening, the blood-testing equipment is shown and explained, and consent to proceed is obtained individually by the person taking the screening sample (*Figure 2*).

Enfield's diabetes care pathway

When adults with learning disabilities are found to have raised blood glucose levels, information is given to their care staff

"Now, if a problem is identified with any service users with learning disabilities on our diabetes caseloads, liaison with members of the multidisciplinary team can provide us with further information and insight."

or support workers to bring to their GP (*Box 1;* NHS Enfield, 2010). It should be noted that there is flexibility within this protocol when dealing with this cohort of patients; for example, if a patient has come to the screening session within 2 hours of eating, a fasting blood glucose may be required.

Box 1. Screening parameters used within Enfield's diabetes care pathway.

- If random blood glucose is 6.0–11.0 mmol/L, perform a fasting blood glucose and further tests.
- If random blood glucose is ≥11.1 mmol/L, send this information to the GP for a diagnosis of diabetes to be made.

From: NHS Enfield (2010).

Results

There have been six teaching sessions delivered to adults with learning disabilities in Enfield since 2007; the results of the random blood tests performed at the health drop-in sessions for this group over the past 5 years are shown in *Table 1.* We realise that our record keeping has been suboptimal; however, this project was commenced when the diabetes team's activity did not need to be as robustly justified as it does within the current NHS environment.

All of the information collected from the screening sessions was entered into the service users' healthcare records by the organisers. From the perspective of the Enfield diabetes team, few data were kept from these sessions; anecdotally, three people have been diagnosed with type 2 diabetes and several more with impaired glucose tolerance during this period.

We have begun collecting essential data that are inputted into our clinical activity database *RiO* (CSE-Healthcare Systems Limited, Sheffield); during group sessions we are now keeping specific records relating to screening results.

Table 1. Results of random blood glucose tests performed on adults with learning disabilities over the past 5 years as part of the "Living a healthy life" programme.

Year	Number of sites visited	Number of people screened	Random blood glucose results (range, mmol/L)	Notes
2008	2	51	4.1–7.3	
2009	2	39	3.4–10.2	
2010	3	78	No results	Data not kept
2011	2	51	4.2–19.1	
2012	2	57	3.6–16.5	

Conclusions

Throughout the past 5 years, the Enfield diabetes nursing team have been on (and continue to be on) a journey with a steep learning curve. The team has enjoyed this valuable work and would like to see this extended to more people throughout Enfield. We have been approached by groups within Enfield, inviting us to do further work with groups of adults with learning disabilities; unfortunately, this is on hold as a result of commissioning issues while Enfield Clinical Commissioning Group is being established.

We have improved links with our colleagues who work with adults with learning disabilities. Now, if a problem is identified with any service users with learning disabilities on our diabetes caseloads, liaison with members of the multidisciplinary team can provide us with further information and insight.

We recognise that our data collection has to be more robust, and we are making improvements regarding what data are collected and how they are collected.

In regard to improving our education and screening sessions, we are looking at ways of making the explanation of diabetes more interactive as well as providing certificates for achieving target blood glucose testing results. Information handouts on healthy eating for service users to take home will be printed in the future if funding is found to facilitate this. ■

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Department of Health (2001) *Valuing people: A new strategy for learning disability for the 21st Century*. DH, London. Available at: http://www.archive.official-documents.co.uk/document/cm50/5086/5086.pdf (accessed 06.02.13)

Department of Health (2008) *Healthcare for all: Report of the independent inquiry into access to healthcare for people with learning disabilities*. DH, London. Available at: http://bit.ly/8PgwoV (accessed 28.02.13)

DESMOND Collaborative (2008) *Developing quality, structured education in diabetes*. NHS, London. Available at: http://www.desmond-project.org.uk (accessed 06.02.13)

Diabetes UK (2009) *Diabetes UK launches DVD to help people with learning disabilities*. Diabetes UK, London. Available at: http://diabetes.org.uk/About_us/News_Landing_Page/Diabetes-UK-launches-DVD-to-help-people-with-learning-disabilities/ (accessed 06.02.13)

Diabetes UK (2012) *What type of diabetes do I have?* Diabetes UK, London. Available at: http://www.diabetes.org.uk/Guide-to-diabetes/What-type-of-diabetes-do-I-have/ (accessed 06.02.13)

Disability Rights Commission (2006) *Equal treatment: Closing the gap*. Disability Rights Commission, London. Available at: http://bit.ly/WRaKg7 (accessed 06.02.13)

Emerson E (2011) *Health inequalities and people with learning disabilities*. Improving Health and Lives: Learning Disabilities Observatory. Available at: http://www.improvinghealthandlives.org.uk/projects/particularhealthproblems (accessed 06.02.13)

Hicks D, McAuley K (2006) Redesigning diabetes services and its benefits. *Journal of Diabetes Nursing* **10**: 304–8

MENCAP (2012) *More about learning disability*. Available at: http://bit.ly/VIF8hL (accessed 06.02.13)

NHS Enfield (2010) *Enfield diabetes care pathway*. Available at: http://bit.ly/VIEEIn (accessed 06.02.13)

NHS Information Centre (2010) *Access to healthcare for people with learning disabilities*. Available at: http://bit.ly/XW0PFo (accessed 06.02.13)

Rey-Conde T, Lennox N (2007) Delivering diabetes care to people with intellectual disability. *Diabetes Voice* **52**: 16–8

Royal College of Nursing (2010) *Dignity in health care for people with learning disabilities*. RCN guidance. RCN, London. Available at: http://bit.ly/ZDTk9h (accessed 06.02.13)

"In regard to improving our education and screening sessions, we are looking at ways of making the explanation of diabetes more interactive as well as providing certificates for achieving target blood glucose testing results."

Adults with learning disabilities attending a "Living a healthy life" educational session on diabetes and healthy living proudly show their certificates of participation.