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## Further information

Send contributions for the next issue by 1 October 2008 to the Editor:

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**Those of you who work in diabetes but live with the condition, or are close to someone else who does, may be interested in the following information.**

## PROUD: Professionals United by Diabetes

PROUD began its life in 2004, initially as a network for professionals working in the field of diabetes and who live with the condition, or who are close family members or carers of others living with diabetes. Following searches into other long-term conditions, PROUD appears to be a unique group, with its members combining their professional expertise with their experiences of being patients. They believe that their professional and personal “dual insight” brings another dimension to the understanding of living with a life-long and incurable health condition.

PROUD is an independent organisation, run by a small multidisciplinary committee whose members are or were involved in diabetes care professionally and represent type 1, type 2 and other types of diabetes and the specialist, primary care/community and academic sectors. PROUD is funded by an unrestricted Novo Nordisk Educational Grant and aims to:

- Provide a mutually supportive and discussion network for its members mainly through its website and via email.
- Influence and lobby for the continuing improvement in the health and quality of life of people with diabetes and those at risk of diabetes.
- Develop educational initiatives based on members’ “dual insights” and experiences, to benefit the diabetes and health service community more widely.
- Operate as a consultation group for organisations, for appropriate research and other projects and to carry out relevant research itself.

Since 1994, the membership of PROUD has expanded to include other professionals working in the diabetes field and any health care provider who works in the NHS and the private health sector. The majority of PROUD members at present are in the UK but membership is open to those who qualify and live overseas, and there are currently members in Europe, Canada, New Zealand and the USA.

PROUD’s first and continuing major project has been the production of *Diabetes narratives*, which can be viewed on the website and which are also available as a set in hard copy. The narratives are short accounts by our members of significant or interesting events in their lives with diabetes, including their professional and personal insight and key messages of educational value to the health care community.

Since it was founded, PROUD has been involved in key diabetes conferences and events in the UK and abroad. By invitation, PROUD has participated in several academic projects on different aspects of diabetes education and care, and has been involved in national initiatives regarding current and future diabetes services in the UK.

Should you wish to apply to become a member of PROUD, or if you would like a hard copy set of the *Diabetes narratives* please contact: Mary MacKinnon, Chair, PROUD. Telephone: 0114 236 5967. Email: [mackdiab@aol.com](mailto:mackdiab@aol.com) Website: [www.proud-diabetes.org](http://www.proud-diabetes.org)

**Harriet Castleden**

## Letter from the Editor

Dear colleagues,

Welcome to the summer edition of *Diabites!* As you can see, we have another collection of very interesting experiences of diabetes nursing, reflecting how varied the specialty really is. I sometimes get asked (by people who don't know!) if I get bored just giving people insulin and telling them not to eat too much. As diabetes affects people of all ages in a variety of settings in so many ways, it is never boring!

Our congratulations go to Yvonne Coughlin as the winner of the RCN Diabetes and Cardiovascular Disease award this year, who also shows us there are always new ways of supporting people to understand and manage their diabetes. We are grateful to Servier for sponsoring this award for the last two years but sadly they are unable to continue this. But do keep letting us know if you are doing anything new.

If you would like to contribute to future editions of *Diabites*, or would like to make any comments about the content of this newsletter, please contact me by email: [jill.hill@benpct.nhs.uk](mailto:jill.hill@benpct.nhs.uk)

**Jill Hill**

### Did you know you can read this newsletter online?

**This and other forum newsletters are available on the RCN website even before they are mailed out to members.**

So if you would like to be one of the first to read the next issue log on to **MyRCN** at [www.rcn.org.uk/myrcn](http://www.rcn.org.uk/myrcn), or call RCN Direct on **0845 772 6100**, to register your email address and opt in to our email services. You'll then be sent an email with a link through to the newsletter each time it is published.

**Help us reduce our carbon footprint and save some trees!**

**SARAH TAYLOR** is a diabetes specialist nurse working in Shropshire with an interest in maturity-onset diabetes of the young.

## Maturity-onset diabetes of the young

I have been a diabetes specialist nurse in secondary care for over 10 years. A few years ago I attended a conference and responded to a flyer from the Royal Devon and Exeter Hospital asking for maturity-onset diabetes of the young (MODY) link nurses. I was accepted and attended for initial training. What followed has been the most enlightening and educational two years of my career so far. I visited Exeter regularly to liaise with the other link nurses and to receive education and updates from the Exeter diabetes and genetics teams.

What I have learned has challenged my previous experience of dealing with diabetes and has shaped the way that I assess and manage people with diabetes currently. In particular, I pay more attention to reviewing their family history and mapping out a family tree. The name of the MODY link nurses has now changed to genetic diabetes nurses, as more and more is learned about this subject it is very apparent that the term MODY fails to encompass all that this involves.

### What is MODY?

MODY affects 1–2 per cent of people with diabetes and typically develops before the age of 25. Diabetes also runs in families from one generation to the next. There are different types of MODY – the most common are glucokinase and HNF1- $\alpha$ , and they are often misdiagnosed as type 1 or type 2 diabetes. Knowing the type of diabetes that a person has can help to determine the correct treatment for them, and ensure the correct advice is given to family members.

The Exeter genetics team also discovered

a mutation in gene Kir6.2 that causes neonatal diabetes. Patients were found to respond to sulphonylureas and in some cases were able to come off insulin.

### Role of the link nurse

One of the main roles of the link nurse was to inform others about MODY and genetic diabetes. This involved giving talks to other health care professionals including my own team and teams from other hospitals. I received referrals for possible patients with MODY and liaised with Exeter regarding appropriate action and advising on genetic testing. I have also been involved in counselling family members regarding predictive genetic testing (to determine if they carried the faulty gene and will develop diabetes). Due to other commitments I am no longer a MODY link nurse but continue to apply the principles when assessing patients. I continue to take referrals locally and remain as a link with Exeter to offer advice and guidance.

Having this additional knowledge has answered some of the questions that diabetes poses, particularly regarding diagnosis, which is not always black and white. It has made my role as a diabetes specialist nurse more complex but in addition has enhanced my confidence and skills in relation to decision making and treatment options. It has been particularly satisfying to provide an accurate diagnosis and in some cases to facilitate changes in treatment, including the discontinuation of insulin therapy.

For more information about MODY and genetic diabetes visit: [www.diabetesgenes.org](http://www.diabetesgenes.org)

**Sarah Taylor**

## Letter from the Chair

Dear colleagues,

2008 is hopefully a year of collaborative working for the Nurses Working in Diabetes Forum. The RCN clinical governance framework now requires forums to submit an operational plan outlining their planned workstreams for the next financial year. The forum has identified three key areas of work that we are hoping to address in collaboration with the relevant forums within the RCN.

What started off as an exploration of issues of hypoglycaemic management in the workplace looks to be expanding to the whole issue of diabetes in the workplace and hopefully in combination with the Occupational Health Managers

Forum we are hoping to develop some clear guidelines in this area and hope to deliver a joint conference on the topic in September 2009.

Education of nursing and residential home staff to enhance the care of residents with diabetes will hopefully be addressed by joint working with the RCN Forum for Nurses Working with Older People to establish what education tools are already available in this area and how their access to all can be enhanced by the development of web-based guidance and access to educational tools.

In conjunction with the Prison Nurses Forum we aim to explore whether care in the prison service meets the needs for individuals with diabetes as set out in the diabetes national service framework.

If deficits are identified then we will work with the prison governors to develop a framework to address them.

All these topics have been chosen and developed as a result of feedback received from members of the forum about areas of care they have problems with or concerns about. These three important areas are likely to keep the forum committee very busy over the next 12 to 18 months, but please continue to highlight areas for discussion or review as they arise.

A considerable amount of positive feedback was received following the publication of the winter 2007 edition of *Diabetes* and I hope this edition elicits a similar response.

**Mags Bannister**

KATH TROOP and TRISH STEWART tell us what they have been doing to address the management of people with diabetes living in residential care.

## Diabetes management in residential care

We are two district nurses working in Nottingham City and Nottingham County Teaching PCTs. Our project evolved over several years as we came to realise the gap that existed in the knowledge and practice of carers and nurses working in residential facilities. At that time there was a newly appointed lead specialist nurse in diabetes working for Nottingham City PCT. With her support we developed and facilitated a link group for district nurses in diabetes. This incorporated nurses from both Nottingham City and Nottingham County. District nurses are in a unique position to reach people in these facilities, as they are aware of, and often have connections with the homes in their localities. We undertook a small audit of six homes within Nottingham City PCT which looked specifically at the knowledge of carers and clients, and identified gaps in care.

Two of our number with a special interest in rest homes designed a teaching package with support from

the specialist nurse. We are currently delivering this in the homes over short sessions to small numbers of carers and nurses, often going into the home two or three times to capture all staff. In doing so, working relationships are forged and built upon to establish trust. The teaching package includes signs and symptoms, treatments, and short-term and long-term complications. We tailor each session to the individual needs of the home, for example, talking about the treatments and particular difficulties of the clients the home caters for. We provide a named link, offering advice, support and monitoring equipment where and if indicated, to fit in with individual patient care plans.

The package has been well received in the homes; and knowledge and practice have improved. Carers' and nurses' feedback include such comments as: "Thank you, I've learned loads" and "The most interesting and relevant course I have been on".

Our plan for 2008 is to:

- undertake a needs analysis to inform training requirements
- prioritise the training of nurses and carers in the homes according to this information
- roll out training to all homes
- design an audit to measure the effectiveness of the intervention and undertake this at 12 months
- plan future interventions according to the results.

We are also considering (following recent enquiries) extending our link group to incorporate representatives from nursing homes. We feel that this would benefit practice in several ways:

- learning and discussing information
- building networks
- further improving working relationships.

This is a substantial amount of work that has not taken priority in the past. In addressing this, we anticipate that a huge impact can be made to the quality of life for our elderly residents.

The RCN diabetes forum is planning to develop some guidance in this area. If you are interested in contributing to this, or have any experiences, whether good or bad, about what has worked in your area, please contact Margaret Stubbs. Email: mimarg@sky.com

MARGARET-ANNE MACMILLAN, last year's winner of the RCN Diabetes and Cardiovascular Disease award, updates us on her work.

## Smoking cessation education

The Diabetes and Smoking Cessation Education Programme (DSCEP) is going from strength to strength and has been a success in terms of gaining a greater understanding of patients' smoking behaviours past and present.

The research element, however, has not been so successful. Patients were requested to attend the programme at three-monthly intervals and to date only one patient has kept their appointment. This may be attributed to a few things. For example, patients often have to take time off work to attend the diabetes clinic and may not feel that smoking cessation is important enough to take time off. Also many individuals do not regard smoking as an illness that requires a medical intervention.

### Meeting the aims of the programme

57 patients have entered the DSCEP to date. The patients' baseline knowledge of health risks associated with smoking with diabetes was assessed with the following results:

- most patients believed themselves to be at risk of lung cancer
- very few patients were aware of the risk to their circulation due to smoking
- very few patients were aware of the risk of coronary heart disease and cardiovascular disease due to smoking
- very few patients were aware of the risk of stroke due to smoking
- none of the patients were aware of the risk of retinopathy due to smoking
- none of the patients were aware of the risk of neuropathy due to smoking
- none of the patients were aware of the risk of nephropathy due to smoking
- none of the patients had heard of atherosclerosis.

Motivational interviewing techniques were used to explore patients' beliefs and personal values regarding their smoking behaviours with the following results:

- most patients said that they smoke due to habit

- most patients said that they smoke due to enjoyment
- some patients said that they smoke due to boredom
- very few patients admitted to smoking because they are addicted
- all patients said they were tired of people "nagging" them to stop smoking
- some patients said that they felt too old and had smoked too long, to try to stop.

When asked what they **like** about smoking, patients responded that:

- it relaxes them
- it is a social activity among friends
- It gives them "me" time
- it can act as an icebreaker when in the company of strangers
- it is something to turn to in times of crisis
- it is their only pleasure

When asked what they **dislike** about smoking, patients responded:

- cost
- smell
- risk to health.

It is interesting to note that cost and smell were either the first or second most popular answers. Risk to health was the last response in every case.

The DSCEP raised patient awareness of the health risks associated with diabetes and smoking by informing patients of circulatory issues, atherosclerosis, coronary heart disease, cardiovascular disease, stroke, retinopathy, neuropathy and nephropathy.

Information was then provided about the smoking cessation services and products available in Forth Valley that patients can access. All patients were given:

- ASH *Factsheet 23: Smoking and diabetes.*
- ASH *Factsheet 11: What happens when you stop smoking.*
- NRT, Zyban and Champix information sheets.

- Forth Valley Smoking Cessation Services leaflet.

- NHS Scotland *How to stop smoking and stay stopped booklet.*

At the end of the consultation, patients set manageable goals regarding their smoking behaviours and booked an appointment for three-month follow-up.

### Evaluating the programme

This has proved more difficult. Only one of the 30 patients who booked a three-month follow-up appointment with the DSCEP attended their appointment. This could be attributed to not wanting to stop smoking or to patients in employment who have to take time off work, often unpaid, and do not view stopping smoking important enough for this.

These patients originally attended diabetes care for their review and when identified as smokers, were invited to participate in the DSCEP. Depending on their glycaemic control, some patients attend annually and some bi-annually and therefore for some, biomedical measures can be taken at six-month follow-up but for others it will be 12-month follow-up.

### Feedback from diabetes care staff

The DSCEP is firmly established within diabetes care in Falkirk District Royal Infirmary with consultants and registrars now referring patients directly to the programme. The feedback from diabetes care staff who have spoken with patients on the programme is positive and we are currently in the process of designing leaflets and posters to advertise the introduction of the programme in SRI.

The DSCEP is scheduled to run in Falkirk District Royal Infirmary for the remainder of 2008. Advice on how best to engage patients at three-month and nine-month intervals is currently being sought from academic supervisors at Queen Margaret University, Forth Valley Diabetes Care and Forth Valley Smoking Cessation Services.

**Margaret-Anne Macmillan**

Congratulations to YVONNE COUGHLAN, who won this year's RCN Diabetes and Cardiovascular Disease award with a very unusual initiative.

## HeartArt workshops

HeartArt is a series of art and health workshops that have been designed to help people with diabetes learn about their heart, using art. They are run by Yvonne Coughlan who is a practice nurse and artist at The Bromley by Bow Centre in East London.

Patients from the surgery diabetes register have been invited along to a series of four weekly art workshops where they can meet other people with diabetes and explore their heart health in a relaxed and creative way.

The first HeartArt session starts with understanding your heart through the use of printmaking – mono printing and drypoint printing.

The second workshop looks at the different layers of the blood vessels, how the surfaces are structured and the damaging effect to them of smoking and poorly controlled blood pressure. The workshop uses collage to explore these surfaces and to explore the consequences of vessel damage.

Workshop three looks at cholesterol through the activity of paper marbling with oils and inks. Participants make beautifully patterned paper whilst discussing the importance of cholesterol control and management.

The final workshop in the series is still life drawing of fruit and vegetables with pastels and a round table discussion of the



benefits of healthy eating and exercise.

Each of the workshops uses a visual means to engage with a health topic with the additional bonus of having a sociable and creative session.

Yvonne has also run a number of art and health projects at The Bromley by Bow Centre around other health issues such as iron deficiency anaemia and children with asthma.

GILL HOOD, Diabetes Research Network Manager for North East London, outlines the role of the Diabetes Research Network.

## Diabetes Research Network

Members of the RCN Forum for Nurses Working in Diabetes may now be familiar with the Diabetes Research Network (DRN) funded by the Department of Health. There are eight DRN localities within England placed in secondary and primary care sites covering most of the country.

The primary goal of the DRN is to achieve benefits for people with diabetes, or those at risk of developing the condition, through excellence in clinical research. Our own network – the North East London Diabetes Research Network – was officially launched in the Great Hall at Barts on 20 November 2007 and is led by clinical leads Graham Hitman and Chris Griffiths. We currently have six nurses, two research dietitians, a primary care co-ordinator, administrator and network manager.

People with diabetes, their carers and the public are also involved in the network in deciding what the research priorities

should be. For example, in East London we have a large black and minority ethnic population who are at greater risk of developing diabetes. Therefore research which aims to prevent diabetes is a priority. Studies on diabetes education, attitudes towards healthy eating and genetic factors are other areas of our work.

Research generated by investigators from different disciplines is most welcome. We have many pharmaceutical and epidemiological studies that interact with basic and clinical science. But research led by nurses is not so widespread. Our DRN aims to support and encourage nurses and other professionals allied to health who have an interest in diabetes research, both in hospitals and the community.

There is a formal process by which studies are adopted into the network which includes funding by a recognised organisation. Once this is achieved, the research may qualify for various types of assistance from the network which may

include help with recruitment, practical advice on ethical applications or even secondment aid for staff wishing to take time off to conduct the study. All such requirements are negotiated on a case-by-case basis.

The aim of the DRN is to facilitate diabetes research and thereby improve care for people with diabetes. Nurses must be encouraged and supported in their research ideas and studies because they have a crucial role to play in helping us achieve those aims.

Nurses wishing to know more about the network should in the first instance look at the website ([www.ukdrn.org.uk](http://www.ukdrn.org.uk)). If they have specific enquiries for diabetes research in North East London and Essex they should contact Gill Hood at [gillian.hood@bartsandthelondon.nhs.uk](mailto:gillian.hood@bartsandthelondon.nhs.uk)

**Gill Hood, Diabetes Research Network Manager, North East London**

**ELIZABETH PRICE**, a student nurse working in mental health, shares her experience of supporting someone with diabetes who also has depression.

## Helping to maintain nutrition in a person with depression and diabetes

I am a first-year mental health student nurse. While on placement on an acute ward I gained insight into the relationship between diabetes, depression and nutrition.

A diabetes diagnosis can have a great impact on a person's health and they may feel stigmatised by their diabetes because of cultural reasons or lack of understanding by others. Function in everyday life can be affected for someone who has diabetes who is also depressed and their glucose control can suffer as a result.

Mary had been diagnosed with diabetes some few years prior to admission on the acute ward. Mary was frightened by the diagnosis and had lost confidence; her depression had progressed and this resulted in a loss of appetite and poor diet. Mary stated that she had lost her appetite because of her depression and had lost all motivation to care for her diabetes. Medication had been started to treat her depression.

I helped implement the healthy changes put forward by staff and support Mary in reaching attainable goals. I gave reassurance to Mary about the improvement in health that occurs once diabetes is well controlled. Helping the patient to value themselves and keep a diary of their achievements may help overcome low self-esteem and aid recovery, so I helped to initiate healthy dietary changes by offering fruit on the ward at meal times and encouraged Mary to fill in her food diary.

Mary was unaware of her normal glucose levels and welcomed education and support with this. I encouraged Mary to take an active part in managing her diabetes by assisting in monitoring her blood glucose levels after developing a rapport and working with her, as Casement (1999) states it is important to learn from and comment helpfully to the patient. My interaction with Mary played an active part in providing holistic care which is an important part of the nursing process.

Mary's progress was discussed with the nurses and I gave them feedback as I had spent time listening to Mary's worries which in my experience is an important part of supporting the patient with their diabetes.

At the end of my placement, Mary thanked me for spending time with her and listening to her problems and as a result of this feedback I felt I had contributed in aiding Mary's management of her diabetes and ongoing recovery.

Mary eventually gained control over her diabetes and made considerable progress.

### Elizabeth Price

#### References

Casement P (1999) *On learning from the patient*. London: Tavistock Routledge.

## Diabetes Prescribing Network

Professor Molly Courtney from the School of Health and Social Care at Reading University and Jill Hill, your *Diabetes* editor, have recently set up a network for nurses and non-medical prescribers who prescribe for patients with diabetes.

Members of the network have the opportunity to meet three times a year for an informal but informative set of interactive workshops, and also receive a quarterly newsletter with information about headline issues that could influence prescribing.

The next meeting will be held on 10 June 2008 in Birmingham and will include sessions on lifestyle and self-management, including who should test blood glucose and how often; prescribing for obesity; what works in smoking cessation; and empowering consultations.

For more details, contact  
Nichola Carey  
Telephone: 0118 378 5983  
Email: [n.j.carey@reading.ac.uk](mailto:n.j.carey@reading.ac.uk)

## Wanted!

The memories of a nurse from a Caribbean background who worked on a diabetes ward during the 20th century are needed to be recorded for an oral history project based at the Oxford Centre for Diabetes, Endocrinology and Metabolism.

If you fit the bill, please contact the interviewer, Helen Lloyd by email: [helenlloyd@blueyonder.co.uk](mailto:helenlloyd@blueyonder.co.uk)

Alternatively write to Sue Beatty, Research Nurse, OCDEM, Churchill Hospital, Headington, Oxford, OX3 7LJ.