

## DAFNE USERS ACTION GROUP

Type I diabetics are keen to champion an education course that has changed their lives and given them the freedom to manage their diabetes rather than let it manage them. They are graduates of DAFNE, short for Dose Adjustment for Normal Eating, a five day course that teaches patients self management and how to match their insulin to their chosen food on a meal by meal basis.

Emma Ward, a 28-year-old pharmacy assistant from Essex who was diagnosed when she was 16 says: 'I remember feeling incredibly alone because I thought it was only me, I didn't know anyone my age the same. I was forever being told what to do and when to do it. I got to the point of pure frustration because nothing seemed to be working and I had begun to think I would never understand.

My moment came in summer 2006 when I took part in a programme called DAFNE, it seemed to be a defining moment in my struggle to understand my condition, and it changed my life in every way and more. I finally began to understand how to live my life with diabetes in it, I finally felt free to make my own healthcare decisions, to choose whatever food to eat and when to eat it instead of sticking to a set routine of getting up at certain times to do injections. DAFNE taught me to understand why and I have never looked back.'

While Peter Rogers, diagnosed at the age of ten, says: 'The course, the first diabetes training I had received in over 40 years, teaches carbohydrate counting, how to match insulin dose to food intake and how to adjust for exercise and sickness. Now, at last, meals did not have to be eaten at specific times and insulin could be adjusted for days where more or less carbohydrate was eaten. In a job which requires regular global travel, the flexibility provided by DAFNE has been a huge benefit and my last measurement of long term control, was the best ever.'

Why is it so important to achieve good blood glucose control for Type I diabetics? There is strong evidence that keeping blood sugar levels close to those of non diabetics reduces the risk of diabetic microvascular complications that can lead to kidney failure, foot ulceration, deteriorating vision and cardiovascular disease.

Both Emma and Peter are members of the DAFNE Users Action Group which was elected to work along side Health Care Professionals in shaping the future of this structured education programme for Type I diabetics in the UK and Ireland.

The aim of the group is 'To promote and support the continuing development of the DAFNE structured education programme and to represent the users so as to improve the quality of life for Type 1 diabetics and their families in the UK and Ireland.'

The fourteen members of DUAG, who were elected by the DAFNE User Group, set themselves a formidable number of tasks at their first meeting in September, which are to work with health care professionals on shaping research projects and contribute to the strategic development of DAFNE; campaign to increase awareness of DAFNE; lobby for sustainable funding to increase the number of DAFNE centres and represent the views of the DAFNE User Group.

All the members of DUAG are Type 1 diabetics who have been through the course and for them it is something of a personal crusade.

For the newly married Annette Bell, it changed her life: 'My diabetes nurse at the Hallamshire hospital recommended me for the course after my then new husband came with me to an appointment to see her. Alan and I had not been together long when I had severe hypoglycaemia during the night requiring the help of paramedics. It took them five hours to bring me round. This had happened three times when he decided to come with me and tell Lesley what had been happening. Since doing DAFNE my life has changed completely. I have not had any major hypos and I can eat what I like when I like, or not at all if I'm not hungry. For example, I went out to the theatre with some friends from church and on the way home they decided they'd like to go into an Indian restaurant for a curry. This was at 10.30pm. Previously I'd have had to refuse and go home. With the DAFNE system it meant I could join them in this spur of the moment meal and had a really good time with no adverse consequences. DAFNE has given me freedom to live a normal life without restriction and I would recommend it to anyone with type 1 diabetes'.

More than 14,500 patients have gone through the DAFNE course at seventy three Centres across the UK and Ireland and it has also been adopted by 20 centres in Australia, one in New Zealand and six centres in the Irish Republic. But these numbers are tiny compared to the Type 1 diabetics in the UK and Ireland who could benefit.

As Peter Rogers says: 'The dilemma of achieving good blood glucose control without producing hypoglycaemia was overcome in 2000 with the introduction of DAFNE. This provided a structured five day education programme which was initially run at three centres and has since been rolled out across the UK. Staff are trained by existing centres and are then audited to ensure consistent delivery across all centres. It has taken from 2002 for 73 centres to be trained to deliver courses in 113 localities.. The effect for me was that DAFNE was not mentioned at the clinic I attended. I heard of it from my sister, who also suffers from type 1 diabetes, who attended a clinic at one of the initial three centres. She came back from her course enthused about the virtues of the training and its positive effect on her control. Eventually the hospital I attend became trained in DAFNE and I attended the first course run in November 2007.'

And DUAG member Robert McKnight adds: 'I was lucky enough to attend one of the two hospitals in Northern Ireland which has had the foresight to provide DAFNE as well as the resources needed to deliver the programme. With empowerment comes greater responsibility in how I manage my diabetes, and I still have to meet the ongoing challenges of living with Type 1 diabetes and how it affects me, my family, my work and all aspects of my life.'

The members of DUAG have set up four work streams and these are the Liaison Group, the Awareness Group and the Lobbying Group and the Involvement Group whose task is to encourage DAFNE graduates to join the DAFNE User Group and become more active.

Their other crucial role is to become involved as users in new DAFNE research projects from the beginning providing the health care professionals with a 'critical friend'

All DAFNE graduates are invited to join the DAFNE User Group. Find out more at [www.dafneonline.co.uk](http://www.dafneonline.co.uk) or [www.dafne.uk.com](http://www.dafne.uk.com)

## Background

DAFNE is a high quality skills based structured education programme in intensive insulin therapy and self management where people with Type 1 diabetes are taught to match their insulin dose to their chosen food intake on a meal by meal basis. DAFNE provides 35 hours of structured group education and is delivered by specially trained diabetes specialist nurses and dieticians to groups of between six and eight over a consecutive five day period on an outpatient basis. DAFNE is an evidence based, evaluated, professionally delivered, quality assured peer reviewed and audited education package for Type 1 diabetics. DAFNE meets the four criteria required to fulfil the NICE requirements.

DAFNE has a solid evidence base. The programme has been developed over more than 25 years of rigorous research. This includes a randomised control trial in Northern Europe and a feasibility trial and economic analysis here in the UK.

## Patient Stories

Emma Ward, pharmacy assistant, Essex

To live your life in a constant state of anxiety would be how my life seems to have been so far. Since I was diagnosed 12 years ago at the age of 16 I have spent my whole adult life trying to understand what living with diabetes would mean.

I have vague memories of being made to practice injection techniques on an orange with a strange plastic device with insulin in it, being given a comprehensive list of foods I could eat and foods I could not (you can guess which was longer). I never really understood the importance or need to do any of the things I had to learn to take care of on a day to day basis. I remember feeling incredibly alone because I thought it was only me, I didn't know anyone my age the same. I was forever being told what to do and when to do it. I got to the point of pure frustration because nothing seemed to be working and I had begun to think I would never understand.

My moment came in summer 2006 when I took part in a programme called DAFNE, it seemed to be a defining moment in my struggle to understand my condition, and it changed my life in every way and more. I finally began to understand how to live my life with diabetes in it, I finally felt free to make my own healthcare decisions, to choose whatever food to eat and when to eat it instead of sticking to a set routine of getting up at certain times to do injections. DAFNE taught me to understand why and I have never looked back.

I was given the opportunity to mix with people just like me, I never realised how liberating it would feel to sit in a room with seven other people and for the first time since my diagnosis feel totally normal, knowing that everyone else had no doubt had the same experiences as I, comparing notes, swapping stories, feeling accepted.

DAFNE gave me back the freedom to choose, the freedom to live without fear and uncertainty, it gave me life. I make my own choices because I have been taught the skills and knowledge to do so.

Since that summer three years ago I have gone from strength to strength. I now play an active role in recruiting new patients to take up the DAFNE way of life, I believe that if DAFNE can make such a difference to me, just one person, then everyone should have the opportunity to live a life of total freedom from diabetes.

## ROBERT MCKNIGHT

I'm Robert McKnight, aged 53, from Northern Ireland, married to Margaret with a 15 year old daughter Victoria.

In the early nineties, there were a number of major changes which occurred in my life. Within a period of 6 months, I was diagnosed with Type 1 diabetes, got married, moved to live in Dromore, Co Down from a small family farm in the Mourne Mountains, got held hostage by one of the terrorist organisations operating throughout the Province at that time, and changed jobs to join Lisburn City Council as Assistant Director of Leisure Services.

When I was diagnosed with Type 1 diabetes in 1991, I had in hindsight all the classic symptoms of weight loss, thrush, frequent urination, tiredness and cramps, but although these symptoms were there, I finally decided to see the doctor when my eyesight became blurred. Driving home that evening, by coincidence, I was listening to the radio and there was an interview with Gary Mabbutt, the Spurs player, who is a Type 1 diabetic. As he outlined the symptoms of diabetes, I ticked every box and instead of going home, I went to the doctor's surgery and asked to be seen urgently. One test was enough to show my blood sugar level was 16 and arrangements were made to admit me to hospital where I spent a week getting stabilised and started on an insulin regime.

Over the past 18 years, there have been a few milestones or what I would see now as stepping stones in managing my diabetes. In 1991, and for the next 10 years, I was on two injections a day of mixed insulin - a strict regime of when I injected, and what I ate. Meal-times were crucial and I had to inject at least 20 minutes before eating which proved difficult and inflexible especially with my job where meetings could run into lunchtimes.

Moving to four injections a day allowed greater flexibility in eating and lifestyle in general, although it was my consultant who planned my daily insulin dosage. During this period, I would have on occasions given myself an extra unit or two if I was going to eat a large meal, but I would never reduce the amount of insulin from the consultant's recommendation.

Around 3 years ago, at the diabetic clinic, the specialist diabetic nurse explained to me about the benefits of DAFNE and I enrolled on the next available course in September 2007. The course gave a clear understanding of how I could better manage my diabetes control. It quickly became clear to me that if I get my 24 hour insulin dosage at the correct level, then the fast-acting insulin is only required to deal with the carbohydrates eaten at my meals.

The main benefits to me since starting DAFNE are

- Greater flexibility in injection times and when I eat
- More regular blood-sugar monitoring

- The ability to adjust insulin dosage based on blood-sugar level and carbohydrate
- Injections are now given when it is clear how much carbohydrate has been eaten during a meal
- The ability to make adjustments to the amount of insulin to take, based on the data from the trends in monitoring my blood-sugar levels -
- I feel that I am now more in control of my diabetes
- Help is at hand at the end of the telephone if I have difficulties or am sick
- Networks exist through the DAFNE user-group and DAFNE on-line for support
- Annual workshops from the diabetic clinic and regular telephone contact

I am lucky enough to attend one of the two hospitals in Northern Ireland which has had the foresight to provide DAFNE as well as the resources needed to deliver the programme.

With empowerment comes greater responsibility in how I manage my diabetes, and I still have to meet the ongoing challenges of living with Type 1 diabetes and how it affects me, my family, my work and all aspects of my life.

Annette Bell

My name is Annette Bell. I was on the, at the time two year, waiting list for the DAFNE course at the Sheffield centre from summer 2007. Fortunately for me someone dropped out of the course in January 2008 and I was given their place.

My diabetes nurse at the Hallamshire hospital recommended me for the course after my then new husband came with me to an appointment to see her. Alan and I had not been together long when I had a severe hypo during the night requiring the help of paramedics. It took them five hours to bring me round. This had happened three times when he decided to come with me and tell Lesley what had been happening.

Before meeting Alan (on an internet dating site!) in June 2006, my blood sugars had been very erratic, with several hypos while at work as a receptionist at Sheffield Children's Hospital. My lifestyle was very restricted having to do two fixed quantity insulin injections per day and eat fixed amounts at regular times. This had been my life from the age of 12. (34 years).

When I was first diagnosed we had to use glass syringes kept in methylated spirit and boiled once a week. Disposable needles were not available on prescription, and the only means of testing sugar levels was urine in a test-tube – add a tablet & check the colour of the resulting solution!

Since doing DAFNE my life has changed completely. I have not had any major hypos and I can eat what I like when I like, or not at all if I'm not hungry. For example, I went out to the theatre with some friends from church and on the way home they decided they'd like to go into an Indian restaurant for a curry. This was at 10.30pm. Previously I'd have had to refuse and go home. With the DAFNE system it meant I could join them in this spur of the moment meal and had a really good time with no adverse consequences.

DAFNE has given me freedom to live a normal life without restriction and I would recommend it to anyone with type 1 diabetes.

Peter Rogers

For me DAFNE (Dose Adjustment for Normal Eating) was a salvation. I was diagnosed with type 1 diabetes in 1966, aged of 10. At that time diabetes was controlled with a strict diet and a daily injection of insulin. The diet was based on a fixed carbohydrate intake at the same times each day. Control was measured by testing urine for glucose - an indirect means of monitoring blood glucose level which could only be measured directly at a laboratory.

Treatment has become more sophisticated since then. The number of injections increased and different insulin types were introduced. Testing blood glucose at home also became the norm. The first meters were introduced in the early 1980's and now measurement can be made in seconds with a minimal quantity of blood using a meter which will easily fit in a pocket. However, whilst advances were made, the dietary restrictions remained.

Type 1 diabetics are now encouraged to keep blood glucose close to non-diabetic levels as doing so reduces the risk of diabetic complications. However there is a risk of hypoglycaemia (low blood glucose). This results in confusion, disorientation and eventually unconsciousness and is feared by type 1 diabetics.

The dilemma of achieving good blood glucose control without producing hypoglycaemia was overcome in 2000 with the introduction of DAFNE. This provided a structured 5 day education programme which was initially run at three centres and has since been rolled out across the UK. Staff are trained by existing centres and are then audited to ensure consistent delivery across all centres. It has taken from 2002 for 73 centres to be trained to deliver courses in 113 localities.

The effect for me was that DAFNE was not mentioned at the clinic I attended. I heard of it from my sister, who also suffers from type 1 diabetes, who attended a clinic at one of the initial three centres. She came back from her course enthused about the virtues of the training and its positive effect on her control. Eventually the hospital I attend became trained in DAFNE and I attended the first course run in November 2007.

The course, the first diabetes training I had received in over 40 years, teaches carbohydrate counting, how to match insulin dose to food intake and how to adjust for exercise and sickness. Now, at last, meals did not have to be eaten at specific times and insulin could be adjusted for days where more or less carbohydrate was eaten. In a job which requires regular global travel, the flexibility provided by DAFNE has been a huge benefit and my last measurement of long term control, was the best ever. DAFNE does not suit everybody as the additional blood tests and injections can be seen negatively. However, for anyone who leads a varied life and needs flexibility, or anyone who needs to improve their control, I cannot recommend the course enough. It has changed my life. I can now control my diabetes rather than having it control my life.