

Foundation:

Group education for people with newly diagnosed type 1 diabetes

Program:

Session 1 (3 hours 3-6pm)

- **Welcome**
- **Aims and expectations** - discussion of course content and your expectations of the course.
- **What is diabetes** - what happens in the body with type 1 diabetes. Discussion of your symptoms and how you felt when you were told you had diabetes.
- **Treatments** - discussion of insulin treatment, your blood glucose levels and what we are aiming for with treatment.
- **Introduction to dose adjustment** - how to solve problems with blood glucose levels by adjusting insulin.
- **Hypoglycaemia** - what is hypoglycaemia, what causes it and how to treat it.
- **Food** - relationship between food, blood glucose levels and insulin.
- **Questions & Answers**

Session 2 (3 hours 3-6pm)

- **Welcome**
- **Review** - Remember what was covered last time. Review any changes you have made since last week and work through dose adjustment examples.
- **Food and dose adjustment** - Further discussion of food, insulin, physical activity and blood glucose.
- **The annual review** - What to expect at your yearly check-up. Why it's done, discussion of the complications of diabetes, what you can do to stay healthy with diabetes.
- **Fun Quiz;** covering other issues affecting diabetes management including; alcohol, physical activity, what to do when you are ill and driving.
- **Social issues and Dr's questions** - time to discuss your questions, a diabetes consultant joins us for this session and will talk to you about any other issues you may have.

Focus groups - type 1 pathway

- **Think back to when you were first diagnosed and up to the first 3 months, what comes to mind about the care you received.**
 - **that was negative**

Cut adrift, more reliant on family and friends with DM rather than HCP's sometimes got conflicting advice.

Feeling poorly at the beginning can't take it all in.

Just doing your own thing, some specialist nurses were more up to date than others, undermined confidence.

Like bringing home a new born baby, didn't know what to do but didn't seem like HCP's knew what to do either. Didn't know who to turn to.

Someone should explain that BGL's will vary and that you're unlikely to get it right and that it will take a long time. There is an expectation that you will get it right and then when you don't it undermines your confidence.

Bad inpatient experience-referred to as "the new diabetic" and discovered that the records at the end of the bed were inaccurate.

Differing advice from different HCP's how accurate was this advice? Seemed like some HCP's were giving out of date advice.

I thought that someone would be able to tell me exactly what to do, but you can't you have to find out for yourself.

Some reference to DAFNE that they only really felt like they understood what was going on after doing the DAFNE course.

- **Think back to when you were first diagnosed and up to the first 3 months, what comes to mind about the care you received.**
 - **that was positive**

When I was diagnosed I was seen by a specialist, I'd no idea what diabetes was. He explained that it's down to you to sort yourself out and there are no definitive answers. I saw him every three months for the first couple of years, I don't take any notice of anyone else.

Dr.....was just a bit more realistic. Live your life and then suit it to your life.

GP said I'm not a specialist but we'll work through this together. Gave really helpful practical advice.

All the nurses I've seen have been quite helpful and quite nice.

Having the phone number of the specialist nurses was really good I could ring up and give my numbers, but I think it would have been better to see someone face to face, it was 3 months before I saw someone again and I think that was too long.

The specialist nurse that I saw was very down to earth.

It would have been nice to speak to another diabetic...that's what you want.

That would be good but the person I spoke to belittled how important it was to me, she dismissed it.

If we're talking about the first three months what would be good is something like this.

.....someone with real life experience.

When we were newly diagnosed we came to a group...("where they all newly diagnosed?") yes they were all like us.

Access for the first three months to some kind of hotline...so you have someone to turn to....

But you have the specialist nurses here.....but you don't always get the same one...

The nurses on the DAFNE course are fantastic

But they tell you not to test too much....but when you're doing stuff you've just got to know....another diabetic would understand that.

It's a case of not doing anything about a high test in between meals.

Since you were first diagnosed when you think about the care you have had what has been negative?

When I come to clinic here (LGH) I don't think I've once come away not feeling cross, not with anything specific, it's about customer care and customer service. Some of the staff because there seeing how ever many they see you are just a number. Someone comes and stands over you with drops and says "put your head back" and you think what's this for? what's this about? And you have your annual review with the consultant and people just walk in and out.....and the person that's talking to you loses your train of thought.- much agreement with this.

I think what would be really useful is if everyone who came to clinic got a customer care thing, instead of what was positive and what was negative.....what could we do better.....you know, not talk to you like an idiot and not interrupt you.

When I was first diagnosed and admitted they never once referred to me by my name I was always "the new diabetic" I thought hello I'm a human being! If you speak to me I might be able to answer some of the questions your asking (each other) about me! The stuff they'd written in my notes was absolute garbage they hadn't asked me any of the questions they had ticked in their book I thought if you speak to me you would know that that doesn't apply to me.

When you come to the annual review it's pretty good everything that's done but you do feel as if you don't matter...it's just like you're being shunted through.

I've been given a choice if I want to come here or see my GP....(Interrupted-I'd stay here I would.....yes these are the experts here)

I didn't know you could get discharged...can you get discharged?

That must mean your control's spot on if they've discharged you?

Or you're a real pain in the arse!.....all laugh.

Since you were first diagnosed when you think about the care you have had what has been positive?

DAFNE....agreement from others who had been on the DAFNE course.

The thing that was really interesting.....on the course that I went on...I'm not sure that DAFNE would suit everyone in-so-much-as the course I went on there was a lady and she really struggled I think she found it not enlightening...I felt as if someone had switched the light on but it completely did her in.

I don't think you could put everyone on it you need a certain level of intelligence.

But fundamentally the information you got was and really sound...it just depends how you put it across, not everyone is as intellectual as everyone else but the information that you get is essential.

Oh it's fantastic, I mean you could do bits of it...like the bit about annual review, why do they do that? What's that test? What's it for? I'd been diabetic for 12 years and that's the first time I knew! I was still in the phase where they say put your head back and put these drops in (-shrug)

Some of the really basic stuff... my drink of choice is orange juice...second day of the course it's a hypo treatment...just sorting that out dropped my readings to normal levels...I mean that's just 1 little bit of information. When they said oj works quicker than insulin I thought what's that how come I didn't know this before...and that was just one little bit of information.

What you're saying about not knowing stuff, when I go I just question it. I say well what are you doing this for what're you doing that for? I found out like the drops that you can sit in a dark room for half an hour...that's how I've found out these bits of information...just question everything like.

I think that depends on what kind of person you are (interrupted yes you just accept everything)

If you just sit there thinking I don't know what's going on it keeps happening.

I think the huge majority think they're the experts...they do as they're told, I would guess you're in the minority. I think I'm fairly challenging by nature but I wouldn't challenge everything.

It's not challenging really it's just asking for more info so you get a bit more background.

Knowing what questions are ok to ask so that you don't feel stupid. that's the thing because you're sitting in a room with experts and you think well if I ask that they'll just laugh me out of the room.

But they might not have thought of that. They might think we're pie in the sky experts but they might not have thought about it in the real world.

That's the thing about DAFNE when Dr.....came down we were firing all these questions at him and he said well I never thought of it like that...yes you could do it like that...so it gave you that sort of...push.

When I went on my DAFNE course I'd been on the course for people who were newly diagnosed and there were people there who'd had it for 20-30 years and I knew more than some of those who'd had it for 20 odd years.

But isn't that part of the danger of discharging people?..yes
Because if you've been discharged for five years you slip into just going for that prescription and you don't know what's changed and what's new. You just roll along and wait until something goes wrong and *then* you go back again (to secondary care). It's too late.

I think you've got to suss out how to work through problems yourself..thats how I do it.

Yes patient empowerment is all right but you're not the expert that's the trouble.

I think when you're first diagnosed if they explain that this is like a fluid thing and you've got to suss it out for yourself at least you're hearing that from the expert. So you know that you can have a play sort of thing.

When I was diagnosed they told you what to do and you went home and did it. And then it all went all over the place. But they didn't sort of say well if it goes high you can do this.

I think when you're first diagnosed you need to be told. When I was diagnosed was told have this insulin and I went home and I had the insulin but I couldn't fit enough cereal in my bowl, I had to have a break and then have some more!

I got told different...I got told do this for a start and then if you find that you're eating too much just reduce it, and I always have done.

It's a difficult thing (what you're talking about) when you first start from day 1 to get to that point where you feel as though you understand it and you understand your body. it's about when you're just diagnosed how do you get these people to that watershed.

Yes where they feel confident.

If you were diagnosed tomorrow what service should be provided? What care should you expect?

The first thing is an explanation for why you're being admitted if you need to be admitted cause I still don't know why I was admitted.

Also I was told I had type 2 and it wasn't until I went on the DAFNE course that there was a big row about whether I could go on the DAFNE course cause it's for type 1's but I was never told I was type 1 until then.

(2 pts in same conversation)

Some face to face contact either weekly or depending on the person...

Weekly I think at the beginning because you're so alone.....

.....yes because you do different things every day and you're trying to get on with your normal life but your bloods are stopping you wanting to do them because you don't think you understand what you're doing with them. So just a chance to see somebody once you're back into reality to work through things with them.

Almost like if you could have some kind of diabetic buddy (yes-lots of agreement) someone who you could rely on (interrupted.....yes someone you could ring up). I was fortunate in that my brother is diabetic....if you could have someone... not to give you definitive medical advice but reassurance...but there's a lot of stuff that you get really worried about that you don't need to worry about.

Yes just a bit of information...like you said about your orange juice.

I think when you're first diagnosed.....I think you need the hope of going on a DAFNE course I think you need it explained that a lot of things will make sense once you've done it.

The DAFNE course could be something that you could aspire to.

I think when you're first diagnosed a think a think a lot of the gems of the DAFNE course you should pull those out just the little bits like hypo treatments and just explain those bits.

Hypo treatments are really important.

You could almost have like a leaflet or a recorded thing where you could ring it if you wanted more information and someone could almost talk you through it. You know the highlights without going into detail.

Or some kind of hotline or helpline.

I think the scary thing is when you're first diagnosed you just don't know what to do.

Yes and you feel so ill.

I think I got some dead good information, really practical about real life, and I kind of sussed it straight away....but it was perhaps the way it was put across to me...it wasn't in a technical or medical way. It was just if your blood sugar goes up you do this...have a go and give us a bell.....just see what happens. Cause it was so basic and practical and pretty obvious, it wasn't sort of flowered up or anything, it was just dead easy really. Well it wasn't dead easy to do but it was easy to take the information in.

Yes that's good.

The idiots guide....(laugh.)

I mean even injecting yourself they just come along and you think I can't do that....needles...but you have to get on with it.

I mean Dr.....was always dead practical you could have a chat about real life stuff and he was alright about it...there was never anything technical.

You almost feel as though you've got to put your entire life on hold, you are not your own person doing your job you are now a diabetic. Period. And everything has got to go on hold.

You need someone to give you some confidence.

The danger is if you don't get this information and I'd go and do it then it would just stop working so I used to play with it myself once you start playing with it sometimes it works and sometimes it doesn't then when they have a look at your book-and to be honest some of it was fabricated-but then what would happen the consultant would see it, they're not daft but they'd give you some more advice based on the book.

When I was first diagnosed I went the other way....i thought I can do this and I'm going to do everything as normal and walk the dogs as normal, because I was so angry about it I think. So I think HCP's need to have the contact regularly with you so that they have the opportunity to recognise how that individual is coping with their diagnosis rather than say this pathway means that when someone is diagnosed this is what we'll do.

(Much agreement)

Everyone's different.

This is what's fundamental to it, that you can't really start teaching people until they're ready to learn. (Much agreement)

Until you're in that space where you're ready to start learning...

Yes you've got to get rid of that scary period..

It's like that 0-3months...there's no point bombarding people, because it might take some people a day and it make take six months for some people. Now if you've gone through your three month pathway and you aint ready yet...then what?

But you could be seen what maybe three or four times?

I was seen every 4 weeks for little bits of information.

It's so difficult because everyone is so different.

That's the other point though, I'd never been ill, I'd never been in hospital or anything and then to suddenly have to start planning my life around hospital appointments....I think I would have had a problem with that. Cause if I was in that denial phase and someone was telling me to come in in two weeks three weeks I probably would have said look I'm not moving in forget it I'll deal with it at home.

There needs to be a recognition there should be a drop in or something so that when people are ready to get advice they can come in.

Or even that drop in thing that you knew that every Thursday or something that there would be a diabetic specialist and maybe an experienced diabetic.

Yes you could just run something by them.

I didn't know any diabetics until last year...I'd never even had a chat with anybody who was a diabetic.

My brother is a diabetic and I could talk to him and it just makes you feel more human.

Part 1

Use this template to create and action plan for your centre

What aspects of the current service are good?

What can be developed or improved on?

What new things could be introduced?

Part 2

Which of these am I going to tackle?

What problems/barriers am I likely to encounter?

How will I deal with this?

Who can I ask for support?

Time line

Next week

End of June

Before Christmas!!

Preparing for DAFNE from diagnosis - *structured education for people with newly diagnosed diabetes*

Background/Introduction

Considering the work produced by Sue Roberts on a new approach to type 1 diabetes (see below), the workshop aims to look at the part of the pathway in figure 1 between confirmation of a diagnosis of type 1 diabetes and attending a DAFNE course. What are the options for helping an individual to prepare to attend a DAFNE course?

In Leicester we have developed the Foundation group, a structured group education programme which can increase an individual's self-efficacy in managing their diabetes (see DUK poster presentation). It also aims to address deficits in knowledge and skills in the initial months post diagnosis by providing a comprehensive curriculum covering key themes. Indirectly we feel this helps to signpost people towards MDI and eventually DAFNE while giving them a taster of what group education using an adult learning approach feels like.

Learning outcomes;

- Share and discuss models of care considering Leicester's foundation group as one example. (bearing in mind that the Foundation programme was not developed specifically with DAFNE in mind)
- Discuss how these models may be adapted and incorporated into the existing DAFNE service.
- Discuss the key knowledge and skills themes that should be covered between diagnosis and DAFNE (may wish to use Leicester's timetable to facilitate discussion).

