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Stourbridge, Dudley & District
Voluntary Support Group
Your Group, working for you

Public Meeting held Tuesday 15 March 2011
David Lloyd Leisure Club, Brierley Hill

Panel Members

Peter Shorrick	Manager, Diabetes UK Midlands, and Chair for the evening.
Joe Gutteridge	Long Term Conditions Commissioning Project Lead, PCT
Dr Jane Dale	Medical Services Head, Adult Diabetes and Endocrine Service, Dudley Group of Hospitals
Dr Tim Horsburgh	Dudley PCT Clinical Lead for Children's Services and a local GP
Sue Bacon	Lead Diabetes Nurse and Manager of the PCT Diabetes Team

Key Questions and Comments

Simon Hanson, Group Committee Member, presented the results of both the adults' and children's surveys. The full reports are available on the Group's website.

The following notes are not verbatim, but are simply a record of the key questions raised and answers given.

Q1 – Will we still have free foot and nail care? Appointments are approximately 5 months apart and lots can go wrong in that time.

A1 – If you have diabetes and any problems with your feet you can be pretty confident that you will continue to receive foot care from a podiatrist. If your feet are checked at your annual review and no risks identified, then it is left at that. If risks are identified you will be referred to a podiatrist for specialist care.

Q2 – What about the (lack of paediatric) nurses when they go off to have babies?

A2 – This is a problem because there isn't anyone else out there in the West Midlands to take their place; it's not a financial issue.

Q3 – What does tingling in your feet mean?

A3 – The annual foot exam is the best tool to decide if your feet are at risk. Mention any tingling etc at this review. If normal pulses etc are found, then it may not be a major problem at that point in time, but you should definitely mention it to your Doctor.

Q4 – At what age are the feet checked?

A4 – Children are checked from the age of 12, but preferably from a younger age, although it depends on when the child was diagnosed.

Q5 - We are going abroad this year for the first time since being on insulin and I would like some advice on the best way to carry the insulin both during the flight and while on holiday.

A5 – Contact your medical team for advice on your travel itinerary and general advice on taking insulin through Customs, crossing time zones etc. If concerned about appointments being cancelled, you should contact the Consultant's Secretary.

Information provided following the meeting by Diabetes UK:

Insulin should ideally be kept in a FRIO style pack while travelling, to ensure it is kept at the correct temperature, some airlines will want to keep the insulin in their fridge while in transit. All equipment and insulin should be kept in separate bag, and shown to the check-in staff, along with a letter from their GP confirming they have diabetes. It's a good idea to check with your own airline, before travel, as some have different regulations. The following links should be of help:

http://www.diabetes.org.uk/MyLife-YoungAdults/Treatment-and-care/Insulin/Storing_insulin/

<https://www.diabetes.org.uk/OnlineShop/Promotional-items/Insulin-cool-pouch/>

http://www.diabetes.org.uk/Guide-to-diabetes/Living_with_diabetes/Travel/Air_travel_and_insulin/

<http://www.diabetes.org.uk/FAQ/Travel-questions/Will-they-let-me-take-my-insulin-in-my-hand-luggage-on-the-plane/>

You can also call our Careline on 0845 120 2960*, Monday to Friday, 9am to 5pm. The lines are staffed by trained Careline counsellors who would be happy to offer whatever support they can.

Q6 – My child was diagnosed in September and has already had their consultant appointment cancelled in February, therefore, it will be 6 months before we see a doctor in May.

A6 – If you are not happy about your appointment being cancelled, you should contact the Consultant's Secretary to see what other arrangements can be made.

Q7 – I don't feel that contacting the Secretary helps at all, as this problem has been going on for a long time.

A7 – There has been a specific problem this year with staff sickness affecting the service which was unexpected and unavoidable. We are looking at the booking system and considering a 'partial booking service' which should improve things. We also need to know that parents will keep the appointments that are made for them. Watch this space

Q8 – What difference, if any, will the new commissioning process being given to GPs make to diabetes care locally?

A8 – The White Paper is still going through Parliament and not finalised as yet. Previous 5 Practice Based Commissioning Groups in Dudley are to be merged into one over next year to pull all the GPs together to buy / commission services in the Borough. This relates to hospital and community services, and diabetes services are a big priority.

The PCTs of the Black Country are to be grouped together into a Black Country Cluster which will be above the commissioning groups, to look at the more specialist services. Shared development and commissioning of services should help the services to develop more effectively.

Our area is going for early adoption of these new arrangements ('Pathfinder' status) as early as from April this year. There is very strong GP input into diabetes services, with GP Lead being adopted earlier this year, Dr Helen Moran.

A lot of services now for adults are delivered in the community and it may be that there is not enough resource in consultant clinics to deliver the services in the traditional way, which may result in them being delivered via GP services in the community closer to where people live.

The White Paper is very much an outline at this stage, with more detail required.

More information is available via the weekly newsletter on the PCT website with links to other useful documentation, minutes of meetings etc - www.dudley.nhs.uk/gpbrief.

Q9 – My GP does not believe in diabetes pumps, so who will fund this?

A9 – This service is commissioned through the acute trust. Nobody in Dudley is being turned down due to lack of funds. If your GP says no, then ask to be referred to a diabetes specialist.

Q10 – How are you going to undertake the care of children and adults during this new commissioning process?

A10 – This will impinge on things, but there is no intention to change the services at the moment, so they will continue as normal. The vast majority of GPs in our area will not be spending their time doing the commissioning; a small, core group will focus on this, with the rest continuing with the service as normal. We are aware that there is a lack of paediatric nurses in the community but they are simply not easy to come by.

There is training available to the nurses to specialise. A couple of years ago, a post was created to develop a nurse (ie Alison Peasgood) which enabled Alison to take over when Louise and Hayley both went away on maternity leave.

Q11 – Will that post remain when the other two Diabetes Nurses return?

A11 – That is very difficult to say. We are commissioned for just over two PDSNs.

Q12 – Who do we put a complaint into regarding inadequate services?

A12 – You can send any comments in writing to Sue Bacon, or to Tracy Lee in her role as a patient/parent representative on Standards 5 & 6. The next meeting is scheduled for Friday this week.

Q13 – In view of IDDT publications regarding artificial insulins, does the NHS have any concerns, and if so what are they?

A13 – The Insulin Dependent Diabetes Trust (IDDT) is a private forum which looks at various insulins in use. A few years ago there was a big transition from animal to artificial/analogue/human insulin. Some people felt unsettled by that change, but medical research has since shown that modern insulins are better for people. If you feel as an individual you are treated better by a particular insulin then discuss with your GP. Manufacturers do tend to withdraw insulins as demand falls.

Q14 – Which studies shows these insulins are better?

A14 – There are many studies. We used to see an awful lot of problems with localised issues in the body fats which is seen much less now with the new insulins. For one or two individuals this is not always the case, in which case we are happy for people to use another insulin.

Q15- Is there the option to mix human and animal insulins, due to potential cancer risks?

A15 – The European Agency says there is no link to a cancer risk to the current insulins being used. Discuss the right treatment for you with your healthcare professional.

Q16 – Are there any natural supplements (herbal) that can help control diabetes type 2 in addition to traditional pharmaceuticals?

A16 – Taking herbal medicines *only* causes problems so please don't stop taking any of the research-based products that we currently recommend. There isn't any real evidence showing one is better than the other because there is no way we could say that it would work for you. Our main recommendation is that you have a well balanced diet.

Q17 – I have problems with vitamin B with Metformin.

A17 – Metformin can cause stomach upsets in some people, but there is a second formulation – slow release Metformin - that is much gentler on the stomach, so it is recommended you try that before giving it up.

Q18 – How long does that tablet stay in your system, as it makes me sick?

A18 – If you are taking a tablet that's making you sick you need to speak to your doctor about changing your treatment.

Q19 – On average, how long is someone on tablets only before needing to inject insulin when they have type 2 diabetes?

A19 – This is a very difficult question to answer. Type 2 diabetes is probably caused by a lot of different reasons. One person can be on insulin right from the start with type 2, whereas someone else can manage on diet alone for over 20 years. What we do know is that people do tend to need more medication the longer they have been diagnosed, but it is different for everyone.

Q20 – I understand children are tested annually for coeliac. Are adults tested annually?

A20 – With adults with type 1 diabetes they are screened about every 3-5 years for coeliac disease. That is a long time so it can be overlooked, so if you think it has been missed then do ask.

Q21 - Should this be brought in as a protocol rather than just good practice?

A21 - Yes, probably.

Q22 – My son was diagnosed with type 1 diabetes three months ago, then had an adverse reaction overnight and became very poorly. It was suggested by someone else that he could be reacting to his insulin and that it should be changed. Why didn't the consultant think that it could have been the insulin?

A22 – Experience shows that this is usually a very rare problem, and it may take quite a while to work through the potential problems.

Q23 - The consultant wasn't prepared to consider it and told to come back in a few months.

A23 – We need these cases to come back through our service so that we can review them and see if we need to alter the way the services are given to people. We don't have all the answers and we are learning all the time. We will take this to Standards 5 & 6 on Friday.

Q24 – Up to a year ago my eyes were fine, then I was told I had background retinopathy. This year I was told that it had disappeared – is that unusual?

A24 – This is quite normal as background changes can wax and wane.

Q25 – I have been diabetic for 29 years; in Spain I can buy at least a dozen different types of biscuits that are sugar free. Diabetes UK says you shouldn't have biscuits – we deserve these kind of treats!

A25 – I shall have a word with those who made that decision! The advice from Diabetes UK is not about avoiding biscuits or jam, it's about not recommending diabetic or low sugar options. Eat moderate amounts of normal food, not specific 'diabetic food'.

Q26 – Type 1 diabetics are offered DAFNE course for nutritional advice; is there anything similar for those with type 2?

A26 – 'Discovering Diabetes' is available in Dudley which is a one day course. It is run by a dietician with helpers from Diabetes UK. We are looking to extend that in the future with the 'Xpert programme', which will be 2.5 hours per week over 6 weeks. An insulin course is also run for those with type 2.

If you want more information ask your GP or healthcare team. A lot of leaflets have recently been printed which we will be sent out to GPs and the Support Group in the next few weeks.

Comment – The ‘Discovering Diabetes’ day course is very good indeed. Everyone who attends thinks it’s well worth going along.

Q27 – Why has retinopathy screening been cancelled at Russells Hall?

A27 – That is a difficult question, and we are sad that it was. There is a national directive to centralise the retinopathy screening; under the new contract it is run by Heartlands Hospital, it was not viable to run it any more at Russells Hall. The PCT are looking for another community location – probably Brierley Hill Health Centre within next few months. Screening by the local Opticians is still available.

Q28 – Comments were made in the questionnaires about it being very useful being a one-stop-shop for feet and eyes.

A – It is the GP’s responsibility to do the annual review, so probably before that came into place it would have been done in one place. Some of the unintentional effects of these decisions can make people’s lives more difficult.

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