



Minutes of meeting Thursday 23rd June

Present

Peter and Diane Barker, Nigel and Dawn Hammond, Sarah and Mark Hibble, Viv Ryan, Alistair Scott, Neil Griffith, Mary Hartley

Mary Hartley

Mary began by introducing herself and her role. She works as a commissioning manager in the Primary Care Trust (PCT). She explained that the PCT has two roles, half of its responsibility lies in providing services for example GP's, District Nurses, Diabetes Specialist nurses etc. The other half is around looking at what services they can buy and how to make the funding spread around the services, this must also be linked to targets for example National Service Frameworks (NSF's) and National Institute for Clinical Excellence (NICE) guidelines.

The NSF has sparked a local planning group called a Local Implementation Team (LIT) The team consists of professionals such as Consultants, Nurses, Optometrists, Dieticians etc who meet to look at the targets, look at what Milton Keynes has got and what we need to get to and how the PCT can provide what is needed.

Mary explained that there are currently around 104 children on Jan Murrays caseload who Milton Keynes PCT are responsible for, the PCT are aware that they are not providing enough hours for Paediatric Diabetes Specialist Nursing and that there is a standard to reach. There are some very hard decisions to make regarding funding but the LIT Team has made a bid for more hours. Mary expects that they will know by December/January about next years funding.

A lot of questions and concerns were raised from parents about there not being enough support or contact points, also that the children were being treated by a General Paediatrician and not Paediatric Diabetologist meaning that the service we get is more reactive rather than proactive. There were many accounts of parents feeling they were leading in their Childs care rather than being led.

There also seems to be a lack of psychology support, there were a few families who were reaching a major crisis before being offered psychological support, there are counseling services within the community but they are not easily tapped into.

Podiatry – the Nice guidelines suggest that all children have a yearly foot check from a podiatrist however this is still not happening.

Following concerns from a few parents around the level of knowledge amongst GP's which appears to vary across the trust Mary explained that with the new GP contracts they have targets to achieve within Diabetes care, for example for each diabetic registered with them who has an HBA1C at 7 they score points which is linked to funding for the practice, this however is linked to adults only at this time.

Mary gave some background information on work being undertaken by Milton Keynes Council who are reviewing provision by schools which tends to be variable. Mary will feed back to the group that from a parent's point of view the first year from diagnosis especially is crucial. A suggestion was made that there should be a clinical protocol written, that all schools are contacted and made aware of newly diagnosed children and offered some background information and support. Although this service is provided by Jan it is on an ad hoc basis and dependant on parents to make the decision as to whether she contacts the school.

The group asked if there was any information on how many patients was an acceptable caseload, Mary was not aware of any statistics.

Mary praised the group on their efforts in highlighting the difficulties faced by families when contacting MP's, which helps alongside the NICE guidelines, and NSF to support her bid for more funding.

Nigel then handed over letters from other families who were unable to attend highlighting some of the problems they had faced. A concern from the group was around an apparent lack of contact from the paediatricians to the diabetologist; Mary informed the group that there was currently a paediatric medicines review as there are many medicines not licensed for children. Mary suggested lobbying NHS Direct to arrange 24hr specialist phone support, as often the advice from them was not adequate

Mary has offered to keep the group updated via e-mail to Nigel.

Sherrington Fete

Alistair has all the tombola prizes in his van. Angie Gardiner kindly donated a Lord of The Rings special edition picture, it was felt that the best way of getting the most amount of money for this valuable donation was to sell it on ebay. Sincere thanks go to Angie.

Swimming Pool fun night

Mark has booked the Middleton Pool at Newport Pagnell for Saturday October 22nd, 6-7pm in the pool and 7-8pm dry time. More details to follow.

Research Projects

It was decided to carry this over to the next meeting.

Next meeting Tuesday 19th July Caldecotte Arms 8pm