APPENDIX B

Local Services for children with type 1 diabetes in East of Berkshire

Introduction

Paediatric diabetes care involves diabetes care for children under the age of 18 years [before their 19th birthday] including new diagnosis, regular follow-ups and the clinic reviews. The majority of them have type 1 diabetes but a minority do have type 2 diabetes or other forms such as CFRD [Cystic Fibrosis Related Diabetes] or MODY (Maturity Related Diabetes in the Young).

What is Type 1 diabetes?

Type 1 diabetes develops when the insulin-producing cells in the body have been destroyed and the body is unable to produce any insulin. Insulin is the key that unlocks the door to the body's cells. Once the door is unlocked glucose can enter the cells where it is used as fuel. In Type 1 diabetes the body is unable to produce any insulin so there is no key to unlock the door and the glucose builds up in the blood.
http://www.diabetes.org.uk/Guide-to-diabetes/Introduction-to-diabetes/What_is_diabetes/What-is-Type-1-diabetes/

Aims of the Service:

- To enable the child or young person with diabetes to lead a full active and healthy life.
- To educate the child and family about diabetes and its management
- To educate those involved with the child at school about diabetes and its management
- To monitor and optimise normal growth and puberty.
- To be aware of, and offer help for, any psychological problems
- To ensure that all hospital staff are aware of current policies
- To be available to families for discussion of problems, and to offer a consistent approach.
- To keep up-to-date with current best practice and to have an active involvement in audit and research.
- To participate regularly in local and national audits and be part of the regional paediatric network, share best practice and keep all staff up to date on evidence base

Type of service:

They are both in reach and out reach and cover all 3 sites. It includes home visits, school visits and telephone advice.

All managed in Wexham Park Hospital (Frimley Health)
As of 2003 records there are:
170 pts
162 with T1DM
6 with T2DM
2 with other forms

Location/Types of services
Wexham Park Hospital x 5 children's clinics monthly

Heatherwood Hospital x 2 children's clinics monthly

St Mark's Outpatients x 1 outpatient clinic monthly

King Edwards Diabetes Centre (follow on adult centre), King Edward VII Outpatients, Windsor

Inpatient service beds: As per need, within Ward 24.

Treatments and Procedures Offered: All aspects of diabetes care.

Support Groups: Parent support group has recently formed and they are setting up a charity fund for the service

Education Sessions

Monthly Education sessions are held in either the post graduate centre at the hospital of in the seminar Room in the Children's Clinic. Various topics covered include insulin pumps, carbohydrate counting, exercise and travel, sick day management & ketone testing, HbA1C, long term complications, sex, drugs and alcohol, moving on up and transition for beginners etc.

How to Contact

http://www.heatherwoodandwexham.nhs.uk/services/paediatric-diabetesdiabeticchildren@googlemail.com

Quality of care and performance monitoring:

What is **Best Practice Tariff [BPT]** for Paediatric diabetes?

Best Practice Tariff (BPT) for Paediatric Diabetes became mandatory in 12/13 for all providers to achieve the 14 required service standards. The tariff meant that providers are paid a year of care tariff for all non-admitted care rather than the standard new or follow up outpatient appointment tariffs. Achievement of these standards should denote very high quality care provision and this 'best practice' may reduce future care required and therefore health spends. If they met the standards, the PCT [now the GP commissioners] would pay the providers a nationally agreed standard tariff ~ **£3500** [plus Market forces Factor] per child per year.

There are regular scoping/performance monitoring meetings between the commissioning, contracts and the provider organisations to make sure that all the 14 criteria are met and children are offered the best available care locally and close to their homes. The providers [acute care] are also expected to regularly collect patient experience feedbacks and offer guidance on self-management, refer to appropriate patient support groups locally or through the Diabetes UK. The local service provider for children and young people <19 years of age [acute care] needs to submit data and be able to demonstrate that they can meet each of the 14 individual Best Practice Tariff [BPT] criteria, also taking into account the provider's performance on the National Paediatric Diabetes Audit, their commitment for additional investment to increase the MDT capacity, IT/software/data collection and collecting qualitative information and patient/carer's feedback. The 14 indicators must be met for at least 90% of children and the BPT is paid on an all or nothing basis.

These criteria are underpinned by:

(a) DH guidance: *Making every young person with diabetes matter*93;
(a) NICE guidance: *CG15: Diagnosis and management of type 1 diabetes in children, young people and adults*94 and *TA151 Diabetes – insulin pump therapy*;95 and
(b) NHS Diabetes guidance: *Commissioning services for children and young people with diabetes*96.

Local status of paediatric diabetes performance with recommendations:
In summary:
In summary there has been a massive improvement in clinical outcomes, especially in terms of achieving one of the best HbA1C outcomes, fewer complications with good clinical leadership. There are a lot of new policies/protocols which have been brought into effect. There is a commitment of investment for extra staff but with no timelines on when they will actually deliver these additional clinics.
In view of our recent anecdotal problems about the provision of a shared care in school settings for a child we are working towards developing a diabetes school care policy, which needs to be agreed with all the local authorities in the East of Berkshire, This is not however a specific requirement of the BPT
The clinical best practice should also be reflected through qualitative data like user/family/carer's surveys /feedback and through robust data systems. The methodology for record keeping, logging clinical visits/conversations, data retrieval and analysis need to be robust. We need to have enhanced communication between the different stakeholders like the CCG's/commissioners, providers/ acute care consultants/ specialist nurses, Voluntary organisations like the Diabetes UK, patient support groups and the children and their families. We need to improve access have a data base on shared care.

Background and supporting information

The Best Practice Tariff (BPT) criteria are underpinned by:

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Diabetes UK Website
www.diabetes.org.uk

Juvenile Diabetes Research Fund Web
www.jdrf.org.uk

Link to insulin pump homepage
www.medtronic-diabetes.co.uk

Online pump school
www.pumpschool.minimed.com

Carb counting e-learning module
www.bdec-elearning.com

Pump upload page
www.carelink.minimed.com