**The Leeds Children and Young People’s Diabetes Team**

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Leeds Diabetes Transition Policy

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**SECTION 1: Introduction**

Diabetes Mellitus is a chronic disease that has a major impact on morbidity and mortality. Caring for children and young people with diabetes is a complex process that must be firmly focused on the child or young person and their family and other carers, supported by health care professionals who have skills and expertise in all aspects of diabetes management. NICE guidelines (2004) recommend that children and young people with Type 1 diabetes (and other types) should be offered an on-going integrated package of care by a multi-disciplinary paediatric diabetes care team; this includes smooth transition from paediatric to adult services.

Evidence indicates that many young people are lost to follow up when transferred to an adult system increasing the already significant risk of premature morbidity and mortality (Pacaud et al 2005). The National Service Framework for Diabetes (NSF 2001) Standard 6 and NSF for Children and Young People “Growing into Adulthood” (2006) highlights transitional care as an integral component of care for all young people, and stresses the importance of smooth effective transition that is arranged in partnership with the young person.

A smooth transition is further supported by the intercollegiate report “Bridging the Gaps: Health Care for Adolescents” [2003], guidelines from the Royal College of Nursing [2004], “You’re Welcome” standards for adolescent-friendly services [DoH 2011] and is in keeping with the objectives of “Every Child Matters” [DfES 2004] and “Every Young Person with Diabetes Matters” (DOH 2007)

**Definition of transition**

Transition is a “planned, purposeful movement of the young person from a child centred to an adult orientated health care system”. It is a process that evolves over a considerable period of time and should not be considered an event. (Blum 1993)

Transitional care is a multi-dimensional, multi-disciplinary process that addresses not only the medical needs of young people as they move from a children’s service to a young adult service, but also their psychosocial, educational and vocational needs and the needs of their parents.

**The aims of transitional care are to:**

1. Provide high quality, co-ordinated, uninterrupted health-care that is patient-centred, age and developmentally appropriate and culturally competent, flexible, responsive and comprehensive with respect to all persons involved;
2. Promote skills in communication, decision-making, assertiveness and self-care, self-determination and self-advocacy;
3. Enhance the young person’s sense of control and move towards independence
4. Provide support for the parent(s)/guardian(s) of the young person during this process
5. Maximise lifelong functioning and potential (McDonagh 2003,2005a).

**SECTION 2: Purpose**

This policy sets out the guidance to ensure that the 3 Leeds CCGs and the Leeds Teaching Hospitals NHS Trust are effective in making suitable arrangements for the transition of young people with type 1, type 2 or other forms of diabetes from a paediatric to a young adult service.

The aim of this policy is also to ensure that children/young people and families are fully involved in the process of transition and that all staff are aware of the process.

All staff must ensure that all aspects of equality and diversity (E&D) are considered in order to ensure the child/young person and their family/carer receives appropriate care and treatment, and should include:

* interpreters (for non-English speakers or hearing impaired),
* access, aids and adaptations (for physical, sensory and learning disabled people) and
* religious and cultural factors – for example, ensuring specific dietary advice is provided.

These should be considered prior to any decision relating to transition.

For further information about E&D issues, please contact EqualAccess.Admin@leedsth.nhs.uk

Safeguarding children and young people

* All those who come into contact with children, young people and their families in their everyday work, including staff who do not have a specific role in relation to safeguarding children, have a duty to safeguard and promote the wellbeing of children and young people.
* All staff should be familiar with the trust policy and procedure for safeguarding children and young people, ‘what to do if you are worried a child is being abused’
* All health professionals working directly with children/young people should ensure that safeguarding and promoting their welfare forms an integral part of all stages of care.
* All staff should be alert to the potential indicators of abuse and neglect in children/young people and know how to act on their concerns and fulfill their responsibilities. There are a range of single and inter-agency training courses available. Individual staff members and their managers will need to identify the correct level of training to enable the individual to fulfill their roles and responsibilities.

All trust policies, procedures and advice on training is available on the Trust Intranet.

1.References/ related documents:

HM Government (2006) *Working together to safeguard children: A guide to interagency working to safeguard and promote the wellbeing of children.* London; accessed at [www.ecm.gov.uk](http://www.ecm.gov.uk/)

2.Local safeguarding policy

**SECTION 3: Background to the service**

Services were previously provided on two sites, Leeds General Infirmary (LGI) and St James’s University Hospital (SJUH), with two different models of Transition. The diabetes services have now merged, with all outpatient facilities at SJUH.

* The Transition Team consists of Consultant Paediatricians (Dr. Fiona Campbell, Dr. James Yong), Young People’s Diabetes Nurse Specialists (Julie Cropper, Jayne Poole, Michelle Clarke), Children’s Diabetes Dietitians (Frances Hanson, Laura McDowall), and has input from a Consultant Diabetologist (Dr. Ramzi Ajjan), Clinical Psychologists (Kate Hall, Rebecca Waldron) and other professionals as necessary.
* Transition clinics are now held at the Children and Young People’s Diabetes Centre every Wednesday morning for 16 – 19 year olds.
* Joint transition and young adult clinics are held twice each month, with both paediatric and young adult healthcare personnel present in the consulting room for 18 – 19 year olds in the year prior to transfer to the young adult service. . Young people should not move from the transition to the young adult clinic until they have the maturity to function effectively in an adult service, including the ability to negotiate services independently.
* As part of the preparation for transfer to the young adult service, all young people aged 16-19 are encouraged to be seen on their own in their clinic consultation. Their parents are encouraged to join the latter part of each consultation.

**SECTION 4: Key elements for an effective transition programme**

1. A written policy
2. A preparation period and education programme with an individualised approach, which addresses psychosocial and educational/vocational needs, provides opportunities for the young people to express opinions and make informed decisions and gives them the option of being seen by professionals without their parents.
3. A co-ordinated transfer process with a named co-ordinator and continuity in health personnel when possible.
4. Administrative support
5. Primary health care and social care involvement.

 (Viner 1999, DoH 2003.2004.2006, McDonagh 2005a)

**SECTION 5: Age ranges and clinics.**

There must be a flexible approach to transition that takes into account the developmental readiness and links to other social transitions such as leaving school. However for the purpose of the document age ranges and movement through the clinics have been defined as follows**:**

* Paediatric up to 16 years old.
* Transition 16-19 years old
* Young Adult 19-25 years old
* Adult over 25 years old.

**SECTION 6: Philosophy of Transition**

**Aims of the service**

Leeds Teaching Hospitals NHS Trust wishes to offer an excellent service to all children and young people with diabetes and their parents and carers. We will do this by delivering good quality care that delivers excellent clinical outcomes, which is provided by a multi-disciplinary team that empowers the patient and their parents and carers.

* A transition programme is an essential part of quality care for young people with diabetes.
* Effective transition must recognise that transition in health care is only one part of the wider transition from dependent child to independent adult.
* Transition services must also address the needs of the parent/guardian(s) whose role is evolving at this time in their son/daughter’s life and health-care.
* In moving from child-centred to adult health services, young people undergo a change that is cultural as well as clinical.
* Transition services must be multidisciplinary and involve both paediatric and young adult diabetes teams and any other parties involved in the care of the young person.
* Transition services should also include education, social services and voluntary agencies. Service development must be undertaken in collaboration with the young person involved, enhancing their sense of control and independence in their healthcare.
* Coordination of transition care is critical and a key worker should be identified for each young person to oversee his or her transition, who links with a counterpart within the young adult service to ensure seamless transition.
* Transition is NOT synonymous with transfer. Transition is an active *process* and not a single event like transfer. Transition must begin early, be planned and regularly reviewed and be age and developmentally appropriate.
* Transition services must undergo continued evaluation.

**SECTION 7: Preparation for Transition**

**Principles**

* Both the young person and their parent(s) need to be prepared for transition and eventual transfer to the young adult service.
* Young people should only be transferred to the young adult service when they have completed growth and puberty and have the necessary skills to function in a young adult service, largely independent of parents and staff e.g. decision-making, communication, self-care, assertiveness. When this is not possible due to cognitive impairment and/or severe disability, appropriate advocacy, preparation and developmentally appropriate care in the young adult service should be ensured prior to transfer.
* Transition planning must begin well before the anticipated transfer time – preferably in early adolescence when a series of educational interventions should address understanding of disease, the rationale of therapy, source of symptoms, recognising deterioration and taking appropriate action, and most importantly, how to seek help from health professionals and how to operate within the medical system, including primary and emergency care.
* Young people should be helped to take appropriate responsibility for their diabetes and their parents should be encouraged to help them to do so.
* The concept of independent visits must be introduced well in advance e.g. age 12 to prepare the adolescent and their parents for this. “In the next couple of years you may feel able to start seeing the doctor on your own….” The aim should be to see the young person by themselves for some time during clinic visits from approximately age 14 years. NB Parents must remain involved and should be seen with the adolescent at some time during the session (note research into this by Weissberg-Benchell, Wolpert and Anderson, 2007)
* In preparation for young people to be seen independently, the transition and young adult clinic will provide continuity of professionals at each visit. The young person should also be given (where possible) the option of seeing a professional of preferred gender if necessary. Team members (including departmental visitors’ e.g. medical students) must be kept to a minimum in these individual consultations i.e. a maximum of 1 extra.
* A schedule of likely timings and events should be given in early adolescence and the young person should be involved in developing detailed timings for their own transition. Details should be documented on the Diabetes Management System (DMS) to ensure continuity, especially if seen by different members of the multi-disciplinary team.
* Leaflets and material about the transition process and clinic should be provided in clinic settings from early adolescence.

**SECTION 8. Timings and age**

Timing of transition MUST be flexible and not restricted to age criteria only. Timing of transition and transfer depends on

* chronological age,
* maturity,
* adherence,
* independence,
* readiness of young person,
* parental readiness.

Flexibility will also be required depending on the young person’s medical status. Transfer should not take place during a crisis e.g. repeated admissions for Diabetic Keto-Acidosis (DKA)

1. **Earliest discussion of transition to adult care**

This should take place at 11 or 12 years during their first year at high school. A transition plan for ALL young people should be in place by the age of 14 years and reviewed at least annually thereafter.

1. **Beginning of active preparation for transition**

At age 11-12 years, information is given that they will begin transition between 12-14 years. The information will highlight the process of transition for both the young person and their parents over the next few years.

1. **Age of effective transfer to transition service**

Aged 16 years.

1. **Age of effective transfer to young adult service**

Aged 18-19 years.

1. **Age of effective transfer to adult service.**

Aged 25 years.

1. **Exceptions to above timing**

Young people who have other physical or mental health problems, or physical or learning disabilities, or are vulnerable due to problems such as homelessness may need extra support and preparation prior to transfer to the young adult service. There may be exceptions to the transfer of young people aged 25 years old into adult services if they are undergoing a crisis, e.g. development of long-term complications that may impact on their clinic attendance. However, this must be discussed with the young person and the young adult team and transfer take place as soon as possible after the age of 25 years.

Young people diagnosed between the ages of 16–18 will be under the care of the transition team but they will be admitted to the adult ward. They will be discharged as soon as possible and education continued in the Children and Young People’s Diabetes Centre on a daily basis as needed. Mature young people who are diagnosed between the ages of 23-24 may wish to enter the adult service straight away.

**SECTION 9. Process of transition**

**Initiation & co-ordination of transition**

Every consultant, nurse and dietitian seeing children and young people in the clinic is responsible for ensuring discussion of transition when they see a patient aged 11-12 years old. Full documentation that this has taken place must be recorded on the DMS.

**First discussion of transition**

Young people will be identified by an alert on the DMS that they will begin transition at the next appointment. Their named nurse (Children’s Diabetes Nurse Specialist) will act as the key worker for the patient until they move to the transition clinic. They will then be offered a nurse-led clinic appointment to meet the Young People’s Diabetes Nurse Specialist who will become their new key worker. This will ensure transition is discussed with every patient and identify the key worker responsible for the process.

**Educational programme**

* Introductory leaflet which includes meaning of transition for the young person and parent at the initial discussion at 11-12 years.
* Gradual increasing emphasis on increasing self advocacy for the young person in clinic. This includes involvement in decision making, being seen alone and other issues which impact on their life.
* The competency checklist that is used by the paediatric diabetes department will transfer with the young person as they move into the young adult service.

**Assessment of readiness for transition**

This will involve individual discussion with the young person and their parents with the diabetes team, taking into account their individual needs and wishes.

**Transfer process to Young Adult Service**

The young person will be introduced to staff from the young adult team prior to transfer and any specific issues discussed in the joint transition clinics during the year between the ages of 18 and 19. The young adult clinics are held in the Manny Cussins Diabetes Centre. The transfer defines the move from a paediatric to an adult service and accordingly correspondence and appointments will need to be sent to the young person. Issues of confidentiality must be considered e.g. how permission is sought from the young person to give information to their parents if requested. Young people will be encouraged to attend a Dose Adjustment for Normal Eating (DAFNE) course.

**Transfer process to Adult Services**

Transfer to the adult service will be at 25 years. This service may involve a change of staff but the venue remains the same. Consideration needs to be given to how to avoid non attendance and identification of key personnel. For young people who have not attended DAFNE, further information will be given before transfer.

**Involvement of GP in transfer process**

The GP needs to be sent a copy of the transition plan and is involved in telephone discussions about the patient if this is considered necessary

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