Paediatric Diabetes:
Young people and Transition Guidance
**Title:** Paediatric Diabetes: Young people and Transition Guidance

**Executive Summary:** Diabetes Mellitus is a chronic disease which has a major impact on morbidity and mortality. Caring for children and young people with diabetes is a complex process which 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 (NG18 2015 & NG43 2016) recommend that transition should be developmentally appropriate, person-centred with care that is planned and managed. Adult and paediatric health care teams should involve young people and carers in service design, delivery and evaluation. Adult and paediatric healthcare teams should work jointly to provide assessment and services to young people.

**Supersedes:** Paediatric and Adolescent Diabetes Transition Policy V1.

**Description of Amendment(s):** The document was updated and reviewed to reflect new guidelines and evidence in May 2016 – references.

**This guidance will impact on:** Paediatric diabetes services, Adult diabetes services

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SECTION 1: INTRODUCTION

Diabetes Mellitus is a chronic disease which has a major impact on morbidity and mortality. Caring for children and young people with diabetes is a complex process which 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.

There are 27,600 children and young people in England and Wales with diabetes; this is continuing to rise in line with global trends at 4% pa (NPDA 2016).

NICE guidelines (NG18 2015 AND NG43 2016) recommend that children and young people with Type 1 diabetes should be offered a planned coordinated transition between paediatric and adult services.


Along with poor glycaemic outcomes and increases in physical co-morbidities associated with lack of engagement with health services (DCCT1983, EDICT 2005), mental health issues in people with diabetes is increasingly recognised. There are strong correlations between anxiety and depression where young people have dis-engaged with services (Garvey et al 2013). Young people with diabetes are also at significant risk of eating disorders (Philpot 2013). Timely and ongoing access to mental health professionals is recommended throughout the transitional process.

Furthermore there is evidence to suggest that milestones for adulthood are now reached at a later developmental age, with young people being dependent upon parents for longer for emotional, practical and financial support (Furstenburg 2015). A new developmental stage “Emerging Adulthood” is suggested by Arnett (2000) which along with the understanding of emerging neuro-developmental findings help in assisting the understanding of adolescent behaviours’ which impact self-management and independence (Dovey-Pearce 2013).


A smooth transition is further supported by the “You’re Welcome” standards for adolescent-friendly services [DoH 2005] 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-centered to an adult orientated health care system”. It is a process which 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 person’s 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 self-efficacy and move towards independence
4. Provide support for the parent(s)/guardian(s) of the young person during this process
5. Maximise life long functioning and potential [McDonagh 2003,2005a].

**SECTION 2: Key elements for an effective transition programme**

1. A written policy (the trust has produced this guidance document to support staff to provide personalised care and support in line with individual transition needs of patients).
2. A preparation period and education programme with an individualised approach, which addresses psychosocial and educational/vocational needs, provides opportunities for adolescents 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.


**SECTION 3: Purpose**

This guidance provides a framework for ensuring suitable arrangements are made for the transition of young people with diabetes from a paediatric to adult /young person’s service.

It aims to ensure that children 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 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 refer to the Equality and Human Rights Policy and Interpretation and Translation Policy.

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.
- 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 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, know how to act on their concerns and fulfill their responsibilities. A range of single and inter-agency training courses are 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.
- Where there is a current safeguarding concern consideration should be given during the transition period as to whether this will continue to be a concern into young adulthood and to whether referrals to the Trust Adult Safeguarding team and Adult Social Care are required.

All trust policies, procedures and advice on training is available on the Trust intranet or from the trust’s safeguarding team.

Related documents:
- NICE NG 18 (2015). Diabetes (Type 1 and Type 2) in children and young people: diagnosis and management.
- NICE NG 43 (2016) Transition from childrens to adults’ services for young people using health or social care
- Lost in Transition – key objectives, RCN
- Trust safeguarding children policy
SECTION 4: Roles and Responsibilities

Clinical Matron

- The role of the clinical matron is to support and oversee the Paediatric Diabetes team in the management of the service, act as advocate for the service in relation to the service development and to ensure the team have adequate skills and knowledge to manage transition.

Paediatric Diabetes Nurse

- The role of the paediatric diabetes nurse is to ensure there is an appropriate individualised transition for patients in adherence to this guideline.

SECTION 5: Background to the service

- Young Person clinics are currently held on the fourth Wednesday of every month. The clinics are held in the main out-patients department between 15:00 hrs and 18:00 hrs. Each patient is offered a 20 minute appointment.
- The clinics are currently staffed by the adult physician. The paediatric diabetes specialist nurse (PDSN) and paediatric consultant will attend for any young person aged 16-18 years booked into this clinic.
- Young people who are treated with multiple daily injections and who have completed their GCSE’s and wish to be seen in an adult setting will be assessed during their regular clinic visit regarding suitability for transfer. If felt appropriate, a letter of referral is sent to the adult diabetologist and an appointment is sent within a 3 month time frame. If preferable to the young person and their family a referral may be sent to the university town which they plan on attending.
- Young people on CSII will be referred to the adult diabetologist at Manchester Royal Infirmary or University Hospital of Royal Stoke (Patient preference) when they approach their 18th birthday. If preferable to the young person and their family a referral may be sent to the university town which they plan on attending.

SECTION 6: Age ranges, admissions and clinics.

There must be a flexible approach to transition which takes into account 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 follow:

- Paediatric Clinic up to 18 years.
- Young Person 17/25 years.
- Adult 25 years.

All adolescents attending the paediatric service will be referred to as young people from the age of 14 years.

Newly diagnosed young people with diabetes
All young people with suspected new diagnosis of diabetes, below the age of 18 years, should be admitted to the children's ward. This is irrespective of clinical presentation. If the young person wishes to be admitted to an adult ward between the ages of 16-18 years then this choice should be respected. Adult ward staff will inform the PDSN of the admission immediately.

To have full access to all services required for the initial education and support required at diagnosis all young people will be under the care of the consultant paediatrician and clinical lead for diabetes. Follow up will be in the paediatric outpatients department by the consultant paediatrician, paediatric specialist nurse and dietitian.

If the young person wishes to be seen by adult services this will be respected and follow up care will be by the adult consultant for diabetes.

**Young people with existing diabetes**

All young people under the age of 18 years to be admitted to the children’s ward if unwell with diabetes related illness. If not diabetes related please inform paediatric diabetes specialist nurse of admission. (Data is required for national audit purposes)

**Diabetic ketoacidosis (DKA)**

All young people aged 16-18 years of age admitted with diabetic ketoacidosis will follow the paediatric DKA pathway. Young people with suspected DKA should be referred to the paediatric on call team and admitted to the children's ward for management.

### SECTION 7: Philosophy of Transition

**Aim of the service**

The trust aims 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 that are 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 person’s 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 transitional 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 person's 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 8: Preparation for Transition

- Both the young person and their parent(s) are prepared for transition and eventual transfer to the young person’s service.
- Young people are only transferred to the young person’s service when they have completed growth and puberty and have the necessary skills to function in a young person’s 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 person’s service should be ensured prior to transfer.
- Transition planning is instigated well before the anticipated transfer time – in early adolescence when a series of educational interventions discuss understandings 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.
- Transitional plans should be discussed at regular clinic appointments and included in the post clinic letter to the young person and parent/carer.
- After 16 years of age, written consent is required from the young person in order for diabetes teams to include parents in written and verbal communication.
- Young People are helped to take appropriate responsibility for their diabetes from as early an age as possible. Furthermore, their parents are encouraged to help them to do so.
- The concept of independent visits is introduced well in advance the aim being to see the young person by themselves for some time during clinic visits from approximately age 13-14 years. NB Parents must remain involved and should be seen with the young person at some time during the session (note research into this by Weissberg-Benchell, Wolpert and Anderson, 2007)
- However an informal or formal chaperone must be present for any physical examination. Any intimate examination must be carried out in the presence of a formal chaperone, an informal chaperone parent / carer or someone already known and trusted by the child/young person may also be present for reassurance and to minimise any distress caused by the procedure. Adolescents/Parents or guardians must receive an appropriate explanation of the procedure in order to obtain their informed consent to examination. (See trust Chaperone Policy)
- In preparation for young people to be seen independently, the paediatric clinic will provide continuity of professionals at each visit. The young people will 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) are kept to a minimum in these individual consultations i.e. a maximum of 1 extra.
- A schedule of likely timings and events is given in early adolescence and they should be involved in developing detailed timings for their own transition. Details are documented in
the notes to ensure continuity especially if seen by different members of the multi-disciplinary team.

- Leaflets and material about the young persons clinic and transition process is provided in clinic settings from early adolescence.

SECTION 9. 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,
- adolescent readiness,
- parental/carer readiness.

Flexibility will also be required depending on the adolescent's medical status. Transfer should not take place during a crisis e.g. repeated admissions for Diabetic Keto-Acidosis (DKA) or if glycaemic control poor. (>70mmol/mol)

1. Earliest discussion of transition to adult care

This should take place at 10 or 11 years during their last year at primary school. A transition plan for ALL teenagers/adolescents should be in place by the age of 14 years and reviewed at least annually thereafter.

2. Age of effective transfer to young persons service

Aged 17-18 years depending upon young person’s preference

3. Age of effective transfer to adult service.

Young people will be seen in the paediatric clinic up to the MDT clinic nearest to their 18th birthday.

4. Exceptions to above timing

Young people on CSII are transferred to the adult diabetologist at an appropriate CSII diabetes centre after their 18th birthday.

There may be exceptions to the transfer of young people aged 18 years into adult services if they are undergoing a crisis e.g. development of long term complications which may impact on their clinic attendance. However this must be discussed with the young person and the young persons team and transfer take place as soon as possible after the age of 18 years. Young people with learning needs or who may have other conditions or have shared care with other centres diabetes may stay in the paediatric diabetes clinic until 19 years, if consistent with the other care providers to avoid confusing and disjointed services.
SECTION 10. Process of transition

Preparation for 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 10-11 years old. Full documentation that this has taken place must be recorded on the patient’s notes and the diabetes database.

First discussion of transition

Adolescents will be identified at pre clinic meetings that they will begin transition at that appointment and a member of staff named as the key worker for the patient. This will ensure transition is discussed with every patient and identify the key worker responsible for the process.

Educational programme

- Gradual increasing emphasis on increasing self advocacy for the adolescent patients in clinic. This includes involvement in decision making, being seen alone and other issues which impact on their life.
- The competency checklist and “goals of diabetes education” that are used by the paediatric diabetes department will transfer with the young person as they move into the adult service.

Assessment of readiness for transition

This will involve individual discussion with the young person and their parents with the diabetes team. The ultimate decision to move to the young person service lies with the young person. This will be assessed at each appointment following completion of the GCSE’s.

Transfer Process to Young Persons Service

The Paediatrician writes a letter of referral requesting an appointment in the young person’s clinic and an appointment is given within 3 months. Issues of confidentiality must be considered in the young persons clinic letters are addressed to the young person, parents are seen with the young person if they wish. During this time young people will be encouraged to attend a carbohydrate counting course if available.

Transfer Process to Adult Services

Transfer to the adult service will be around the age of 18 years. Consideration needs to be given to transport issue, how to avoid non attendance and identification of key personnel. Due to current lack of adult nursing service the PDSN will communicate directly with the young persons practice nurse.

Involvement of GP in transfer process

The GP needs to be sent a copy of the transition plan. To address the current lack of provision to adult specialist nursing services, young people will be transferred back to their GP and practice nurse. Effective communication will take place to ensure the GP team is fully aware of individual care required for each young person. The PDSN (key worker) will accompany the young person to their first appointment.
SECTION 11: Audit

In order to ensure quality of service and achieve best practice diabetes tariff, audit information is provided by the trust on a monthly basis. This information is evaluated against best practice tariff criteria and includes guidelines for transition.

Key performance indicators:

1. The processes and guidance to support effective transition will be available in written format and on the trust intranet.
2. By age 14 a written transition plan is recorded on diabetes database and in a copy is available in the clinic notes.
3. Young people attend the young person’s transition clinic.
4. Young people attend the adult clinic after transfer.

SECTION 12. Acknowledgements and References

Acknowledgements:
This guidance has been based largely on the policy of Salford Primary Care Trust, which in turn was based on the template developed at Great Ormond Street Hospital London by Dr Russell Viner and colleagues; it has been developed further for use in BCH by the BCH Adolescent Strategic Working Party and has been used with their permission. The North West Paediatric Network thanks them and the transition sub-group for its work in making this guidance available.

The document was updated and reviewed due to new guidelines and evidence in May 2016 by Carol Metcalfe with collaboration with Dr Surendran Chandrasekaran and Dr Phyu-Phyu Wai.

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