Paediatric and Adolescent Diabetes Transition Policy

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<tr>
<td>Section 1</td>
<td>Introduction</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Section 2</td>
<td>Purpose</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Section 3</td>
<td>Background to the service</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Section 4</td>
<td>Key elements for effective transition</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Section 5</td>
<td>Age ranges and Clinics</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Section 6</td>
<td>Philosophy of transition</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Section 7</td>
<td>Preparation for transition</td>
<td>6 – 7</td>
<td></td>
</tr>
<tr>
<td>Section 8</td>
<td>Timings and age</td>
<td>7 – 8</td>
<td></td>
</tr>
<tr>
<td>Section 9</td>
<td>Process of Transition</td>
<td>8 – 9</td>
<td></td>
</tr>
<tr>
<td>Section 10</td>
<td>References</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>Section 11</td>
<td>Audit tool</td>
<td>11</td>
<td></td>
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<tr>
<td>Section 12</td>
<td>Appendix.</td>
<td>12 - 25</td>
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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. NICE guidelines (2004) recommend that children and young people with Type 1 diabetes should be offered an ongoing 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. 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 organised 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 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 centred 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 persons services 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 life long functioning and potential [McDonagh 2003,2005a].
SECTION 2: PURPOSE.

This policy sets out the guidance to ensure that ?? PCT and ?? Trust are effective in making suitable arrangements for the transition of young people with type 1 diabetes from a paediatric to adult /young persons service.

The aim of this policy is also 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 contact ??

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.

All trust policies, procedures and advice on training is available on ?? local information.

References/ related documents:
- Lost in Transition – key objectives, RCN
- Local safeguarding policy – name here

SECTION 3: Background to the service

Local information in here
• Types of clinics – e.g. teenage, young adult
• Where clinics are held – venues and times and days is accessible
• Staffing e.g. The teenage and young person clinics are staffed by both paediatric and young person’s healthcare personnel. This enables planning and co-ordination and gives opportunities for teenagers/adolescents to meet the young person’s team and be seen independently from their parents and carers. It is also important to recognise that the teenage clinic sits within the paediatric diabetes service whilst the young persons clinic although staffed by the same personnel sits within an adult service.
• Statement on how young people progress to different clinics – e.g. Teenagers/adolescents should not move to from the teenage to young person’s clinic until they have the maturity to function effectively in an adult service, including the ability to negotiate services independently.

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 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 5: Age ranges 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: (this may vary from Trust to Trust)

• Paediatric up to 12 years old.
• Teenage/ Adolescent 12-16/18 years old
• Young Person 16/18-25 years old
• Adult over 25 years old.

Whilst the diabetes team uses the term young people to apply to all age ranges between 12-25 years and recognises that young people often do not want to be referred to as adolescent, to avoid confusion and ensure clarity young people attending the Teenage clinic i.e. between 12-16/18 years will be referred to as teenagers/adolescents. Those attending the young person clinic will be identified as young people.

SECTION 6: Philosophy of Transition

(may want to vary from Trust to Trust but this is an example)

Aim of the service
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 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 adolescents 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, adolescents 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 adolescent.
- Transition services should also include education, social services and voluntary agencies. Service development must be undertaken in collaboration with the adolescent 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 adolescent to oversee his or her transition who links with a counterpart within the young persons 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 (may want to vary from Trust to Trust but this is an example)

- Both the teenager/adolescent and their parent(s) need to be prepared for transition and eventual transfer to the young persons service.
- Adolescents should only be transferred to the young persons service when they have completed growth and puberty and have the necessary skills to function in a young persons 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 persons 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 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.
- Adolescents should be helped to take appropriate responsibility for their diabetes from as early an age as possible. Furthermore, 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 11 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 teenager/adolescent 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 adolescent at some time during the session (note research into this by Weissberg-Benchell, Wolpert and Anderson, 2007)

- In preparation for adolescents to be seen independently, the teenage and young persons clinic will provide continuity of professionals at each visit. The adolescent and 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 they should be involved in developing detailed timings for their own transition. Details should be documented in the notes to ensure continuity especially if seen by different members of the multi-disciplinary team.

- Leaflets and material about the adolescent clinic and transition should be provided in clinic settings from early adolescence.

**SECTION 8. Timings and age**

*(may want to vary from Trust to Trust but this is an example)*

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 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)

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. **Beginning of active preparation for transfer to teenage clinic.**

   At age 10-11 years information is given that they will move to the teenage clinic between 12-13 years. The information will highlight the process of transition for both the teenager/adolescent and their parents over the next few years.

3. **Age of effective transfer to teenage clinic.**

   Aged 12-13 years.
4. **Age of effective transfer to young persons service**

Aged 16-18 years.

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

Aged 25 years.

6. **Exceptions to above timing**

*(may want to vary from Trust to Trust but this is an example)*

As both the teenage clinic and young persons clinic are held at the same venue and staffed by the same teams there should be few exceptions to the above timing. 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 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 25 years.

7. **Other issues for consideration**

Local units may also want to describe how their transition process works for the following groups:

- Pregnant Young Women
- Patients with Cystic Fibrosis
- Patients with Pumps

These patients may not be considered for transition in the usual way and a clear description of the way their transfer processes will be handled is needed.

**SECTION 9. 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 and making arrangements by a designated team member when they see a patient aged 10-11 years old. Full documentation that this has taken place must be recorded on your local system.

**First discussion of transition**

Adolescents will be identified at post clinic meetings that they will begin transition at the next 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**

*(may want to vary from Trust to Trust but this is an example)*

- Introductory leaflet to the Teenage Clinic which includes meaning of transition for the patient and parent at the initial discussion at 10-11 years.
- Gradual increasing emphasis on increasing self advocacy for the adolescent 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 adult service.

*May state Trust policy or local practice in here*

**Assessment of readiness for transition**

This will involve individual discussion with the adolescent and their parents with the diabetes team and team discussion at post clinic meetings. The ultimate decision to move to the young person service lies with the adolescent.

**Transfer Process to Young Persons Service**

*(may want to vary from Trust to Trust but this is an example)*

The process is mainly administrative as both staff and venue are the same. However 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 young person to give information to their parents etc. To ensure specific issues are addressed the diabetes team aim to have a “transfer in” clinic held three times a year when adolescents will move to the YPC. During this time 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 currently involves a change of staff and venue. Consideration needs to be given to transport issue, 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.

**Acknowledgements:**

This policy 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 policy available.
Blum RW. Garell D, Hadgman CH et al. Transition from child-centred to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. *J Adol Health* 1993; **14**: 570-6


McDonagh JE (2005a). Growing up and Moving on. Transition from pediatric to adult care. Pediatric Transplantation 9:364-72

Royal College of Paediatrics and Child Health (2003) Bridging the Gaps: Health Care for Adolescents. [www.rcpch.ac.uk](http://www.rcpch.ac.uk)


Royal College of Nursing (2008), Central Lost in Transition – moving young people between child and adolescent services, ([www.rcn.org.uk](http://www.rcn.org.uk))

Viner RM (1999). Transition from paediatric to adult care. Bridging the gaps or passing the buck? *Arch Dis Child*; **81**: 271-75

Weissberg-Benchell, J, Wolpert, H, and Anderson, BJ, Transitioning From Pediatric to Adult Care: A new approach to the post-adolescent young person with type 1 diabetes, Diabetes care, Vol 30, Number 10, 2007
The next pages are examples of how you may develop and monitor your policy and its implementation. Approaches may change from Trust to Trust and this is for example only.

SECTION 11: Audit Tool

The audit tool is to monitor the effectiveness of the policy by:

- Ensuring all staff have access to and have read and understood the policy.
- Ensuring that all staff comply with the policy.

Monitoring compliance with the policy:
The policy is available in written format and on the Trust intranet. The audit will focus on every person in the teenage clinic having a written transition plan recorded on **Local records / database / electronic patient record by the age of 14 years.**

Ensuring staff have access to and have read and understand the policy.
All relevant staff will be identified on a list and sign to say they have read and understood the policy. Any new staff will be added to the list.

POLICY SIGNATORY RECORD

The following proforma should be completed by team members who it applies to. This needs to be completed by each team leader. The reason this needs to be completed is to:

a) Satisfy NHSLA requirements. This external review body asks for this as proof that PCT implements NICE guidance. Therefore a random sample will be taken each year for audit purposes.

b) This is a useful tool to use at team level to ensure all your team has read and accepted

**Policy for the Transition for Young People with Diabetes aged 16 – 25 years**

Line managers /CG leads should ensure all the staff have signed the policy record and should retain a copy for their own records.

Staff signatures are taken as an agreement of compliance

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NB the completed signatory lists maybe called for by the clinical governance team for audit purposes.

This needs to be completed if teams are:

a) for any reason unable to comply with the policy
b) you feel the policy needs review

Please return your form to the Clinical Governance Team, ??.

Comments received on DRAFT documents will be incorporated

Comments received on RATIFIED documents will inform the review process
Implementation of Paediatric and Adolescent Diabetes Transition Policy

To be completed by all service managers

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<td>Do you have a local / service specific procedure for implementing the policy / procedure / guideline</td>
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Signed ……………………………………… Date ………………………..

Designation ……………………………………………

A copy of this form is to be forwarded to your Head of Operations / Director.

If you need help to develop a procedure for implementing this policy / procedure / guideline, please contact ??.