Transition to adult care policy

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Protocol Title: Transition to adult care Policy
Cross reference: Transitional Care for Teenagers and Young Adults with Diabetes at Royal Alexandra Children's Hospital, BSUH

Protocol Number: Version number: 1
Approving Committee: CPSQ
Date agreed: 19th October 2017
Review Date: 19th October 2020
Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Key Principles</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Scope</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Responsibilities</td>
<td></td>
</tr>
<tr>
<td>1.0</td>
<td>Introduction</td>
<td></td>
</tr>
<tr>
<td>1.1</td>
<td>Definition of transition</td>
<td></td>
</tr>
<tr>
<td>1.2</td>
<td>Rational for transition</td>
<td></td>
</tr>
<tr>
<td>2.0</td>
<td>Aims of transition</td>
<td></td>
</tr>
<tr>
<td>2.1</td>
<td>Mission statement or philosophy of transition</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Steps in transition</td>
<td></td>
</tr>
<tr>
<td>4.0</td>
<td>Monitoring compliance</td>
<td></td>
</tr>
<tr>
<td>5.0</td>
<td>References</td>
<td></td>
</tr>
<tr>
<td>6.0</td>
<td>Appendices</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Appendix 1 Transitional care plan</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Appendix 2 Patient information leaflet</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Appendix 3 Ready information</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Appendix 4 Steady information</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Appendix 5 Go information</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Appendix 6 Flow chart for Ready Steady Go</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Appendix 7 Key worker document</td>
<td></td>
</tr>
</tbody>
</table>
KEY PRINCIPLES

This policy sets out the Trust’s expectations and provides practical guidance to ensure a structured and coordinated transition to adult health care services for all children and young people at the Royal Alexandra Children’s Hospital. The Trust is committed to improving this experience for all children and young people at the Alex, and for their parents and carers. This policy outlines generic principles of transition and each speciality will have disease specific best practice pathways which will need to be taken into consideration.

SCOPE

This policy sets out the standards expected by the Trust in relation to effectively preparing children and young people for transition to adult care.

This guideline applies to:

- All clinical staff in all specialities caring for children and young people within the Trust.
- All children from age 11 years with a long term condition until they are successfully transferred to adult services. The age of transfer is largely dependent on the progress made by each young person and, where appropriate the caregiver and may be dependant to the young person’s cognitive development rather than simply based on age.

RESPONSIBILITIES

- Director of Nursing: Has responsibility for ensuring that appropriate processes are in place for the transition of young people (11-19yrs) from child-centred to adult orientated care.
- Head of Nursing Children’s Services: Has responsibility for taking action on any non-compliance from the identified measurement tools that monitor compliance against this guidance.
- Safety and Quality committee: Has responsibility to ensure standards are met, actions are carried out and areas of concern are raised and escalated appropriately.

1.0 Introduction

Definition of Transition

Transition is an essential component of high quality health-care for young people. It can be defined as “a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical
and medical conditions as they move from child centred to adult oriented health care systems”. DH (2006)

The importance of transitional care for all young people has been highlighted in the Children’s National Service Framework (NSF) Hospital Standards [DH.2003] and the Royal College of Nursing (2013) with a requirement for children and adult services to acknowledge the needs of this group of patients when planning and developing services.

The period of transition is a process where a young person’s health and social needs should be regularly reviewed and assessed. To get transition right, services need to consider whether the rest of the care is developmentally appropriate. CQC (2014)

Rationale for transition:
More children with long-term conditions now live into adulthood. There is a growing need for Specialised Care and services to ensure seamless transition of young people to adult health care services. This is achieved by maintaining good liaison between Paediatrician, Adult Physician, GP and Allied Health Professionals. Inadequate transitional care impacts on long-term health outcomes for children and young people. Self-management of any illness is often difficult and complex, particularly so during adolescence. This is due in part to pubertal changes, but also due to psychosocial changes such as erratic eating and exercise patterns, poor adherence to medication regimes, risk taking/antisocial behaviours, family stressors, psychological and self-image problems, frequently missed appointments, as well as binge drinking, smoking and eating disorders in a small minority.

Transition to adult services can be a traumatic period for young people, who commonly fall between services (McDonagh and Viner 2006). In some cases there is a risk of non-concordance and morbidity associated with this transition. These are frequently described (Viner 1999) and commonly reported clinical experiences.

There is a perception of a lack of appreciation of young people’s needs and issues, the worry that they will not receive adequate information, the fear about leaving their familiar health care team for an unknown medical provider, and the desire for autonomy and involvement in decision-making (McDonagh2005).

Concerns may be raised with the Child or Adult Safeguarding Teams where young people ‘disappear’ during transition and this will need to be monitored by individual teams to which the young people have been referred.

**The aims of transition are to:**
(i) Provide co-ordinated, uninterrupted health-care that is age-appropriate, developmentally appropriate and comprehensive with respect to all persons involved;
(ii) Promote skills in communication, decision-making, assertiveness, self-care, self-determination and self-advocacy;
(iii) Enhance the young person’s sense of control and move towards independence.
(iv) Provide support for the parent(s)/guardian(s) of the young person during this process
(v) Maximise lifelong functioning and potential

Philosophy of transition
* Transition in health care is one part of the wider transition from dependent child to independent adult.
A transition program is an essential part of quality care for young people with chronic illness.

Transition is an active process rather than a single event. The process should begin early, be planned and regularly reviewed and be age and developmentally appropriate whenever possible.

A "sequential model" of transition is advocated (Forbes et al 2004). Such a model recognises that a young person’s needs are changing and allows them to rehearse and prepare for adult based care.

The age of transfer should depend on the individual’s physical and cognitive development, emotional maturity and state of health. Flexibility is key.

Transition services must also address the needs of the parent/guardian(s) whose role is evolving at this time in their son/daughters 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.

A multidisciplinary approach is most effective and involves the whole multi-disciplinary team at RACH, the adult providers and general practice. Appropriate training needs should be identified to ensure all health care professionals have adequate skills particularly around communication with young people.

Service development must be undertaken in collaboration with the young people involved, enhancing their sense of control and independence in their healthcare.

Coordination of transitional care is critical. A named professional should be identified for each young person to oversee his or her transition who links with a counterpart within the adult service to ensure seamless transition. It is acknowledged that in some cases services available in paediatric care are not mirrored in adult services.

Transition services must undergo continued evaluation. This will be the responsibility of each individual specialty in liaison with colleagues in adult services who must show commitment to the transition process.

Our aim as a provider is to empower the young person and their parents/carers. This is achieved by using the Ready Steady Go programme developed by University Hospital Southampton to equip the young person with the necessary skills and knowledge to manage their healthcare confidently and successfully in both paediatric and adult services. Clearly this will include ensuring they are aware of basic information such as days and time of clinics, location of resources, clinics, laboratories, wards, car parking and refreshments.

Young people formally move from Children’s Services to Adult Services by 19 years of age.

**STEPS**

1) Young people and their carers start the Ready Steady Go transition programme at around 11 years of age, if developmentally appropriate.
   Young people and carers are introduced to Ready Steady Go through the ‘Transition: moving into adult care’ information leaflet and patient and carer information video at [www.uhs.nhs.uk/readysteadygo](http://www.uhs.nhs.uk/readysteadygo).

2) At the next consultation the young person completes a ‘Getting Ready’ questionnaire which, through a series of structured questions, is designed to establish what needs to be done for a successful move to adult services. The issues are addressed over the following 1-2 years and not in a single consultation.
3) In due course the young person completes the ‘Steady’ questionnaire which covers the topics in greater depth and is used to confirm progress and address any on-going issues or concerns.

4) Finally a ‘Go’ questionnaire is completed to ensure that the young person has all the skills and knowledge in place to “Go” to adult services.

5) The young person should be introduced to the adult team – ideally at least a year prior to transfer.

6) The carer completes a separate questionnaire which follows the same format as the Ready Steady Go questionnaires, alongside the young person to ensure that they are also supported through the transition process.

   The actual timing of the move to adult services is one that is mutually agreed by the YP, parents or carers and medical professionals.

7) Any issues /concerns and progress are documented in the transition plan by the healthcare team/keyworker.

8) On transfer to adult services they should commence the “Hello to Adult Services” programme and a ‘Hello’ questionnaire be completed

   Periodically the Hello questionnaire should be re-used to ensure they maintain knowledge and skill levels and that any new or on-going concerns or problems are addressed.

   Those young people or adults whose first presentation with a long term condition is in adult services should be started on the ‘Hello to Adult Services’ programme - this follows the same format as Ready Steady Go. It can be used for all young people and adults regardless of age or sub-specialty.

9) Where the young person has learning difficulties the carer works through the Ready Steady Go programme with the young person engaging as much as possible. Carers with a severely disabled young person also start Ready Steady Go so that they too are prepared for the move to adult services; the programme allowing all concerns/issues to be carefully addressed and progress monitored prior to transfer.

2.0 MONITORING COMPLIANCE

- It is important that we get things right for the patients, therefore monitoring of our approach will occur 3 yearly. To ensure we are complying with transition care plans we will review 25 sets of notes. Results will be reported back to the Head of Nursing.

- If resources allow, young people’s experiences of the whole transfer process should be evaluated on alternate years using a satisfaction survey. This will be done jointly by both the Paediatric and Adult Teams. Recommendations for any changes in practice will be implemented as necessary.
3.0 REFERENCES

Aiming high for disabled children: delivering improved health services (NHS confederation 2009)
Independence: well-being and choice (DOH 2005)
Bridging the Gap: health care for adolescents (RCPCH 2003)
Care quality commission core standards
National Service Framework: children, young people and maternity services (DH, 2004)
RCN Adolescent Transition Care: Guidance for nursing staff (RCN, 2004)
Transition: Getting it right for young people (DH, 2006)
A transition guide for all services: key information for professionals about the transition process for disabled young people (DH, 2007)
0-18 years: guidance for all doctors (GMC, 2007)
Transition: Moving on well (DH, 2008)
You're Welcome Quality Criteria (DH, 2011)
Don't let me down: Ensuring a good transition for young people with palliative care needs (Marie Curie Cancer Care, 2012)
From the Pond into the Sea (CQC, 2015)
McDonagh JE, Kelly DA (2003) Transitioning care of the paediatric recipient to adult care givers. Ped Clin N Am 50 1561-1584
McDonagh JE (2005a) Growing up and moving on. Transition from paediatric to adult care. Paediatric Transplantation 9: 364-72
4.0 APPENDIX

To include 5 Key documents:

- Transitional Care Plan. This document is a checklist to ensure the patient has all the skills necessary for a successful transfer to adult services. (See Appendix 1)
- Patient information leaflet on transition. This describes the transitional care process. (See Appendix 2)
- Patient and parent/carer questionnaires. This is the key tool for identifying the extent the patient is ready for transition to adult services and which skill sets/knowledge base require further development before successful transfer to adult services can be undertaken. (See appendices 3 -5)
- Flow chart on how to use the Ready Steady Go programme (see appendix 6)
- Key worker document. This document supports the key worker by providing additional guidance on how to assess the young person at each stage. (See appendix 7).

Bridging the gap: an integrated paediatric to adult clinical service for young adults with kidney failure’, BMJ 2012; 344:e3718