

# Principles of practice

## **Developmentally appropriate transition care for children and young people as they move from child to teenage & young adult and adult services**

### **Introduction**

Young people aged 13 to 25 years are going through a period of rapid change. The tasks of childhood (e.g. sustaining friendships and achieving academic success) are continuing, tasks of adolescence (e.g. developing the sense of self and acquiring autonomy) are central and certain tasks of adulthood (e.g. focusing on career, intimate relationships, and future health) are emerging.

This rapid period of change and development coincides with the move from child to adult healthcare systems.

Developmentally appropriate care requires children's and adult teams to understand and engage with the needs of the young people they see and provide care that is personalised to the individual's needs. A flexible, multidisciplinary approach is required to work with young people and their families to achieve individual healthcare goals and help minimise the impact of health needs upon other areas of their lives (social; vocational; educational; emotional; leisure; and the move towards independent living).

Transition in healthcare is the purposeful and planned process that addresses the medical, psychosocial, educational, and vocational needs of young people as they move from child centred to adult orientated healthcare systems.

These principles have been developed from NICE (2016) recommendation 'Transition from children's to adults' services for young people using health or social care services', the 'You're Welcome - Quality criteria for young people friendly health services' [DH 2011], and feedback from healthcare professionals, patients, and family members with experience of transition following a diagnosis of childhood cancer.

### **Context**

- These principles apply to children and young people aged 13 to 23 years moving from child to TYA or adult services. Young people transferring from TYA to adult services following their 25th birthday are out of scope although many of the principles will be applicable.
- The guidance aims to support the planning and delivery of care, and young people's experience as they move from children's/Teenagers and Young Adults [TYA] services to adults' services within the South Thames Operational Delivery Network.
- In most cases the team leading a young person's transition will be the child's oncology team based at the Primary Treatment Centre [PTC] with other teams or services [health, education and social] taking a supporting role. For some children it may be more appropriate for the lead to be taken by the child's Paediatric Oncology Shared Care Unit [POSCU], another tertiary centre, education, or social care.

## **Aim**

These principles have been written for the multi-disciplinary teams (MDT) treating children and young people with cancer with the aim of

- reducing anxiety/stress for the young person and their family
- facilitating better access to high quality, coordinated, uninterrupted healthcare that is patient centred, age and developmentally appropriate, flexible, responsive, and comprehensive
- better long-term outcomes for young people

**Six principles have been agreed to use as a framework to define and implement the transition process for young people as they move to TYA and adult cancer services**

## **Principle 1: Timely identification of young people requiring transition and provision of a transition plan**

Transition should begin sufficiently early to facilitate a purposeful and planned transition, particularly for patients seen infrequently. Transition is more than the transfer to adult services. All young people require developmentally appropriate transition care as they move towards adulthood, including those that will remain with the same medical team.

## **Recommendations**

- All PTC MDTs treating children with cancer should have a method of identifying young people requiring transition care.
- Professionals should start talking to all young people and their families about their health needs, transition and/or moving to TYA or adult services at or around the young person's 14<sup>th</sup> birthday.
- For young people diagnosed after their 14<sup>th</sup> birthday transition discussions and shared decision making should start as early as possible after diagnosis, at least 6 months prior to the move to adult services.
- The child and family should be made aware that while most young people move from child to adult cancer services soon after their 18<sup>th</sup> birthday, the timing of the move to adult services is flexible, and that some areas of child orientated healthcare may stop at 16.
- Shared decision making with the young person should include discussion of all the options available for TYA/adult care, including as appropriate, transfer to TYA/adult cancer care at the PTC, TYA designated hospital, local adult cancer services or joint care between two or more centres.
- Transition plans should be revisited at key times points in the patient's treatment pathway – including any discussions on the likelihood of relapse or progression of disease.
- The young person's Consultant oncologist, alongside the MDT, should write a summary that includes of the young person's diagnosis, treatment received, health needs and recommended follow up including plans for transition and long term follow up. This information should be discussed with the young person and updated as the young person progresses through transition.

## **Principle 2: Provision of developmentally appropriate care that empowers young people and supports their families**

Children and young people should be supported to identify their own individual goals for health and well-being and encouraged to learn about their health needs and develop self-management skills as a normal and expected part of growing up. This process of education and empowerment should be guided by the needs and abilities of the young person. It can begin at any age and should continue throughout young people's lives, extending into adulthood.

### **Recommendations**

- Professionals should work with young people to help them develop the knowledge and skills they need to keep healthy and well and give young people the opportunity to talk about how their health needs may impact on their future, including employment, independent living, sexuality, and relationships.
- Professionals should be familiar with the use of age-appropriate holistic needs assessment tools to support this work (HEADSSS, Holistic Needs Thermometer).
- Age and developmentally appropriate verbal and written information on transition should be offered to the patient and family (Appendix I).
- Age and developmentally appropriate information regarding consent and confidentiality should be available to young people and their families.
- Healthcare professionals should be aware the law regards young people aged 16 and over to be adults in respect to their confidentiality. Children under the age of 16 who have the capacity and understanding to take decisions about their own treatment ('Gillick competent') are also entitled to make their own decisions around confidentiality.
- Young people should routinely be offered the opportunity to be seen without their parents/carers for part of their consultation.
- The role of the young person's parents/carers and wider support network should be acknowledged and included in transition planning and care in line with the young person's preference.
- Parents should be involved in supporting the gradual shifting of responsibility for management of the young person's condition to the young person
- Parents should be provided opportunities to talk to health professionals without the young person present while maintaining the confidentiality and trust of the young person.
- Young people should be signposted to other sources of support and advice, including opportunities to meet other young people of similar age and experiences (Peer support).

## **Principle 3: Identification of a transition keyworker for all young people**

All young people should have a planned and coordinated transition. This can be achieved by identifying someone to help the young person and their family transition into a new team. The role of the transition keyworker will usually be fulfilled by the clinical nurse specialist but can be undertaken by any member of the young person's healthcare team.

## **Recommendations**

- All MDTs treating children, teenagers and young adults with cancer should have clear pathways for the provision and coordination of transition care including the sharing of information between child, TYA and adult services.
- Every member of the MDT is responsible for ensuring developmentally appropriate health and transition care occurs at every contact with a young person and their family.
- MDT's will identify a transition keyworker for each young person aged 14 plus.
- The transition keyworker has responsibility for ensuring a plan of care has been devised and agreed with the young person and their family and shared appropriately.
- The transition keyworker will ensure all young people 16 years plus on active cancer treatment are referred to the Primary Treatment Centre TYA cancer MDT.
- The transition keyworker will ensure all young people 16 years plus on active cancer treatment are referred to the local TYA cancer clinical nurse specialist where available.
- The transition keyworker should work in collaboration with the keyworker from the relevant POSCU and adult MDT.

## **Principle 4: Effective communication, shared responsibility, and joint working.**

Good communication should occur between all relevant parties to ensure effective transition, particularly between the young person and the paediatric and adult professionals involved in the young person's care. Close liaison and willingness to work together is required between the referring and receiving teams to ensure that the transfer is seen as a positive step.

## **Recommendations**

- Identification of all individuals relevant to the transition process from the young person's support network and involved child and adult services. This may include professionals from allied health care, mental health, social care, and education. The young person's parents or carers, POSCU, community nursing team, planned TYA or adult cancer team and GP should routinely be involved.
- Communication related to the young person should be addressed directly to the young person and not 'care of parent/guardian'
- A referral letter to adult services should be sent at least 3 months prior to the expected date of transfer
- The young person should be offered opportunities to meet the professionals who will be taking over their care and visit adult orientated health settings they may access following the move.
- At least one joint appointment, led by children's or adult services, should be arranged for the young person moving to adult services, with sufficient time available to discuss the young person's health care and transition support needs. This may be achieved by having separate transition clinics or by allocating a double appointment.
- The young person should have a named contact within both children's and adult services for the first six to 12 months after transfer to ensure handover and settling into the new service is complete and any issues are addressed by both teams.

- Following the transfer to adult services, children's services should be available to provide advice and support to professionals from adult services.
- It should be recognised that Primary Care [GP] often has a significant role in the ongoing management and co-ordination of healthcare for young adults and that they should be kept informed of plans for transition.

### **Principle 5: Provision of support for transition before, during and after the move to adult services**

Transition care should support the young person and their family to feel confident and ready to make the move to adult services and ensure that the young person is settled into adult services prior to discharge from children's services.

#### **Recommendations**

- Readiness to transition is discussed with the young person and they are helped to develop any gaps in skills, knowledge or confidence needed to manage their health and transition to adult care.
- Transition care should be strengths-based. Focusing on what is positive and possible for the young person rather than on a pre-determined set of transition options
- Transition planning should be reviewed at least annually. Young people and their parents/carers offered should be offered an opportunity to complete the 'Ready Steady Go' transition questionnaires and discuss the completed questionnaires with their health care team.
- The decision regarding the timing of the move should ideally be made by the young person, in partnership with their parents/carers and healthcare professionals and take place at a time of relative stability in the young person's life and treatment.
- Young people should only be transferred to the TYA/adult service when they have completed growth and puberty and have the necessary skills to function 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 should be ensured prior to transfer.
- A comprehensive long term follow up package including recommended late effects screening should be agreed for every child or teenage cancer survivor.
- On entry to TYA or adult services the young person should be offered the opportunity to complete 'Hello to adult services' questionnaire and discuss the completed questionnaire with their adult health care team.
- Children's services should continue to provide support to adult services for 6 to 12 months following the move. If a young person fails to effectively engage with adult services amendments and re-establishment of the individual transition plan made if required.

### **Principle 6: Planned route for access to urgent advice and/or emergency care as a young adult**

A young person who has moved into adult services should know what to do and who to call when they are unwell or require advice.

#### **Recommendations**

- Prior to moving to adult services, the transition keyworker should work with the young person's POSCU, receiving adult team and other supporting specialties to ensure that the young person has an appropriate self-management plan and information on how to access urgent advice and/or emergency care.
- Specific information about who to contact for out of hours advice, should be provided for young people and families in a clear and concise way.
- Specific information about access to emergency health care, including for health problems unrelated to cancer, should be provided for young people and families in a clear and concise way.
- Young people should have the information they require regarding their own health needs to enable them to access appropriate care
- Young people/parents having to repeat information to health professionals should be avoided by the use of written information.
- HCP's working with young adults with learning disabilities should be aware that additional advocacy support in order to safely access emergency and inpatient care may be required.

**Authors:** South Thames Childhood Cancer Operational Delivery Network; Transition Working Group. April 2022. **Review date:** April 2023

## References

Care Quality Commission [June 2014] From the pond into the sea: Children's transition to adult health services

DH [April 2011] You're Welcome - Quality criteria for young people friendly health services  
London South Bank University and Great Ormond Street Hospital for Children NHS  
Foundation Trust [2014] Benchmarks for transition to adult health services

NICE [2016] Transition from children's to adults' services for young people using health or social care services [Ng43] <https://nice.org.uk/guidance/NG43>

NICE [2016] Transition from children's to adults' services, Quality standard  
<https://www.nice.org.uk/guidance/qs140>

## Resources

Royal College of Paediatrics and Child Health  
[Transition to adult services | RCPCH](#)

Making healthcare work for young people A toolkit to support delivery of 'Developmentally Appropriate Healthcare' in the NHS [nhs-making-healthcare-work-web-02.pdf \(northumbria.nhs.uk\)](#)

Adolescent Health Programme e-learning

<https://www.e-lfh.org.uk/programmes/adolescent-health/>

The supporting paperwork and further information about the Ready, Steady, Go and Hello to Adult Services transition assessment tool is available from

[Ready Steady Go - TIER Network](#)