

Guidance for: Paediatric to Adult Critical Care Transition



Endorsing Organisations



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Introduction

More young persons, with complex and potentially life limiting diseases, are surviving into adulthood and may require critical care input. Many illnesses once thought to be confined to childhood, such as cystic fibrosis or metabolic disorders, now need to be managed as diseases that begin in childhood but continue into adult life⁽¹⁾. For instance, the life expectancy for a cystic fibrosis patient has lengthened significantly as medical advances have progressed. The median life expectancy for those patients born between 2013 and 2017 is now 44 years or greater, and with this comes the need for greater input from adult services⁽²⁾.

The number of children on long-term ventilation (LTV) in the UK has grown significantly in recent decades. In 1975 there was only one child documented as being on LTV in the UK, by 2013 this had increased to nearly 1,400 and continues to rise year on year⁽³⁾. Following a NCEPOD review, recommendations have been published on areas identified in the care of young persons (up to 25 years old) receiving or who had received LTV⁽⁴⁾. This report included guidance on the transition from child to adult services.

Paediatric critical care medicine has evolved and approximately 50% of admissions are children with life-limiting conditions⁽⁵⁾, of whom a proportion will be extending into young adulthood. Several multi-professional and inter-professional services are involved, including those in the hospital and community. Many of these young people, families and carers have established trusting relationships with their specialist clinical teams. It is imperative to work effectively with the families as they have an expert understanding of, and often coordinate, the young person's care.

Guidance aims

This subset of patients, who frequently have complex medical, nursing, and psychosocial needs, may present acutely for the first time to an adult setting where minimal information is known about them. The aim of these standards and recommendations is to improve the experiences and care of those young persons who require this input as they enter the domain of adult critical care services.

Standards and recommendations for the establishment of the Transition Pathway

The standards and recommendations set out below will assist in the establishment of a working paediatric to adult critical care transition pathway, applicable in all Hospital Trusts. It is recognised that a “one size fits all” approach cannot be used for critical care transition and that certain aspects will be tailored to the specific working requirements of the Trusts involved.

Operational Delivery Networks may be helpful in providing an overview of Transition in their specific geographical area, including the young persons who require this process and the contacts of all involved.

It is also not possible to stipulate an exact age to begin the transition process, but it is important to keep the young person, their families and their carers fully informed and involved throughout the transition planning. It may only become apparent that the young person may require adult critical care services as they are nearing the age of sixteen. However, the aim should be to begin the process of transition at the age of fourteen where possible.

Standards

- 1) **All young persons who are likely to require future input from adult critical care services must be identified in a timely manner.**
- 2) **A suitable transition pathway to adult critical care services must be initiated and followed for all eligible young persons. Admission to adult critical care must not occur until this is complete.**
- 3) **A bespoke Critical Care Transition Pathway must be in place to ensure clear documentation and communication through the process.**
 - See *Appendix 1 – Paediatric to Adult Critical Care Transition Checklist* to aid you in assuring that the key transition steps are met.
 - See *Appendix 2 – Paediatric to Adult Critical Care Transition Pathway*, which provides an example of the document and communication which must be in place. You may use this to complement any local documentation you may have.

Recommendations

- 1) **The transition process for critical care should be led by children’s services.**
 - The Hospital Trust(s) involved should identify both a medical and nursing lead for transition.
 - If the young person is well known to critical care services, the Paediatric Critical Care Consultant should lead the process. If the young person is not known to Paediatric Critical Care Services, their primary specialty consultant should lead the process.
- 2) **The transition process for critical care should occur in parallel to other speciality transition needs.**
 - The primary speciality should coordinate the whole transition process.
 - If more than one speciality is involved, a designated lead / key worker should be appointed to coordinate the process.

- 3) There should be an Adult Critical Care Transition Lead within each Trust to coordinate the transition process.**
 - The Hospital Trust(s) involved should identify both a medical and nursing lead for transition.
 - These will form the basis of contact between children's and adult's critical care services for the purpose of transition. These services should stay in contact before and after transition until the young person has settled in their new environment.
 - An up-to-date contact list should be readily available, enabling children's services to contact the correct individual.

- 4) A multi-professional approach should be taken throughout the process.**
 - Successful critical care transition relies on input from many members of the multi-professional team – including (but not limited to) Consultant Intensivists, parent Speciality Teams, Critical Care Nursing Team, Physiotherapists, Pharmacists, Dietetic Team, Speech and Language Team, Psychologists, Play Specialists, GP and the Family Support Worker and/or Social Worker.
 - These members should have input to the transition process and ensure details of the young person's needs and the care and support they provide has been handed over to their adult counterparts.

- 5) Where appropriate, multi-professional meetings should include the young person, families, and carers.**
 - Some individual's transition needs may be more complex than others, some may require several meetings to discuss ongoing care and appropriate future treatment plans.
 - Ongoing changes to the young person's baseline physiology (e.g., requirement for respiratory support) should be communicated if they are clinically significant and will influence future decision making.
 - Details of important discussions held with the young person, their families and carers should be communicated to the adult team. For example, the young person's opinion on whether to have a tracheostomy or not.

- 6) All Adult Critical Care Units should facilitate a visit or visits for young people, their families and carers prior to their first admission.**
 - The adult critical care unit environment can be a daunting experience compared to that of a specialised paediatric unit. Visits should occur to allow introduction to the environment and the Critical Care Team to lessen anxiety associated with this.
 - The adult critical care team should also visit the paediatric critical care service, if appropriate, to introduce themselves and explain how the new environment will be, which will help to allay fears and anxieties of the young person moving to their new environment.

- 7) Where appropriate, parallel planning should be in place with the Palliative Care Team.**
 - It is recognised that many conditions that lead to the need for frequent Paediatric Critical Care admissions are life limiting.
 - Early involvement of the Palliative Care Team can allow exploration of the young person's and families' wishes, the goals of care, future planning and management of symptoms should occur alongside the transition process.
 - In some instances, the Palliative Care Team may provide continuity of care into the young person's adult life, sometimes into their mid-20s.

- 8) The transition process should include involvement of the Play Specialist Team, Family Support Workers or school.**
- Some young persons will experience a grieving process as they leave the paediatric team and an environment where they may have spent a significant part of their childhood. The Play Specialist Team, Family Support Workers or school can help prepare them for this change.
 - Creation of a memory book may be vital at some point throughout the transition. Close contact with the young person, their families and carers will enable the young person to relate back to what they have experienced. This can act as a talking point for the adult team, helping to ease the challenges which may come with the change.
- 9) A profile of the young person should be transferred between services and should form an essential part of their care.**
- This profile should include the young person's preferences. For example: their likes and dislikes; communication style; medication; dress and nutrition preferences. This should be completed jointly with the young person and their parents/carers. The hospital passport (if available) should be shared with adult services. Information on important cultural and spiritual practice should be included.
 - This could dovetail with a Child & Young Persons Advance Care Plan (CYPACP) (or similar), which will contain much of the required information.
- 10) Changes in the consent process should be explored and discussed with all young persons and carers. The need for any future Deprivation of Liberty Safeguards (DoLS) should be reviewed.**
- This will help manage expectations and understanding as transition progresses and completes.
- 11) Feedback should be sought from young persons, families, carers, and the Adult Critical Care team during the transition process and after transfer of care.**
- This will help to evaluate the process and improve future practice.

Background

What is Transition?

Transition is the process that addresses the health, psychosocial and educational needs of young people as they move from childhood to adulthood, and health care is moved from paediatric to adult services. The Royal College of Paediatrics and Child Health (RCPCH) make recommendations for clear pathways into adult care⁽⁶⁾. This is replicated within the NICE guidelines QS140⁽⁷⁾, NG43⁽⁸⁾, NG61⁽⁹⁾ and their recommendations. In a typical NHS Trust (serving a population of 270,000), approximately 100 young people with long-term conditions requiring secondary care input reach the age of 16 years annually⁽¹⁰⁾. The age of transfer to adult services is often flexible, depending on the young person's circumstances and their primary specialty. A proportion of this population will require care and input from adult critical care services. Whilst there has been much progress in the field of Transition Services, critical care has not been included formally until now. At the time of writing, NCEPOD are beginning their review of the transition from child to adult health services.

Transition to adult critical care services does not fit effectively into any of the existing programmes but instead requires its own bespoke pathway.

Many successful transition programmes exist, and some are well established. "Ready, Steady, Go" by Southampton Children's Hospital⁽¹¹⁾ and the "10 Step Programme" by Alder Hey Hospital⁽¹²⁾ are excellent examples of programmes that aid in children's services transition.

Transition Pathway Challenges

The setting of adult critical care is often perceived to be greatly different to that of the paediatric setting. Young persons, families and carers experience a vast change in how the care is delivered when they reach adulthood. These changes include:

- Moving from the paediatric setting to the adult critical care environment.
- Differing funding processes.
- New sources of their usual equipment.
- A complete change in all team members who now care for them.
- Changes in consent process.
- Differing practices on processes around visiting for families.
- Different processes for overnight stays (for families and carers).

Transition Pathway Aims

The Transition pathway aims to ensure a smooth and informative handover from paediatric to adult critical care services for patients, families, carers, and the multi-professional teams. It aims to manage all expectations, and to deliver a high standard of care for all involved, whilst ensuring excellent communication throughout the process.

It meets these aims by:

- Introducing the young persons to the new setting of adult critical care.
- Helping the critical care team to understand the young person's needs and wishes.
- Enabling future planning, including agreed goals of care and limits of treatment where appropriate.
- Explaining, discussing, and planning for changes to the consent process.

Consent – The Leap into Adult Services

It would be impossible to plan a transition pathway without citing The Mental Capacity Act (MCA) and its role in the consent process⁽¹³⁾. Young persons, families and carers can find that the change in the consent process is a daunting prospect as they reach adult services. The Transition pathway aims to discuss this as part of the ongoing planning, ensuring that all involved are aligned in their expectations when it comes to future decision-making discussions. The leap from parent / legal guardian consent to that of the young person / medical team is often perceived as one of the most significant and most difficult changes experienced.

Young persons, families, carers, and the involved professionals need to be aware of the legal and consent implications of the Mental Capacity Act. They need to be prepared for the changes that it brings to the decision-making process; these changes should be introduced to the young person, their families, carers, and multi-professional team at the earliest possible opportunity. This will allow repeated discussions to aid understanding prior to the MCA coming into play at the young person's sixteenth birthday.

The Deprivation of Liberties Safeguards (DoLS) are also part of the MCA, and if appropriate, should be discussed during the transition process⁽¹⁴⁾. Often, the DoLS may challenge the way the families and carers have cared for their child over the years. Therefore, the aims of the DoLS needs to be explained to all those involved.

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