

## British Intestinal Failure Alliance (BIFA) Guideline

# Guidelines for Transitioning Adolescent and Young Persons with Intestinal Failure into Adult Service

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### Aim of the guideline

The aim of this document is to provide guidance for health care professionals and patients on how to plan and implement transition from paediatric to adult care for intestinal failure (IF) patients.

*\*Disclaimer: BAPEN Position Statements/Guidelines have been prepared as guidance only to assist qualified healthcare professionals in the decision-making processes surrounding nutritional care. Users of these materials may only do so on the condition that they exercise their own professional knowledge and skills when applying such guidance to specific circumstances. Anyone without the appropriate qualifications must seek the advice of a qualified healthcare professional before taking, or refraining from, any action on the basis of the policies or guidance. BAPEN does not (i) owe a duty of care to users of the policies or guidance who are not qualified healthcare professionals; and (ii) cannot accept liability to anyone using these policies or guidance.*

## How this guideline was developed

Reference was made to existing national guidance and published literature in development of this guideline including:

- Existing national generic guidance (National Institute for Healthcare Excellence (NICE), Royal College of Paediatrics and Child Health (RCPCH))
- British Association for Parenteral and Enteral Nutrition (BAPEN)/ British Society for Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN) guidance
- Literature search of CINAHL database– search terms “paed\*”, “adult”, “transition” “intestinal failure” “chronic condition” “transition of care and IF”

The document is based on the best available evidence and expert consensus (1-4). The document is intended for health care professionals who are involved in the care of IF patients, such as gastroenterologists, surgeons, dietitians, nurses, pharmacists, psychologists, and social workers. The document is also intended for patients and their families who are facing the transition from paediatric to adult care.

## What is transition?

Transition is defined as "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented health care systems" (5). An increasing number of adolescents with life-threatening conditions are surviving into adulthood (6) and therefore requiring transition from paediatric to adult services (7). From the Healthcare professional perspective, this translates to a multi-faceted, active process that attends to the medical, psychological and educational/vocational needs of adolescents as they move from child to adult centred care (5).

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## Why is transition needed?

The main goal of transition is to optimise the health and well-being of the patient, and to enable them to achieve their full potential and independence. Whilst it is known that the transition process can be demanding for any young person and their family, patients with intestinal failure receiving home parenteral support (HPS) are challenged in a different way due to the risks associated with non-compliance (8). Transition can also benefit the patient and the family by improving their satisfaction, confidence, and empowerment. Research has shown that a formalised transition process is associated with better economic, disease-specific and developmental outcomes (9).

Transition can benefit the health care system by improving the continuity and quality of care, reducing the duplication of services, and enhancing the efficiency and cost-effectiveness of the service delivery.

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## Overview of the transition process

Transition is not a single event, but a gradual and continuous process that starts in early adolescence and ends in early adulthood. Key aspects include:

- The transition process should start as early as possible, preferably around the age of 12 to 14 years, or earlier if the patient has a complex or severe condition (8)
- The transition process should be completed by the age of 18 to 21 years, or later if the patient has a delayed or impaired development.
- The transition process should be planned and implemented in a structured and systematic way, using a written transition plan that outlines the goals, actions, and responsibilities of each member of the transition team.
- There should be a key accountable individual who acts as a named worker, responsible for supporting the move to adult services. Helping to co-ordinate care and provide support to the Patient and Family. (10)
- To achieve the transition goal of independence, the process should be patient-centred, developmentally appropriate, and culturally sensitive. It requires the young person to develop knowledge of their condition, medications (including parenteral nutrition) and develop skills in navigating the healthcare system (11), as this is often very different between paediatric and adult systems.
- A multidisciplinary team involving professionals from both paediatric and adult services, community services (including general practitioners) and homecare providers is required to support this process and allow for a more cohesive transition.
- The transition process should be monitored and evaluated regularly, tracking the progress and outcomes of the transition.
- The paediatric team should attend the first clinic appointment in the adult sector. This is to ensure the young person, and their family members feel supported through a new and often daunting experience.

The following sections of the guidelines should be read in conjunction with one another, as they are intimately intertwined. The 3 main areas to be covered are:

- Patient/family related aspects
- Key stakeholders and their roles
- Local/national support

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## Patient/family related aspects

- The patient: The patient is the central and active participant of the transition process. The patient should be involved in the decision-making and planning of the transition, and should be encouraged to express their preferences, concerns, and goals. The patient should also be supported to develop the skills and knowledge necessary for self-care and self-advocacy in the adult setting.
- The patient's family/ carers: The family plays a vital role in supporting and facilitating the transition of the patient. The family should be informed and educated about the transition process and should be involved in the preparation and planning of the transition. The family should also be encouraged to gradually shift their role from being the primary caregiver to being the partner and advocate of the patient.
- Ensure that patients with neurodiverse conditions (e.g. autism, attention-deficit/hyperactivity disorder) are treated appropriately, with their choices and ability taken into account.

### Preparation of young person and family/ carers

The preparation and education of the patient and the family are crucial for a successful transition. The patient and the family should be provided with the following information and education:

- The rationale and benefits of transition, and the expected changes and challenges of the adult setting.
- The transition plan (see below). This should be shared with the adult team and the young person and their family at the start of the process. (12)
- The roles and responsibilities of each member of the transition team.
- Written information should be given to the young person and their family early in the process to support any verbal information given. This has been shown to be a useful way of communicating with transitioning patients (13).
- When a date for transition has been agreed between all stakeholders, an informal visit to the adult department/ hospital should be arranged.
- Young people with neurodevelopmental or learning disabilities should be referred to the adult services vulnerability team to ensure all their needs are being met in the most appropriate manner.

### The plan

A transition plan should be negotiated with the patient and be used as a reference with shared goals and objectives during the transition phase. Note that this is a living document and should be modified as agreed at various time points of transition.

It is recommended that the plan should include the following:

1. Self-advocacy and independence (in general and medical setting).
2. Understanding of own condition/development.
3. Ability to maintain central line care.
4. Ability to administer Home Parenteral Support. (HPS).
5. Ability to care for any enteral devices.
6. Understanding of legal and financial status.

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7. Develop educational/vocational goals.
8. Aspects of lifestyle/social life as an adult.

**Expanding each of the above:**

**1. Self-advocacy and independence (in general and medical setting)**

- Explore desires and aspirations for achieving independence.
- Enquire and explore how the young person is making decisions for themselves in different situations (e.g. in self-care, educational/vocational choices) and how they are supported.
- Be able to care for a stoma independently, if a stoma is present.
- Encourage the patient to attend IF clinics alone. If they wish to have parents/ carers with them, encourage them to have half of the allocated time alone and half with their parents.
- When parents/ carers are in attendance, speak to the patient directly and encourage them to take the lead in the conversation regarding their care.
- Encourage the young person to contact the nutrition support team independently if they have any questions or concerns.
- Ensure the young person has the emergency contact numbers for their supporting team (or those covering) during working and non-working hours.
- Ensure the young person has a copy of the Home Parenteral Support Patient Charter (patients in England).
- Signpost young person to a patient advocacy support group (e.g. PINNT) (14).

**Rationale: allow young person's own views regarding their own destiny and care to be heard as expected of an adult.**

**2. Understanding own condition/development**

- Provide information regarding their diagnosis and resulting clinical status. Consider presenting this in small bite-size chunks with increasing complexity over time.
- Provide education regarding physical changes that accompany puberty.
- Provide education regarding psychosocial and emotional issues, such as coping with stress, anxiety, depression, and isolation.
- Seek understanding from the young person regarding the above.
- Understand any changes to medications during the transition.

**Rationale: ensure decisions regarding the young person's own medical care is based on knowledge of their condition.**

**3. Ability to maintain central venous access device**

- Ensure the young person knows the type of central venous access device they have and the size.
- Young persons should be encouraged to become independent in the management of their device.
- Young persons should be aware of the type of dressing used on their device and how to change this independently.

**Rationale: ensure young person's ability to be able to manage and maintain their central venous device in both daily and in emergency situations.**

**4. Ability to administer HPS**

- Ensure the young person understands their prescription and any changes that will be made to this. In the adult sector,

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aspects which are likely to change in the prescription may include having lipid-free bags, dosing not per kg and no overage, for example.

- Young persons are encouraged to become independent with their connection and disconnection procedures and weekly dressing changes.
- Ensure the young person is aware of their homecare company (transition should be no reason to change company) and how to contact them with issues. In the adult sector, it is often the patient that liaises with the company.
- Ensure the young person is aware of when deliveries are due and how to order stock items. Patients should be encouraged to become self-caring in management of PSHPS stock.

**Rationale: ensure young person's understanding for taking control of practical aspects of parenteral nutrition delivery to their body.**

#### 5. Ability to care for enteral devices (if used)

- The young person knows the type(s) of device(s) they have, and what they are used for, ie, enteral nutrition, medications, irrigation.
- The young person to be independent in the care of any devices, including where relevant, balloon care, how and when tube(s) should be flushed, how to vent from tube and/or attach drainage bag, rotating and advancing, and correct medication (including suitable formulation) administration.
- The young person knows how often their device(s) need to be changed and they are encouraged to independently manage this: for example, changing own balloon gastrostomy tube, or balloon retained low profile device.
- The young person knows their enteral feed regimen (rate and infusion period) and how to connect, to provide this.

**Rationale: ensure young person's understanding for taking control of practical aspects of enteral nutrition delivery to their body.**

#### 6. Understanding of legal and financial status

- The legal and financial issues of the patient, such as consent, confidentiality, insurance, and benefits should be discussed.
- Application of Gillick's competence in making decisions prior to the legal adult age of 18 in the UK.
- If the young person has a condition which might impact on decision making (i.e. impairment of mind or brain e.g. neurodivergent conditions), discussions regarding acting in the best interest of the young person on a case-by-case basis might need to take place.
- Discussions regarding power of attorney should be offered and supported appropriately.

**Rationale: ensures young person's legal status as they transition into adulthood is being considered in a meaningful manner.**

#### 7. Develop educational/vocational goals

- Listen to and support the young person's educational/vocational aspirations.
- Taking any education & health care plan (EHCP) into account in any support provided.
- Discuss career planning with the young person – what do they want to do and what considerations are needed for their condition.
- Help the young person navigate life stages such as attending university and potentially moving away from home.

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**Rationale: ensures the young person reaches their educational potential with consideration to the young person’s wishes and any legal requirement regarding education.**

**8. Aspects of lifestyle and social life as an adult**

- Encourage the young person to socialise with people of their age. Discuss with the young person social activities such as drinking alcohol and the impact this may have on their own health.
- Provide advice to help the young person to be able to go on holidays.
- Discuss family planning and if/how their condition may have an impact on this.

*Rationale: ensures the young person can integrate into as many aspects of adult life as possible with consideration to the young person’s wishes.*

**Key stakeholders and their roles**

Apart from the patient and their family, the other key stakeholders in the transition process are:

- The paediatric IF team: The paediatric service is responsible for initiating the transition process, and for providing the patient and the family with the appropriate information and education. The paediatric service should also identify and refer the patient to the most suitable adult service and should ensure a smooth and timely transfer of the medical records and care plan. The paediatric service should also maintain a supportive and collaborative relationship with the adult service and refer to any national framework documents available.

The Paediatric services should summarise some key aspects important throughout transition:

- 1) Operative procedures with dates.
  - 2) Current residual intestinal anatomy.
  - 3) Enteral feeding approaches with dates and types of enteral feeding tubes used.
  - 4) Central venous access devices with insertion and removal dates.
  - 5) Current central venous access anatomy (if unknown the patient will need an MR or CT venogram to assess central venous access patency).
  - 6) Central venous catheter infections with dates.
  - 7) Parenteral nutrition formulation.
  - 8) Enteral nutrition formulation (if relevant).
  - 9) Complications including any IF associated liver disease (IFALD) including liver biopsies and histology.
  - 10) Other aspects to include are medication history, allergies, relevant past medical history, social and family history.
- For English patients. The paediatric service should inform the adult service of any non-framework ancillaries and/or medication(s) the patient receives, along with any Service Level Agreements (SLA) for these that are in place.
  - The paediatric IF team should close the IF registry data for the patient at the time of transfer of patient.
  - The adult IF team: In supporting the young person and their family through this process, the adult team can help to instil trust in the new team. It is important for the young person and their family to feel familiarity with the adult team. This can be achieved through the adult team attending multiple transition clinics in the Children’s department/ hospital15. It may also be helpful to have an introduction to the team in a written format which can be shared with the paediatric team ahead of the process beginning. The adult IF team should add the patient to the IF registry, once they have been

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discharged from the paediatric team.

- The homecare provider: the homecare provider should be fully informed of the timing of transition to adult services. They should be aware of the changes that may need to be made to the HPS prescription and any nursing requirements in line with the Home Parenteral Nutrition (HPN) framework (English patients).

The adult IF team need to obtain a new Blueteq number for the patient, and ensure a new prescription is sent to the homecare provider once transition has been completed.

A date for when the adult service will take over invoicing and payment should be set between the paediatric and adult service and the homecare provider.

- Community services: As some young persons and their families would have been supported by community services, these services should be informed and be involved in the transition process. They are responsible for providing information pertaining to community care given to the young persons for the transition process. They might also make any recommendations on whether services could be continued or modified in adult care.

The adult IF team will work closely with any community services involved in the young person's care. An example of this may include the provision and funding of any enteral devices the patient requires.

- General practitioners: General practitioners (GP) would have had some involvement in the young person's journey regarding general health needs in paediatric care. In adult care, they will assume a more prominent role in the young person's care. In adult services, the GP will be asked to take over the prescribing of many medications\*, and the GP practice may be asked to provide any non-framework ancillaries. The GP may also be asked to support with other health needs such as facilitating blood tests when needed. It is important that hospital services engage and involve GP's from early on, to ensure they are prepared and able to support the Young Person through transition and beyond.

\*Note: Other relevant specialties involved in the young persons care might need to prescribe and manage as appropriate along with the GP.

### Evaluation and follow up process

The evaluation and follow-up of the transition process are important for ensuring the quality and effectiveness of the transition. The evaluation and follow-up of the transition process should include the following:

- Review the transition plan and monitor achievements/progress of the transition goals. Refer to framework Appendix R – transfer of patient from one purchasing authority to another (English patients).
- If available, use any standardised tools for measuring transition readiness & experience (e.g. Transition Readiness Assessment Questionnaire (TRAQ) & the Transition Experience Survey (TES))
- Obtain local feedback and satisfaction survey from all stakeholders to obtain opinions and perceptions of the transition process and outcomes. This should identify the strengths and weaknesses of the whole transition process.
- Production of a quality improvement plan, based on the above evaluations. This shall be a collective responsibility.

### Local/national related

- Each paediatric centre should have a dedicated transition team
- A transition policy should exist in each paediatric centre with input from relevant stakeholders. This policy shall be used to inform standards required.
- All healthcare stakeholders shall have transition MDTs job planned.

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- Trusts shall provide adolescent developmental training for staff involved in the transition process.
  - Appropriate funding is allocated to transition to support not only the process but its ongoing quality improvement.
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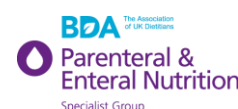
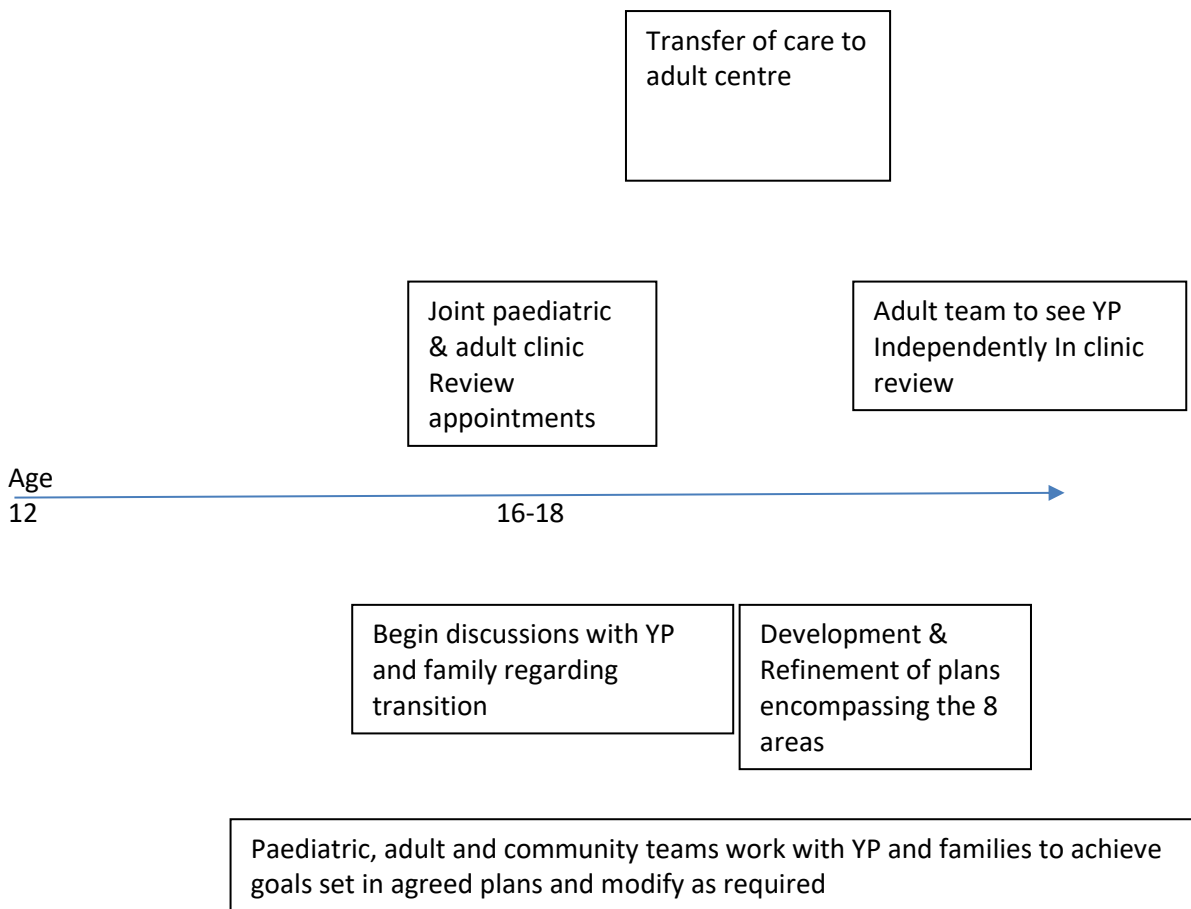


Figure 1. Suggested timeframe for key transition moment



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