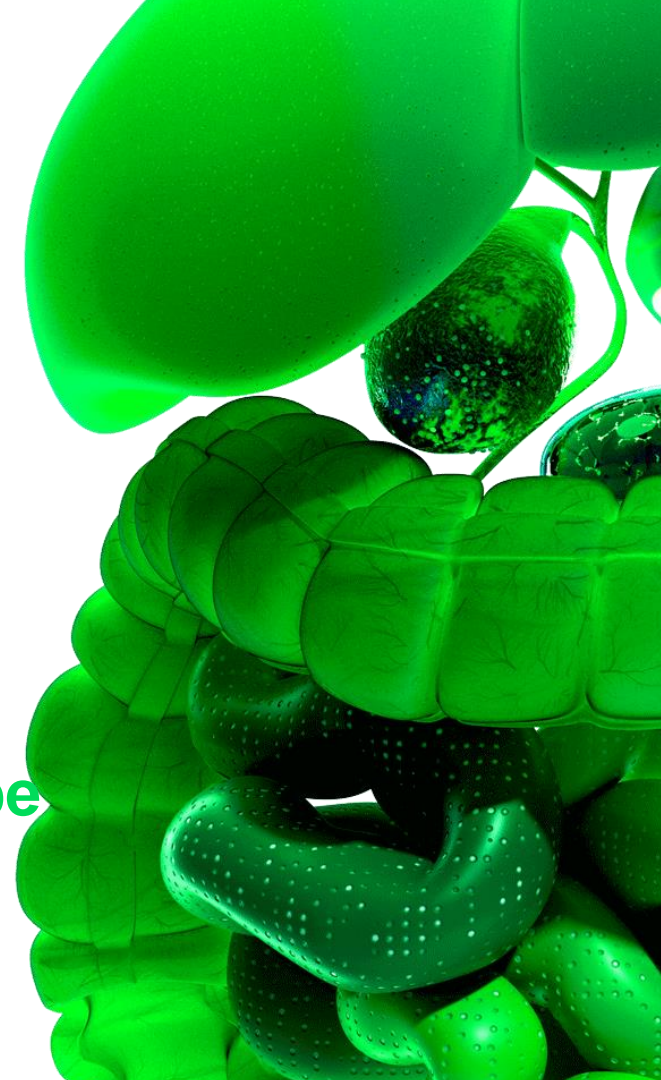


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Enhancing Transitional Care in Digestive Health

Addressing Challenges and
Implementing Strategies across Europe



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The report can be downloaded here:

ueg.eu/publications#public-affairs



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This presentation summarises the latest UEG Public Affairs publication: *Enhancing Transitional Care in Digestive Health. Addressing Challenges and implementing strategies across Europe.*

This Report was presented and launched during UEG Week 2024 during the Digestive Health Roundtable because “despite a growing body of evidence and consensus on its critical role in supporting continuity of care and treatment adherence for patients affected by digestive diseases, transitional care has often been overlooked by both the medical community and broader society”.

This Report calls for a structured transitional care for adolescents with digestive diseases, offering solutions to key challenges and recommendations for better patient outcomes.

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Enhancing Transitional Care in Digestive Health

Introduction

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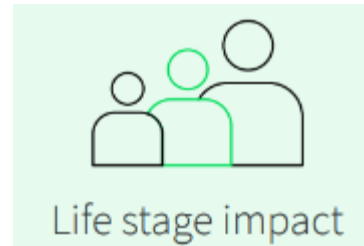
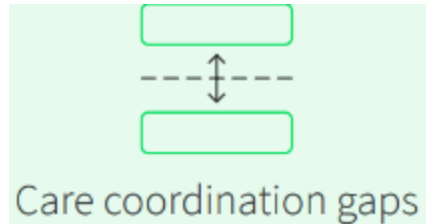
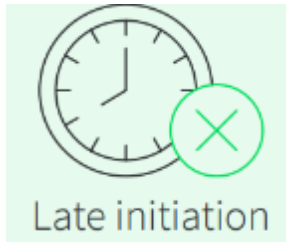
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Introduction:

- Adolescents with digestive diseases that turn adults are faced with another transition: moving from paediatric to adult care.
- Transitional care can be defined as: “purposeful, planned movement of adolescent with chronic medical conditions from child-centred to adult-centred healthcare”.
- This report has been developed following the 2023 UEG Digestive Health Roundtable that identified Transitional Care as priority.

Introduction:

Four key transitional challenges are presented, and recommendations are made to overcome them:



Digestive Diseases and Transitional Care

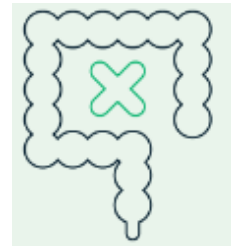
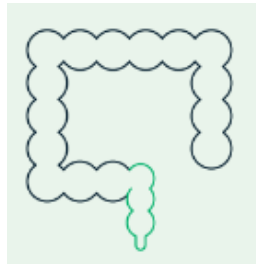
Patients with certain digestive diseases are more in need of transitional care due to their chronic nature and potential long-term effect.

- Coeliac Disease
- Inflammatory Bowel Disease
- Chronic Liver Disease (CLD)
- Liver Transplantation (LT) at Paediatric Age



Other digestive diseases facing additional obstacles

- Digestive cancers (stomach and pancreatic cancers)
- Rare digestive diseases
- Intestinal failure (& other nutritional-related conditions)
- Childhood obesity and gastrointestinal diseases



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Key Challenges 1/4

Late Initiation of the Transitional Care Process

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Late Initiation of the Transitional Care Process

Key Challenges



Delays in transition →
fragmented care delivery



Abrupt transition at 18: general
dissatisfaction



Parents and HC professionals'
responsibilities: passive patient
attitude

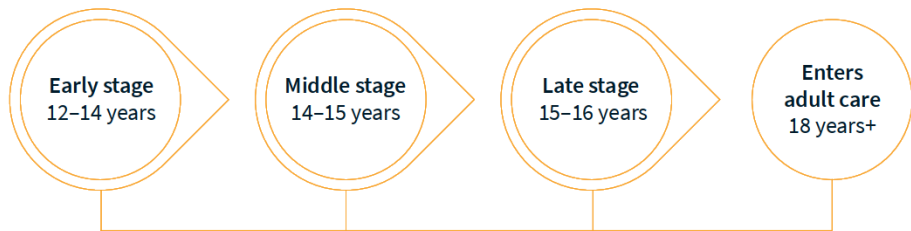


Delays in transition can
compromise patient outcomes

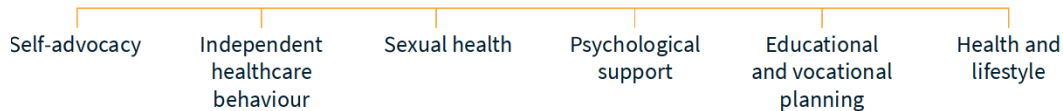
Recommendations

- EARLY initiation of transition process ideally by age of 12, no later than 14
- PREPARE patients and parents
- EDUCATE patients and parents
- STRUCTURED transition programmes with written plans, and age-appropriate checklists, allowing flexibility
- MULTIDISCIPLINARY team involvement
- Schedule FOLLOW-UP appointments

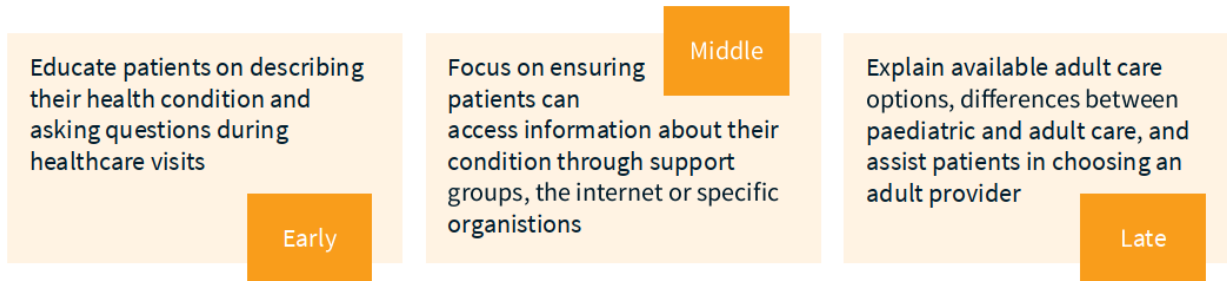
Spotlight on the best practice in Liver Disease



At each stage, the following issues can be explored and resolved by multidisciplinary teams:



As an example, self-advocacy needs to evolve throughout the transition process:



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Key Challenges 2/4

Care Coordination Gaps

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Care Coordination Gaps

Key Challenges

- Gaps in communication and information transfer between paediatric & adult services
- Lack of continuity of treatment plans
- Physicians focusing mainly on clinical aspects overlooking other ones
- Discrepancies between paediatric and adult healthcare professionals
- Unplanned contacts often & more tolerated by paediatric settings
- Paediatricians discussing disease evolution with parents without involving young patients can hinder patient understanding

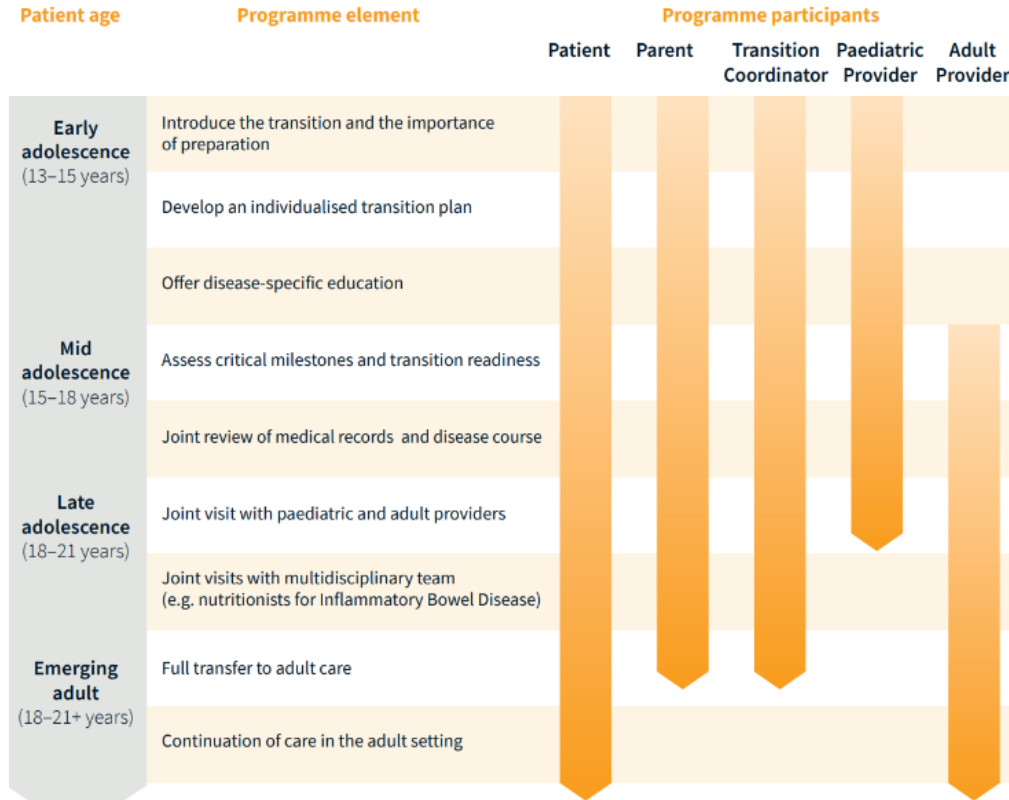
Recommendations

Transitional Care Coordinators (i.e. nurses) at the centre are crucial:

- to facilitate transition process
- to build confidence among patients
- to foster collaboration between paediatric and adult teams, including joint appointments
- to address the evolving needs of patients and parents
- to conduct individual assessments to evaluate the transition readiness
- to guide patients and parents to adult healthcare services



Spotlight on the best practice in Inflammatory Bowel Disease



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Key Challenges 3/4

Recognising Life Stage Impact

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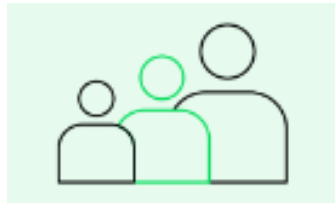
Recognising Life Stage Impact

Medical challenges

- Delayed puberty in certain conditions
- Disease management
- Psychological morbidity
- Gut-brain confusion
- Healthcare professional training

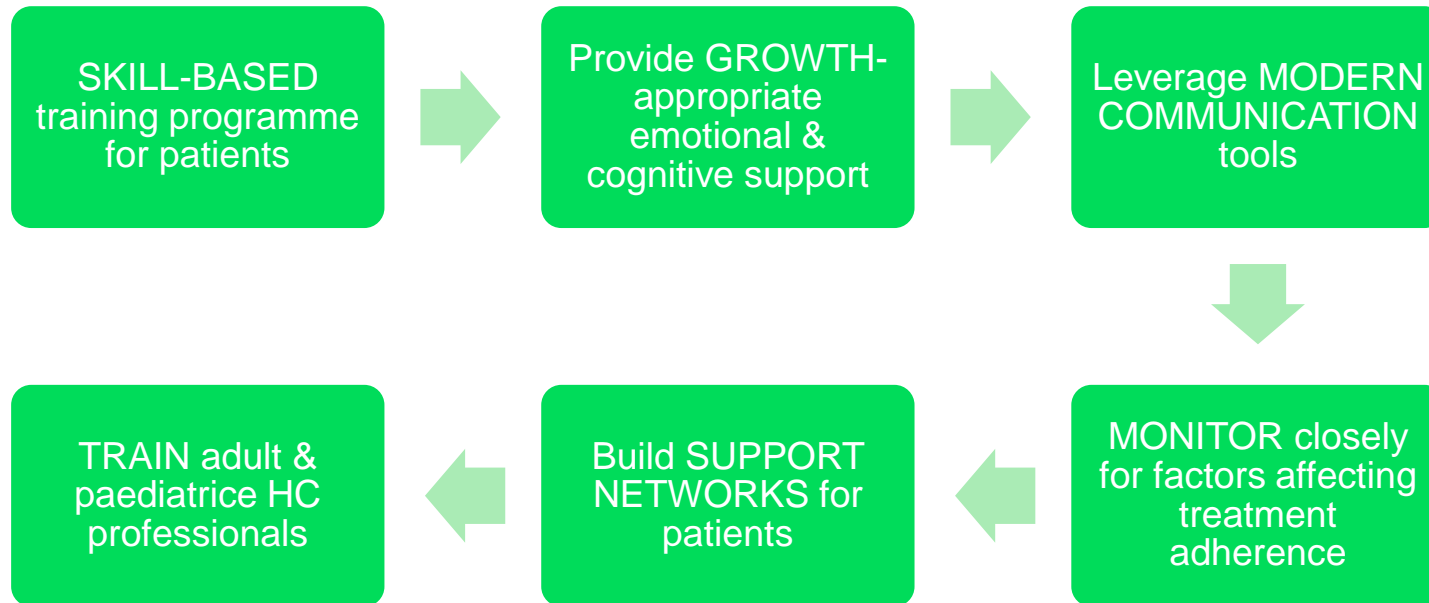
Non-medical challenges

- Developmental differences
- Transition to adulthood
- Multiple transitions
- Non-adherence risk factors
- Outdated communication methods



Recognising Life Stage Impact

Recommendations



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Key Challenges 4/4

Managing Disease Characteristics

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Managing Disease Characteristics

Key Challenges



Diseases behavioural and frequency differences in adolescents vs adults



Patients reaching adult life after several treatments → limited options



The risk of differences in treatment guidelines in paediatric & adult healthcare



Physicians not exposed to these “new” diseases



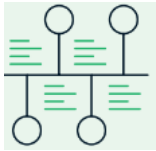
Sudden changes in treatment by adult healthcare professionals



Difficult to evaluate an optimal transition timing (i.e. patient experiencing a flare)

Managing Disease Characteristics

Recommendations



ORCHESTRATE transition timing

- Ideal scenario is to achieve remission before the transition



Treatment REGIMEN COLLABORATION

- aim for treatment regimen consensus among paediatric and adult healthcare professionals (approach differences thoughtfully)



Ongoing HEALTHCARE PROFESSIONAL TRAINING

- create continuous education & training initiatives to keep healthcare professionals adapt in managing evolving diseases and patients

Spotlight on Intestinal Failure

Case study: transitioning paediatric patients with Intestinal failure to adult care

Meet Maria, a 17 years old who has been living with intestinal failure since childhood, a condition stemming from extensive gut surgery during her formative years.

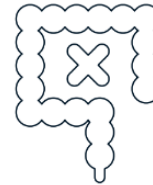


Name Maria Rodriguez

Date of Birth 2 October, 2007

Diagnosis Intestinal failure

Maria faces a unique set of challenges as she prepares to transition from paediatric to adult care. Unlike adult-onset intestinal failure, which often arises from acute events like trauma or disease, Maria's condition is rooted in congenital issues and prolonged reliance on parenteral nutrition. This reliance presents impending hurdles as she navigates the complexities of transitioning to adult care, balancing her medical needs with her educational and personal growth.



For Maria's transition to be successful, several key components are essential:

A specialised multidisciplinary team comprising both paediatric and adult specialists, including gastroenterologists, dietitians, nurses, radiologists, surgeons, stomal therapists and pharmacists.

Comprehensive familiarisation of all multidisciplinary team members with Maria's unique medical history and needs.

Education for all multidisciplinary team members on the nuanced differences between adolescent and adult care for intestinal failure.

Careful planning and seamless coordination among the multidisciplinary team, Maria and her parents, ensuring a smooth transition.

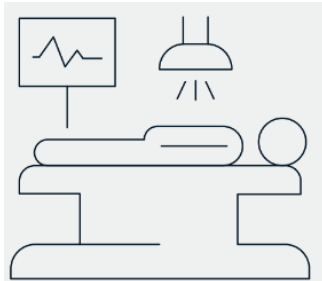
Provision of ongoing support and education for Maria, empowering her to navigate the complexities of her condition as she steps into adulthood.

By implementing these strategies and fostering a supportive environment, Maria can confidently transition to adult care, equipped with the resources and knowledge necessary to thrive despite the challenges posed by her condition.

Spotlight on Surgical Interventions

Patient groups benefiting from transitioning from paediatric to adult surgical care:

- those who have undergone surgery in a paediatric unit and need long-term follow up;
- those receiving ongoing paediatric medical treatment necessitating surgical intervention;
- those newly diagnosed requiring surgery at an age when transition is indicated.



Key components of an effective surgical transition clinic include:

Appointing a dedicated Transitional Care Coordinator to oversee the transition process, coordinate appointments and provide ongoing support.

Involving a multidisciplinary team of surgeons, nurses and other healthcare professionals to support transitioning patients.

Detailed communication between paediatric and adult surgeons regarding past procedures, family dynamics and the psychological needs of patients.

Consideration of joint operations between paediatric and adult surgeons in cases where patients are not yet ready for full transition.

Assignment of a named adult surgeon to patients requiring surgical intervention during transition. This surgeon is involved in the patient's care preoperatively, perioperatively and postoperatively as part of the multidisciplinary team.

Implementing processes for ongoing evaluation and quality improvement to monitor the effectiveness of treatment.

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**Opinion editorial on
Hospital Healthcare Europe:**

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prioritising-transitional-care-in-digestive-health-a-ueg-
roadmap/](https://hospitalhealthcare.com/clinical/gastroenterology/prioritising-transitional-care-in-digestive-health-a-ueg-roadmap/)



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