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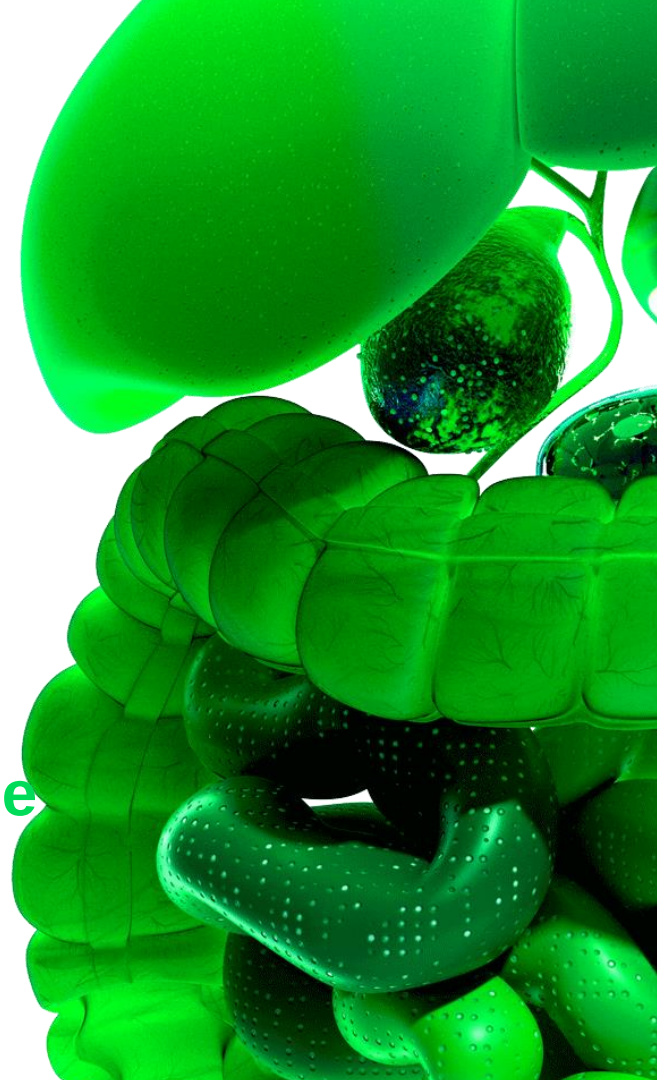
Enhancing Transitional Care in Digestive Health

Addressing Challenges and Implementing Strategies across Europe



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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.

Dr. Patrizia Burra (UEG Public Affairs Group Chair): **Enhancing Transitional Care in Digestive Health. Addressing Challenges and Implementing Strategies Across Europe** (p. 25). UEG 2024 ueg.eu/publications#public-affairs

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Enhancing Transitional Care in Digestive Health

Introduction

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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 chronical 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.

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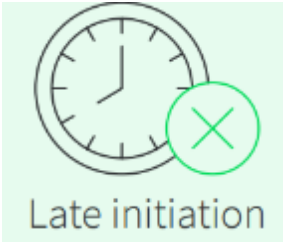
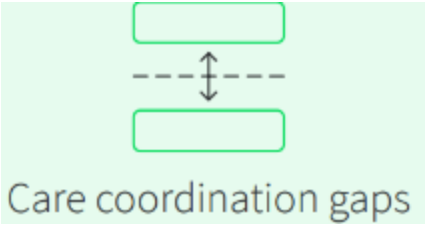
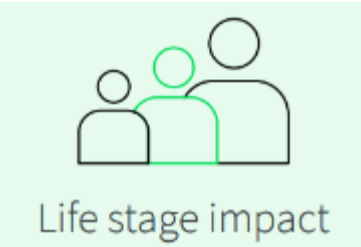
Introduction:

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







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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




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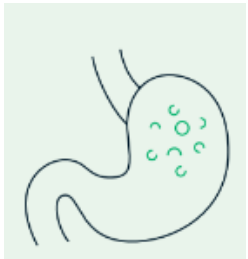
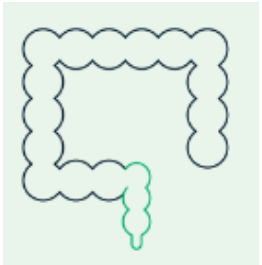
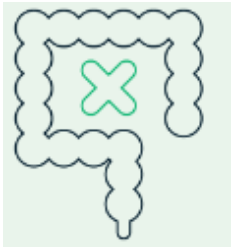
Other digestive diseases facing additional obstacles

- 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

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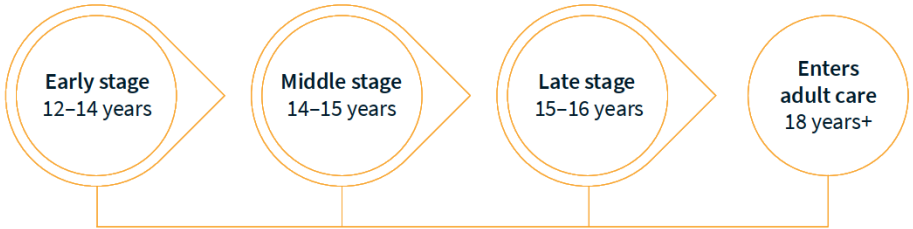
Spotlight on the best practice in Liver Disease



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

- Self-advocacy
- Independent healthcare behaviour
- Sexual health
- Psychological support
- Educational and vocational planning
- Health and lifestyle

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

Early

Educate patients on describing their health condition and asking questions during healthcare visits

Middle

Focus on ensuring patients can access information about their condition through support groups, the internet or specific organistions

Late

Explain available adult care options, differences between paediatric and adult care, and assist patients in choosing an adult provider

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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

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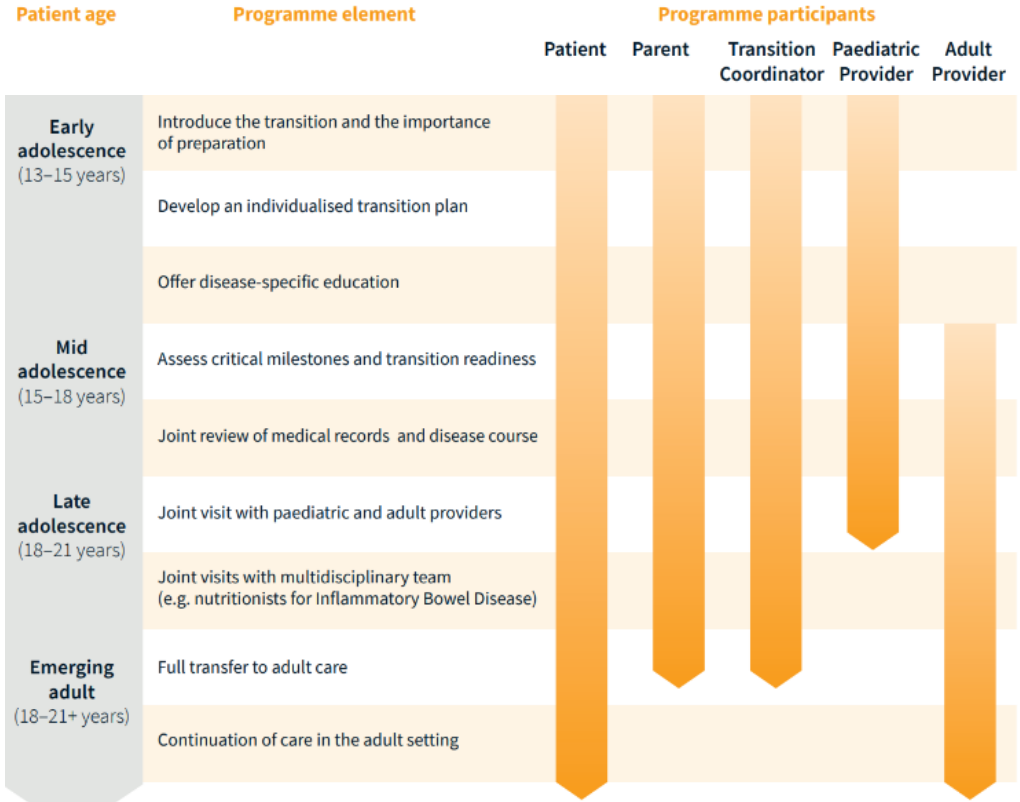
Spotlight on the best practice in Inflammatory Bowel Disease



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Key Challenges 3/4

Recognising Life Stage Impact

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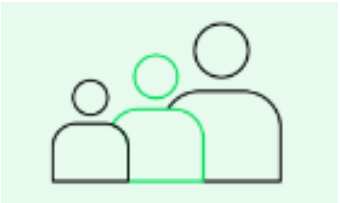
Recognising Life Stage Impact

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



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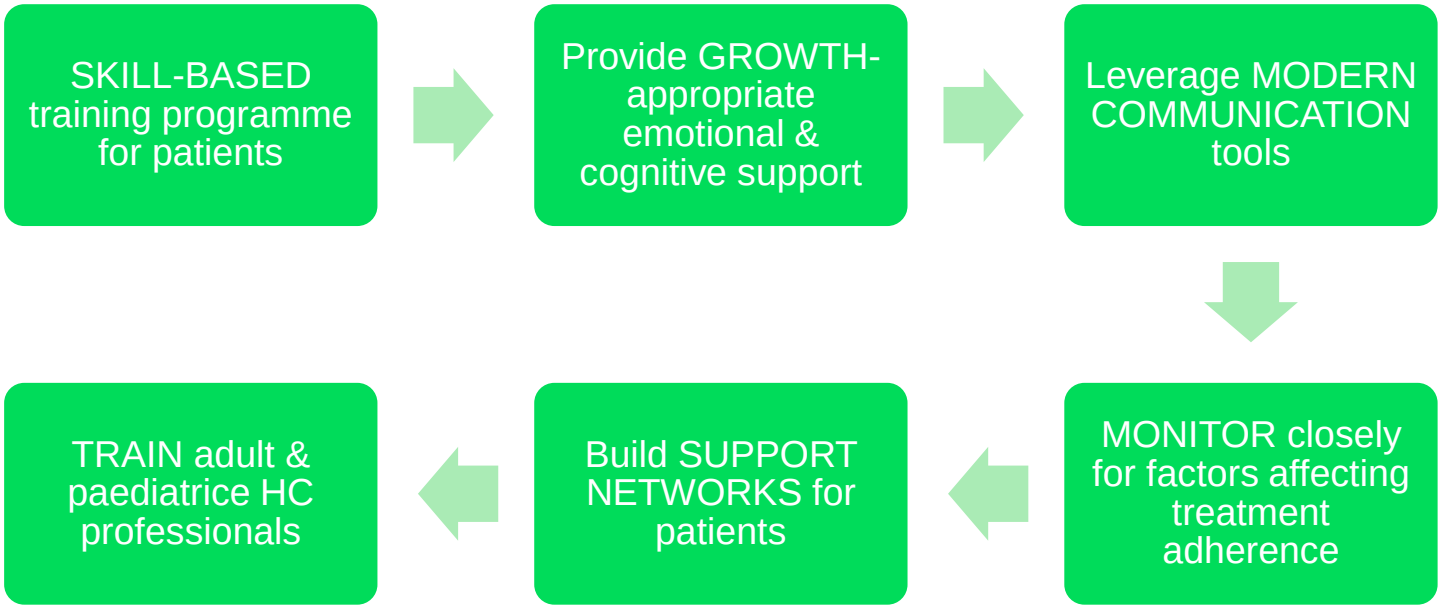
Recognising Life Stage Impact

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
- The risk of differences in treatment guidelines in paediatric & adult healthcare
- Sudden changes in treatment by adult healthcare professionals
- Patients reaching adult life after several treatments ⇒ limited options
- Physicians not exposed to these “new” diseases
- Difficult to evaluate an optimal transition timing (i.e. patient experiencing a flare)

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Managing Disease Characteristics

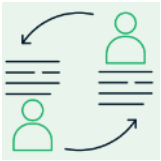
Recommendations

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)



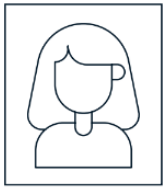
Ongoing HEALTHCARE PROFESSIONAL TRAINING

- 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.

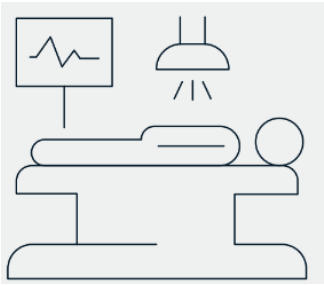
Provision of ongoing support and education for Maria, empowering her to navigate the complexities of her condition as she steps into adulthood.

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

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Thank you for your collaboration!