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# La Transizione nelle malattie polmonari complesse

Dott.ssa Annalisa Allegorico

# Transitional care

Il passaggio dall'adolescenza all'età adulta è un momento impegnativo di cambiamento fisico, psicologico e sociale. Giovani con qualsiasi forma di disabilità, malattia cronica o problemi significativi di salute mentale, si trovano ad affrontare sfide ancora più grandi tra cui importanti cambiamenti nell'assistenza di cui hanno bisogno e nel modo in cui viene fornita.

I servizi sanitari che non riescono a soddisfare adeguatamente i bisogni dei giovani e delle loro famiglie possono comportare un deterioramento dello stato di salute con conseguenze negative a lungo termine. Pertanto, il trasferimento degli adolescenti dai servizi pediatrici a quelli per adulti è un momento cruciale per la salute dei giovani, che potrebbe potenzialmente cadere in un "divario assistenziale" mal gestito.

Molte surveys hanno sottolineato la necessità di interventi per ridurre al minimo i rischi di deterioramento dello stato di salute quando i bambini passano ai servizi per adulti.



Fino a poco tempo fa, la letteratura sulla transizione si concentrava in modo piuttosto limitato su condizioni come il diabete e l'artrite, ma ora sta emergendo come una priorità per tutte le condizioni a lungo termine. Ciò è in parte dovuto ai progressi nell'assistenza sanitaria, con un numero sempre crescente di giovani affetti da patologie croniche, ma anche alla maggiore consapevolezza che i servizi non riescono a soddisfare le esigenze dei giovani.

# Dalla Letteratura....

Il numero di giovani con patologie croniche e disabilità che entrano nell'età adulta è in continuo aumento, pertanto si crea la necessità di formare una rete assistenziale che possa supportare tali pazienti.

Dal 1982 al 2007, la percentuale di individui affetti da fibrosi cistica che hanno raggiunto l'età adulta (oltre i 18 anni) è aumentata dal 27% al 56%. Quasi il 90% dei bambini affetti da cardiopatie congenite sopravvive fino all'età adulta. Inoltre, è aumentata la prevalenza di malattie croniche come l'asma, il diabete (tipo 1 e 2) e l'obesità. Nel Regno Unito, un giovane su sette (15%) di età compresa tra 11 e 15 anni riferisce di aver ricevuto una diagnosi di malattia o disabilità medica a lungo termine, come asma, diabete, epilessia, cancro o disabilità fisica o mentale.



Sempre più bambini diventeranno gli adulti che necessitano di transitare dall'assistenza pediatrica a quella per adulti. La consapevolezza della propria patologia cronica associata ad adeguate strutture sanitarie con formazione professionale del personale, sono considerati imperativi per una efficace «transizione».



# L'adolescenza ...

Si riferisce al periodo di transizione dello sviluppo tra l'infanzia e l'età adulta, in genere comprende l'età tra 10 e 19 anni, secondo l'Organizzazione Mondiale della Sanità (OMS).

Molti servizi sanitari spesso hanno soglie che non si allineano esattamente con la definizione stabilita dall'OMS, con limiti di età massimi spesso fissati a 16 o 18 anni. Inoltre, per politiche interne alcuni servizi sanitari come quello inglese (NHS), continuano a sostenere servizi ininterrotti rivolti a persone fino all'età di 25 anni, riconoscendo il bisogno di un sostegno continuo durante questo periodo cruciale di sviluppo.

Gli adolescenti con malattie croniche affrontano una miriade di sfide che incidono sulla loro salute, sul loro benessere e sulla qualità della vita in generale. Una sfida significativa è l'allineamento dei comportamenti a rischio con i loro coetanei sani.





ERS | *monograph*

## The Transition of Respiratory Care: from Child to Adult

Edited by Alexandra M. Nanzer,  
Peter J. Barry and Brian D. Kent

- Circa 1 adolescente su 5 ha esigenze sanitarie speciali, mentre 1 su 10 affronta limitazioni nelle attività quotidiane a causa di malattie croniche o disabilità.
- Gli sforzi collaborativi tra servizi pediatrici, adolescenziali e per adulti sono fondamentali per far fronte alle sfide sanitarie uniche che devono affrontare gli adolescenti con malattie croniche.
- Comprendere l'impatto delle malattie croniche sul benessere psicosociale degli adolescenti è imperativo per fornire un'assistenza sanitaria completa ed efficace.

La consapevolezza che gli adolescenti, anche con malattie croniche, adottano comportamenti ad alto rischio ha rimodellato gli approcci sanitari, evidenziando la necessità di un'assistenza completa che affronti sia le condizioni croniche sia le esigenze specifiche di questa fascia d'età.

# Transition from children's to adults' services for young people using health or social care services

NICE guideline

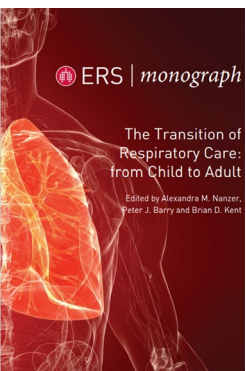
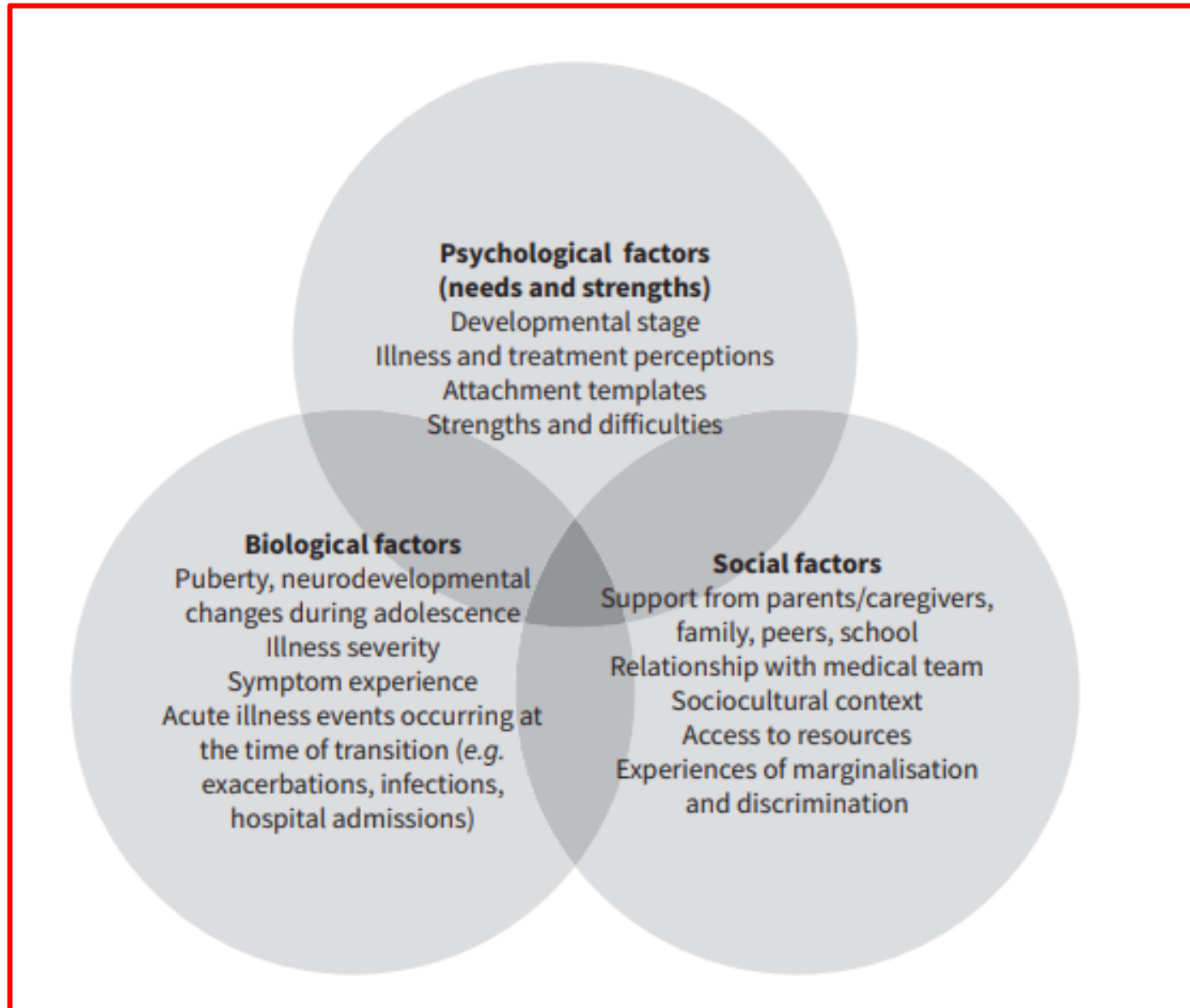
Published: 24 February 2016

[www.nice.org.uk/guidance/ng43](http://www.nice.org.uk/guidance/ng43)

Le linee guida sottolineano che la transizione dovrebbe essere "appropriata allo sviluppo" e promuovere l'indipendenza.

La transizione non dovrebbe essere un evento una tantum, ma piuttosto dovrebbe aiutare a modellare il modo in cui un bambino, un adolescente e poi un adulto si relazionano al proprio corpo e alla propria salute. Nello scenario migliore, gli operatori sanitari lavorano con i bambini per aiutarli gradualmente ad assumersi una maggiore responsabilità nel comprendere e soddisfare le proprie esigenze di salute.

## Fattori che influenzano il percorso di transizione





**Obiettivi:**

1. esplorare il profilo politico internazionale della transizione dall'assistenza pediatrica a quella per adulti
2. documentare obiettivi politici, iniziative e risultati per le giurisdizioni pubblicamente impegnate ad affrontare le questioni relative alla transizione.

**Metodi:** revisione politica internazionale di tutti i documenti governativi pubblicamente disponibili che descrivono dettagliatamente le strategie legate alla transizione utilizzando una ricerca basata sul web. L'analisi internazionale ha incluso nove ricche giurisdizioni con sistemi sanitari comparabili: Australia, Canada, Danimarca, Finlandia, Irlanda, Nuova Zelanda, Norvegia, Svezia e Regno Unito.

**Risultati:** solamente due dei nove Paesi (Regno Unito e Australia) avevano una strategia operativa per quanto riguarda la transizione.

**Conclusioni:** nonostante i rischi e i costi ben documentati associati alla scarsa transizione dalle cure pediatriche a quelle per adulti, è stata prestata poca attenzione politica a questo problema.



OPEN ACCESS

## Health system strategies supporting transition to adult care

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**ABSTRACT**

**Background** The transition from paediatric to adult care is associated with poor clinical outcomes, increased costs and low patient and family satisfaction. However, little is known about health system strategies to streamline and safeguard care for youth transitioning to adult services. Moreover, the needs of children and youth are often excluded from broader health system reform discussions, leaving this population especially vulnerable to system 'disintegration'.

**Objectives** (1) To explore the international policy profile of paediatric-to-adult care transitions, and (2) to document policy objectives, initiatives and outcomes for jurisdictions publicly committed to addressing transition issues.

**Methods** An international policy scoping review of all publicly available government documents detailing transition-related strategies was completed using a web-based search. Our analysis included a comparable cohort of nine wealthy Organisation for Economic Co-operation and Development (OECD) jurisdictions with Beveridge-style healthcare systems (deemed those most likely to benefit from system-level transition strategies).

**Results** Few jurisdictions address transition of care issues in either health or broader social policy documents. While many jurisdictions refer to standardised practice guidelines, a few report the intention to use powerful policy levers (including physician remuneration and non-physician investments) to facilitate the uptake of best practice. Most jurisdictions do not address the policy infrastructure required to support successful transitions, and rigorous evaluations of transition strategies are rare.

**Conclusions** Despite the well-documented risks and costs associated with a poor transition from paediatric to adult care, little policy attention has been paid to this issue. We recommend that healthcare providers engage health system planners in the design and evaluation of system-level, policy-sensitive transition strategies.

**INTRODUCTION**

In recent years, the number of youth with chronic medical conditions surviving into adulthood has increased.<sup>1-4</sup> The transition from paediatric to adult care is known to be a period of risk for poor clinical outcomes, as well as increased healthcare

**What is already known about the topic?**

- ▶ In recent years, there has been a dramatic growth in the number of youth with chronic medical conditions surviving into adulthood.
- ▶ Transition from paediatric to adult care is a risk period for poor clinical outcomes, increased healthcare costs and low patient and family satisfaction.
- ▶ Successful transition outcomes require coordination across multiple care providers, which necessitates well-articulated health system strategies.

**What this study adds?**

- ▶ The findings point to the need for evaluating system-level transition strategies and increasing the policy profile.
- ▶ This study also serves as a reference point for countries with similar health care systems to design efficient transition-related policies and address policy implementation barriers.

chronic medical conditions are provided seamless transition care.<sup>5</sup>

According to Blum *et al*,<sup>9</sup> transition is the "purposeful, planned movement of adolescents and young adults with chronic medical conditions from child-centered to adult-oriented health care systems." A successful transition plan recognises transition as a multifaceted process that engages multiple care providers and accommodates a patient's condition, chronological age and developmental stage.<sup>2,4,10,11</sup>

Many healthcare organisations, including hospitals, have developed transition programmes to help youth exit the paediatric system. However, these programmes are often disease and institution specific, not scalable or universally accessible and remain burdened with capacity and funding barriers.<sup>1-4</sup> The complexity of paediatric-to-adult transitions demands system-level solutions that address the alignment of providers in multiple settings, collaboration across various sectors, facilitated com-



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# Nonostante tale strategia . . .

## Care Quality Commission recommendations for transition services in England

- A key accountable individual responsible for supporting the move to adult health services
- A documented transition plan that takes good account of individual health needs
- A communication or “health passport” to ensure all relevant professionals have access to essential information about the young person
- Health services provided in an appropriate environment that take account of young people’s needs without gaps in provision between children’s and adult services
- Training and advice to prepare young people and their parents for the transition to adult care, including consent and advocacy
- Respite and short break facilities available to meet the young person’s needs and those of their families

Quando la Care Quality Commission (CQC) nel Regno Unito ha pubblicato il suo rapporto sulla transizione dei bambini ai servizi sanitari per adulti, ha descritto un sistema sanitario e di assistenza sociale che stava: "deludendo molti giovani gravemente malati in un momento critico della loro vita".

# Clinical Report—Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home

## abstract

Optimal health care is achieved when each person, at every age, receives medically and developmentally appropriate care. The goal of a planned health care transition is to maximize lifelong functioning and well-being for all youth, including those who have special health care needs and those who do not. This process includes ensuring that high-quality, developmentally appropriate health care services are available in an uninterrupted manner as the person moves from adolescence to adulthood. A well-timed transition from child- to adult-oriented health care is specific to each person and ideally occurs between the ages of 18 and 21 years. Coordination of patient, family, and provider responsibilities enables youth to optimize their ability to assume adult roles and activities. This clinical report represents expert opinion and consensus on the practice-based implementation of transition for all youth beginning in early adolescence. It provides a structure for training and continuing education to further understanding of the nature of adolescent transition and how best to support it. Primary care physicians, nurse practitioners, and physician assistants, as well as medical subspecialists, are encouraged to adopt these materials and make this process specific to their settings and populations. *Pediatrics* 2011;128:182–200

### 1. INTRODUCTION AND METHODOLOGY

With reasonable biological certainty, most adolescents transition to adulthood. There is much less certainty about the manner in which health care professionals support this transition. Transition planning, when present at all, can be implicit, incomplete, or late, and when necessary, the transfer of care to an adult medical home and to adult medical subspecialists involves more of a drift away from pediatric care rather than a clearly planned and executed handoff. In 2002, a consensus statement coauthored by the American Academy of Pediatrics (AAP), the American Academy of Family Physicians (AAFP), and the American College of Physicians (ACP)-American Society of Internal Medicine was published, stating the importance of supporting and facilitating the transition of adolescents with special health care needs\* into adulthood.<sup>1</sup> This statement represented the shared perspectives of health care professionals, families, youth, researchers,

AMERICAN ACADEMY OF PEDIATRICS, AMERICAN ACADEMY OF FAMILY PHYSICIANS, AND AMERICAN COLLEGE OF PHYSICIANS, TRANSITIONS CLINICAL REPORT AUTHORIZING GROUP

#### KEY WORDS

health care transition, youth transition, medical home, children with special health care needs, primary care, adolescent health, quality improvement

#### ABBREVIATIONS

AAP—American Academy of Pediatrics  
MCHB—Maternal and Child Health Bureau  
CCM—chronic condition management  
EHR—electronic health record

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The guidance in this report does not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

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Nel 2011, l'American Academy of Pediatrics (AAP) ha pubblicato un rapporto clinico sul supporto alla transizione sanitaria dall'adolescenza all'età adulta. Il rapporto ha evidenziato sei elementi fondamentali della transizione sanitaria:

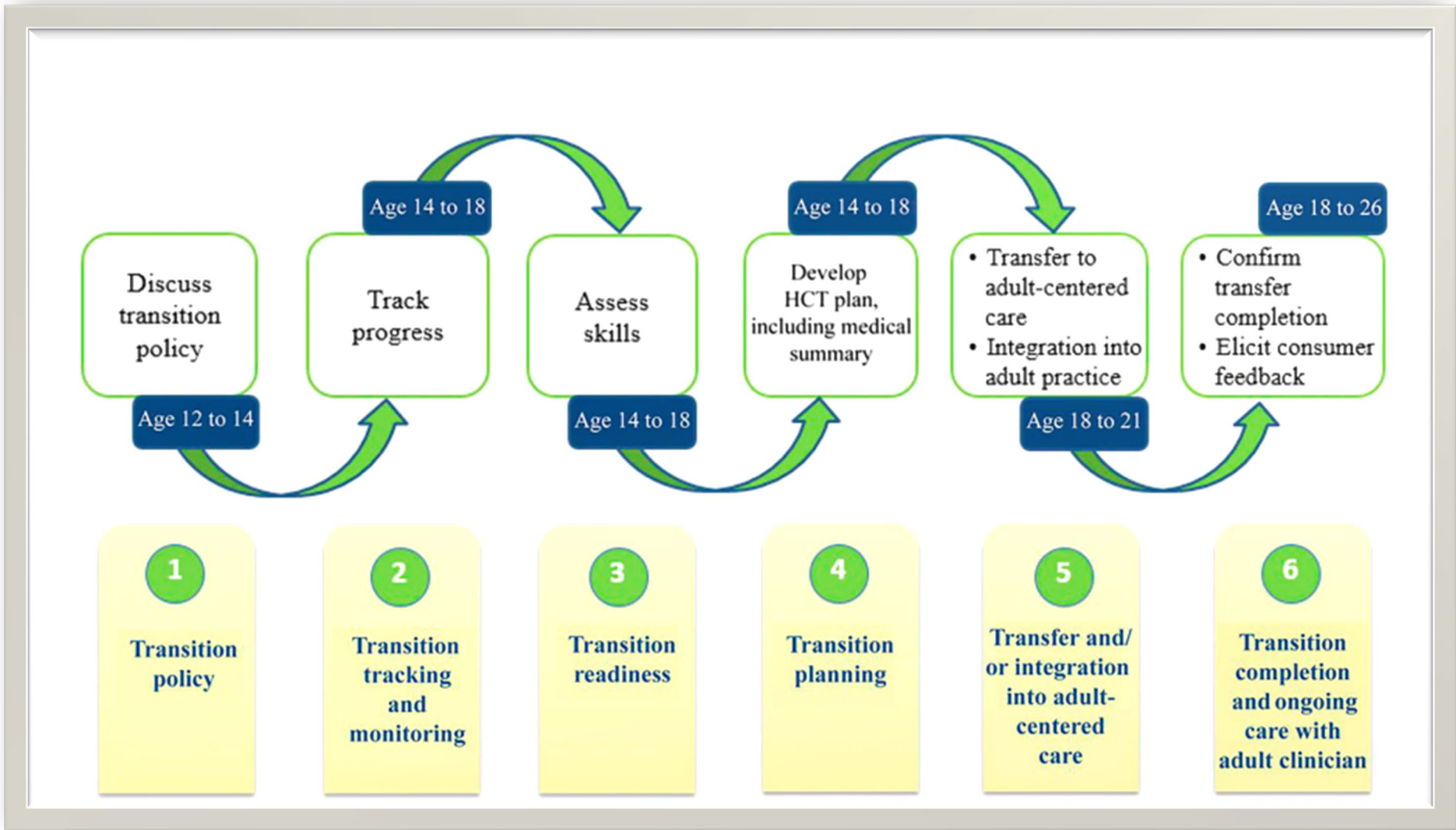
- 1) discussione della politica di transizione
- 2) monitoraggio della transizione
- 3) prontezza alla transizione e/o orientamento all'assistenza per adulti
- 4) pianificazione della transizione
- 5) trasferimento delle cure
- 6) completamento della transizione e assistenza continua con il team sanitario per adulti.

\*Maternal and Child Health Bureau (MCHB) defines children and youth with special health care needs as "[t]hose who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type and/or intensity that is beyond that required by children generally."<sup>1</sup>

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## Effectiveness of transitional care interventions in patients with serious illness and their caregivers: a systematic review protocol

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### ABSTRACT

**Objective:** The objective of this review is to evaluate the effectiveness of transitional care interventions for seriously ill patients and their caregivers.

**Introduction:** Seriously ill patients and their caregivers may have complex health and social care needs that require services from numerous providers across multiple sectors. Transitional care interventions have been designed to enhance a collaborative approach among providers to facilitate the care transition process. However, the effectiveness of transitional care interventions for seriously ill patients and their caregivers, and the effects of such interventions on their outcomes, remain unclear.

**Inclusion criteria:** Randomized controlled trials with adult patients ( $\geq 18$  years old) with serious illness and their caregivers involved in transitional care programs will be considered for inclusion. The patients' outcomes will include mortality and/or survival, symptoms (eg, pain, nausea), and health-related quality of life. The caregivers' outcomes will include caregiver burden, preparedness, and well-being.

**Methods:** The JBI methodology for systematic reviews of effectiveness will be followed. The search strategy will aim to locate published and unpublished studies. Electronic databases, including PubMed, Embase, CINAHL, and the Cochrane Central Register of Controlled Trials, will be systematically searched from 2003 to the present. Studies in English, Italian, Spanish, French, and German will be included. Critical appraisal and data extraction will be conducted using standardized tools. Quantitative data will be pooled in statistical meta-analysis or, if statistical pooling is not possible, the findings will be reported narratively. Certainty of the evidence will be assessed using the Grading of Recommendations Assessment, Development and Evaluation (GRADE) approach.

**Systematic review registration number:** PROSPERO CRD42022319848

**Keywords:** palliative care; quality of life; serious illness; transitional care

*JBI Evid Synth* 2023; 21(4):762–768.

**Obiettivo:** valutare l'efficacia degli interventi messi in atto durante la transizione nei pazienti gravemente malati ed i loro caregivers.

**Criteri di inclusione:** sono stati presi in considerazione studi randomizzati e controllati dal 2003 su pazienti adulti ( $\geq 18$  anni) con malattie gravi e i loro caregivers coinvolti in programmi di assistenza riabilitativa. Gli outcomes considerati per i pazienti sono: mortalità e/o sopravvivenza, sintomi (ad es. dolore, nausea) e qualità della vita correlata alla salute. Gli outcomes considerati per i caregivers: il carico di lavoro, la preparazione e il benessere.

## Effectiveness of transitional care interventions in patients with serious illness and their caregivers: a systematic review protocol

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Sono stati classificati gli interventi di transizione assistenziale in 6 categorie principali basate sui criteri dell'Organizzazione Mondiale della Sanità:

- 1) gestione dei farmaci (l'uso sicuro dei farmaci)
- 2) pianificazione della transizione
- 3) educazione del paziente e della famiglia (formazione/supporto/consulenza)
- 4) trasferimento di informazioni (documentazione standardizzata, condivisione di informazioni)
- 5) follow-up tempestivo e appropriato (attività assistenziali di follow-up efficaci)
- 6) coinvolgimento del paziente e della famiglia (partecipazione attiva del paziente/della famiglia alle proprie cure).

# In conclusione...

## Effectiveness of transitional care interventions in patients with serious illness and their caregivers: a systematic review protocol

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È stato stimato che circa 12 milioni di adulti convivono con una malattia grave.

Le malattie gravi richiedono spesso il coinvolgimento di diversi operatori sanitari per fornire l'adeguata assistenza al paziente, nonché decisioni congiunte.

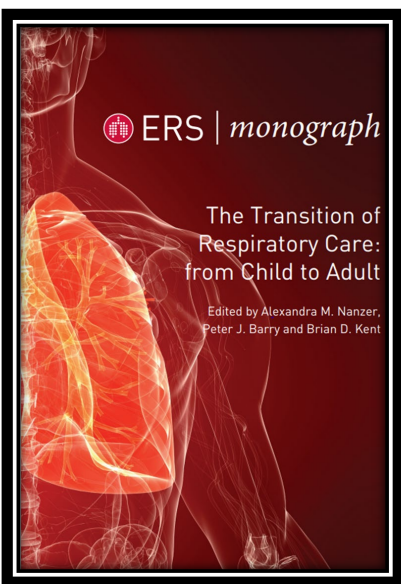
Esiste un ampio consenso sul fatto che i programmi di assistenza durante la transizione dovrebbero includere interventi orientati alla formazione dei professionisti, interventi organizzativi ed interventi orientati al paziente e alla famiglia.

Le prove attuali sulle transizioni dei pazienti medicalmente complessi sono ancora scarse ed inconcludenti. Inoltre, esistono standard di cura limitati per guidare i pazienti affetti da patologie gravi e i loro caregivers durante la transizione, e i risultati sanitari rimangono poco chiari.



Cosa sappiamo sul percorso di transizione nei pazienti affetti da patologie neuromuscolari o in ventilazione a lungo termine?





Nei pazienti con patologie neuromuscolari c'è la necessità di un'osservazione e di una valutazione clinica completa e continua durante gli anni dell'adolescenza.

### Medical problems that can arise or progress at the time of transition

**Bowel problems:** severe constipation, intermittent pseudo-obstruction, volvulus

**Urinary difficulties:** urinary retention, renal/bladder calculi

**Nutritional/swallowing:** requiring supplemental feeding PEG/RIG

**New orthopaedic issues:** hip and hand contractures, osteoporosis, fractures, joint and back pain

**Cardiac complications:** cardiomyopathy, arrhythmia

**Autonomic dysfunction:** prolonged gut transit time, dysrhythmia, postural hypotension, aberrant temperature control

**Psychological problems:** anxiety, depression

**PEG:** percutaneous endoscopic gastrostomy; **RIG:** radiologically inserted gastrostomy.



## A transition program to adult health services for teenagers receiving long-term home mechanical ventilation: A longitudinal qualitative study

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Uno studio qualitativo longitudinale pubblicato nel 2020 ha esaminato il percorso di transizione nei pazienti in LTV domiciliare da un ospedale pediatrico terziario ad un ospedale per adulti. Lo studio ha identificato i seguenti **fattori che favoriscono** un buona transizione:

- discussione precoce sul tema transizione
- visite cliniche congiunte pediatra-medico dell'adulto
- informazioni scritte sui servizi per adulti
- formazione alla comunicazione per gli adolescenti, con l'obiettivo di migliorare la loro capacità di fornire anamnesi mediche accurate e discutere delle proprie esigenze con il team clinico.

Le **barriere** identificate includevano:

- mancanza di indirizzamento ad altri specialisti medici
- difficoltà nel coordinare gli appuntamenti tra più specialisti per adulti e diversi contesti sanitari
- informazioni inadeguate sulle strutture dedicate all'assistenza degli adulti
- coinvolgimento limitato dei medici di medicina generale.

## Innovative care model for patients with complex muscle diseases

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Affiliations + expand

PMID: 25188015 DOI: [10.1097/WCO.000000000000132](#)

Una barriera significativa è la mancanza di team sanitari per adulti a cui i pazienti NMD/LTV possano passare. I pazienti spesso richiedono una assistenza multidisciplinare. Un numero crescente di centri per adulti sta sviluppando modelli di assistenza specializzati "**one-stop shop**", prendendo come esempio il Neuromuscular Complex Care Centre nel Regno Unito, dove i pazienti hanno accesso a tutti gli specialisti medici e ai terapisti che probabilmente saranno coinvolti nella loro assistenza in un ambiente appositamente costruito. Il centro fornirà il primo punto di contatto con accesso telefonico 24 ore su 24, 7 giorni su 7 e consiglierà e supporterà gli ospedali locali nella gestione dei pazienti. Regolari riunioni multidisciplinari di consulenti e terapisti specializzati miglioreranno la comunicazione e massimizzeranno i risultati.

## Recommendations for transition of neuromuscular disease and long-term ventilation patients

### **Transition should be a gradual process, with planning starting early, rather than being left to the last minute**

Education should be provided such that the adolescent and their carers have a good understanding of the medical condition and what is required for transition into the adult healthcare system

The adolescent should be involved in planning discussions and assume the management of their condition to the extent that they are developmentally able and to a degree that is meaningful to them, prior to transfer of care

HCPs should facilitate and encourage the development of self-esteem and self-confidence, to allow successful transition and the assumption of as much independence as their condition allows

### **A formalised approach to transition is recommended**

A formal transition plan should be developed in collaboration with the adolescent and their carers

A comprehensive formalised transfer report including input from every member of the multidisciplinary team should be provided

Joint transition clinics with the paediatric and adult healthcare teams are recommended

It is helpful to have a keyworker identified as being responsible for supporting the young person through the transition process

Any differences in care (such as organisation, monitoring and management of their medical condition) in the adult setting from their usual paediatric care, need to be explained to the adolescent and their carers; this includes changes to homecare support

Should the adolescent be unable to provide informed consent, clarification must be provided regarding who has this responsibility; conversations should take place regarding goals and ceilings of care, and decisions should be clearly communicated to the adult team

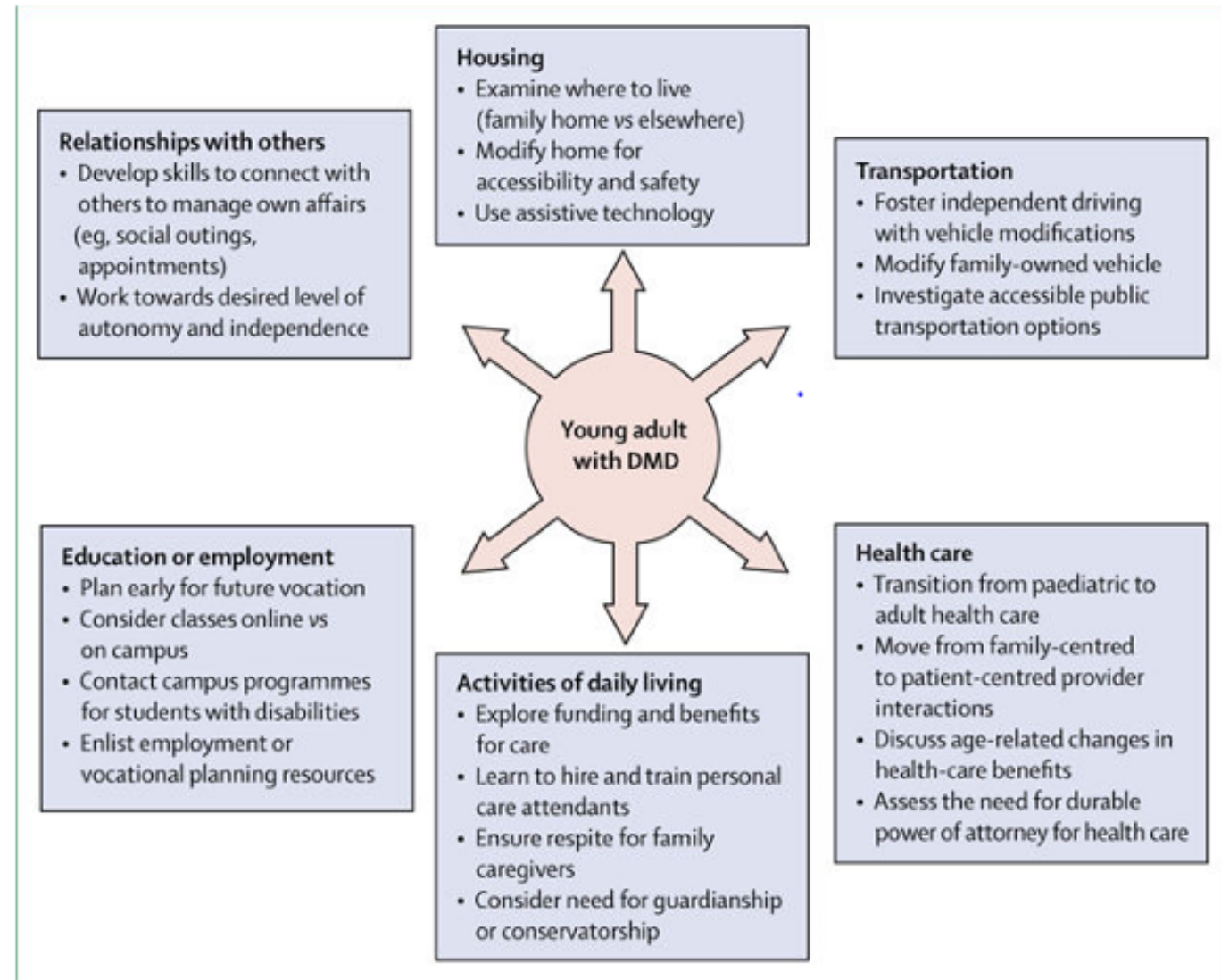
Reproduced and modified from [61] with permission.

La Canadian Thoracic Society (CTS) ha pubblicato le linee guida per la pratica clinica sulla ventilazione meccanica domiciliare pediatrica, fornendo le raccomandazioni in merito alla transizione.



**Diagnosis and management of Duchenne muscular dystrophy, part 3: primary care, emergency management, psychosocial care, and transitions of care across the lifespan**

Durante l'adolescenza i pazienti affetti da DMD hanno spesso crescenti esigenze di assistenza sanitaria e dipendenza fisica dagli altri per le attività della vita quotidiana, il che può creare difficoltà nel realizzare una transizione di successo. I pazienti e le loro famiglie dovrebbero essere informati dei piani per la transizione sanitaria entro i 12 anni di età del paziente, con l'avvio di discussioni e pianificazione della transizione entro i 13-14 anni.



**Components of young adulthood to be addressed during transition planning for individuals with Duchenne muscular dystrophy**  
DMD=Duchenne muscular dystrophy.

# Take Home Message



Gli adolescenti con malattie croniche dovrebbero essere informati sulla loro condizione ed essere coinvolti nelle decisioni che incidono sulla loro cura.

La pianificazione della transizione dovrebbe essere una responsabilità condivisa del team di assistenza, del paziente e dei genitori.

E' necessario un team dedicato assegnato per assistere il processo di transizione e ridurre al minimo le lacune nel servizio.

Introdurre l'idea di transizione il più presto possibile consente di avere tempo per l'accettazione e la preparazione.

In conclusione, la transizione è un processo, non un singolo evento di trasferimento delle cure e di trasmissione di consegne tra equipe pediatrica ed equipe della medicina degli adulti.



grazie