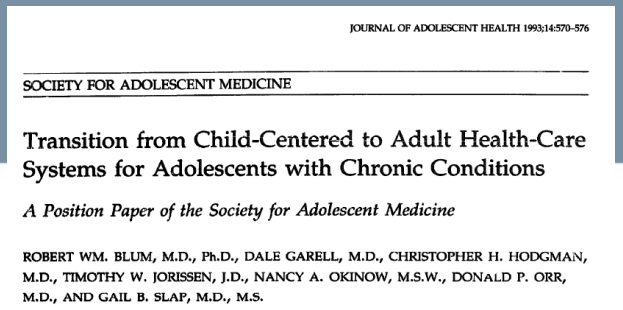
Transition in CEMA Antwerp

Introduction

Kennis / Ervaring / Zorg



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SOCIETY FOR ADOLESCENT MEDICINE

Transition from Child-Centered to Adult Health-Care Systems for Adolescents with Chronic Conditions

A Position Paper of the Society for Adolescent Medicine

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Transition- definition

Purposeful and planned movement of adolescents and young adults with chronic physical and medical conditions from child- centred to adult-oriented health care systems (Society of Adolescent Medicine)

Goal: effective communication to independent self-care and informed decision making, optimizing quality of life and future potential of young adults with chronic diseases

Ideally healthcare during transition is uninterrupted, comprehensive, accessible and individualized

Became important since the 1980's

- 1989: first congress on Growing Up and Getting Medical Care: Youth with Special Health Care Needs.

improved therapeutic possibilities, many grow up into adulthood

- > 90 % of children with a chronic disease have a life expectancy > 20 y

Transition from pediatric to adult care in patients with inherited metabolic diseases
general remarks

Inherited metabolic diseases are rare but there are plenty of patients

Large heterogeneous spectrum of diseases

- Life threatening in early childhood to mostly stable disease in adults

Vs Progressively physical or mental debilitating conditions

- “Simple” conditions with a small team of caregivers to diseases requiring a large multidisciplinary care

Transition has been studied in many chronic diseases but due to their rare nature, studies in adolescents and young adults with IMD are scarce

Transition in metabolic care
CEMA Antwerp protocol

Elien Raets

Kennis / Ervaring / Zorg

What is transition?

Transitioning from child to adult

Transitions occur throughout life and are faced by all young people as they progress, from childhood through puberty and adolescence to adulthood; from immaturity to maturity and from dependence to independence. In addition, some young people experience extra transitions as a result of other life events for example, disability, bereavement, separation from parents and being placed in care' (Department of health / child health and maternity services branch 2006)

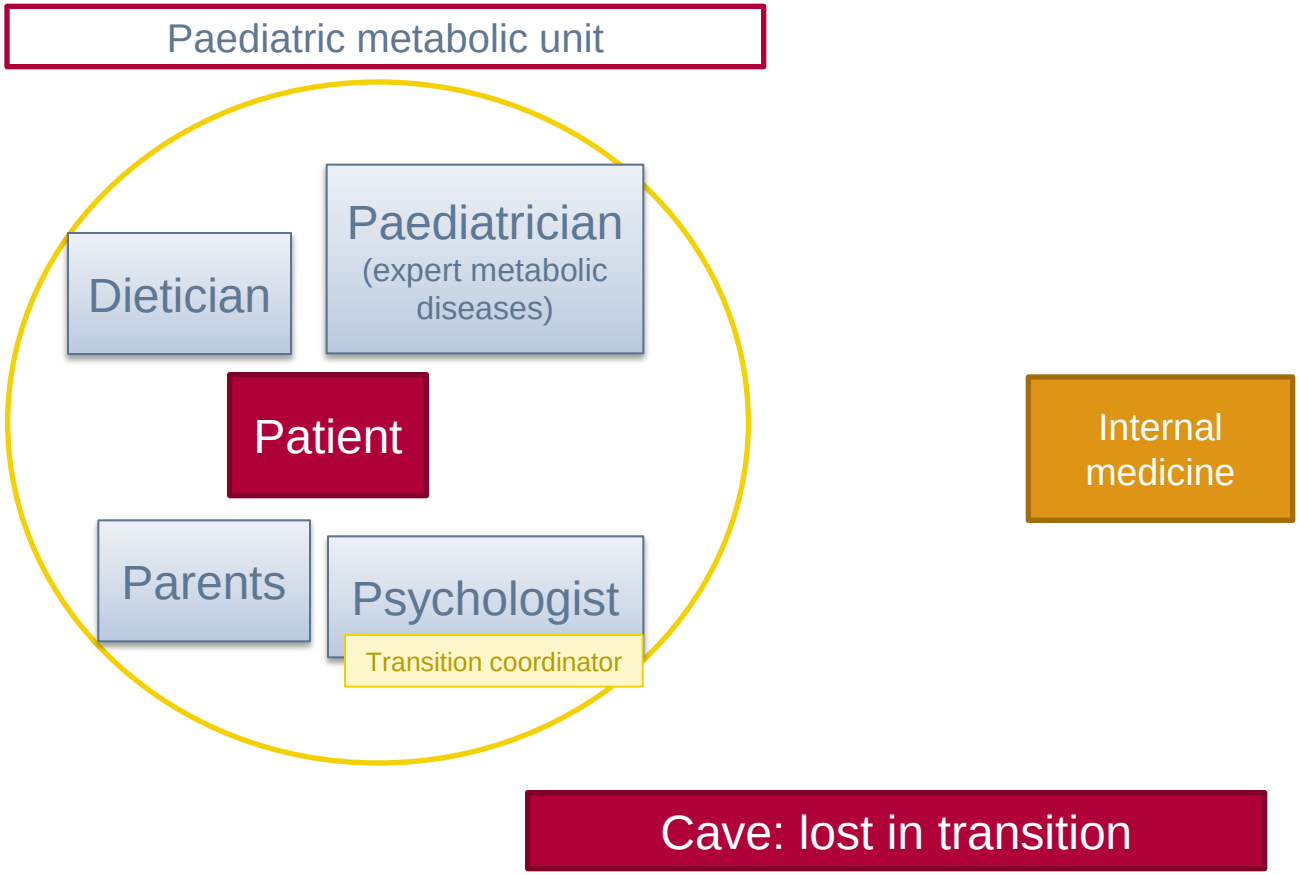
Tasks of adolescence

- Develop and apply a more complex level of thinking – abstract thinking
- Develop a capacity for deeper relationships with peers
- Establish a personal identity – an identity seperate to their family
- Building educational and social skills in obtaining employment
- Renewed relationships with parents
- Develop skills for intimate relationships

Source: Young people with chronic illness: the approach to transition (2007)
A. Kennedy , F. Sloman , J. A. Douglass , S. M. Sawyer

CEMA Antwerp

- Transition from child-centered to adult health care



Program for effective transition

- Preparation phase
- Transition phase
- Evaluation phase

PREPARATION PHASE

Information brochure

CEMA-team

Het CEMA-team blijft volledig ongewijzigd. Dezelfde diëtisten, psychologen, verpleegkundigen, maatschappelijk werker, kinder- en jeugdpsychiater staan voor jou klaar. Als het ware komt de volwassenarts mee in jouw vertrouwde team.

De verschillen

Er zijn best wat verschillen tussen de pediatrische zorg en de volwassenzorg. Ook hierop bereiden we je voor.

Kindergeneeskunde	Volwassenzorg
- Gezinsgericht/holistisch - Sociaal georiënteerd - Informeel en ontspannen - Aandacht voor ontwikkeling	- Individueel gericht - Ziekte georiënteerd - Formeel en direct - Nadruk op behandeling

Contact

Heb je nog vragen rond de transitie, neem dan contact op met de transitiecoördinator Elien Raets via 03 280 49 06 of elien.raets@zna.be

Voor afspraken rond transitieraadplegingen, contacteer Laura Greefs, secretariaat kindergeneeskunde, via 03 821 57 45 of laura.greefs@uza.be

De transitieraadplegingen gaan steeds door bij je kinderarts. Tijdens deze raadplegingen krijg je meer informatie over de contactgegevens en locatie van je nieuwe arts.

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Deze folder bevat algemene informatie en is bedoeld als aanvulling op het gesprek met uw zorgverlener.

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Tel +32 3 821 30 00 / www.uza.be
Volg ons op facebook en twitter

Het UZA draagt het JCI-label voor veilige en kwaliteitsvolle zorg.

Een vlotte overstap van kinder- naar volwassenzorg

Informatiebrochure patiënten

Kennis / Ervaring / Zorg

Key interventions for adequate transitional care

- Transition consultation
- Transition coordinator
- Continuity between the paediatric setting and the adult setting (joint pollicy)
- Transition meetings (multidisciplinary)
- Information brochure
- Increase independence / preparing transition

Transition protocol

Preparation process

- → Knowledge of condition, diet and medication
- → Self-advocacy
- → Guided self-management / responsibility
- → Health and lifestyle
- → Daily living
- → School/career/future
- → Leisure
- → Mental health
- → Transfer to adult care

Source: The Ready Steady Go Transition Programme

Paediatric vs adult care

Paediatric care	Adult care
• Family-centered	•Individual-based care
• Generalistic/inter-disciplinary team approach	•Specialist orientation
• Informal	•Formal/direct
• Holistic focus: developmental and learning issues, school and social functioning	•Disease-oriented focus: treatment, complications and compliance
• Patient is seen as vulnerable, dependant	•Patient seen as coresponsible, self-reliant

Source: Young people with chronic illness: the approach to transition (2007)
A. Kennedy , F. Sloman , J. A. Douglass , S. M. Sawyer

Practice in CEMA Antwerp

Preparation phase	
16 y/o	**First transition consultation**
17 y/o	Regular consultation with paediatrician + psychological consult
18 y/o	**Second transition consultation**
19 y/o	Regular consultation with paediatrician + psychological consult
Transition phase	
20 y/o	**Third and last transition consultation**
Evaluation phase	
20+ y/o	Regular consultation with adult metabolic specialist + evaluation

Practice in CEMA Antwerp

14-16 jaar

STEADY

READY STEADY GO
TRANSITIEPROGRAMMA

Op Eigen Benen nu

Dit is Ready Steady Go: een methode om jou te helpen om nog zelfstandiger te worden. De bedoeling is dat je straks 'op eigen benen' kunt staan en klaar bent om over te stappen naar de zorg voor volwassenen.

Deze vragen kun je met je zorgverlener (bijvoorbeeld arts of verpleegkundige) en je ouders bespreken. Samen maken jullie dan een plan.

Vul alsjeblieft alle vragen in die van toepassing zijn op jouw situatie.
Twijfel je over een vraag of antwoord, overleg dan met je zorgverlener.

KENNIS EN VAARDIGHEDEN	JA	NEE	
Ik begrijp de medische woorden en procedures die te maken hebben met mijn aandoening	JA	NEE	☐
Ik begrijp waar mijn medicijnen voor zijn bedoeld en ken de bijwerkingen	JA	NEE	☐
Ik weet wat elk lid van het medisch team voor me kan doen	JA	NEE	☐
Thuis ben ik verantwoordelijk voor mijn medicatie	JA	NEE	☐
Ik vraag zelf om herhalingsrecepten en haal de medicijnen op. Ook plan ik zelf mijn afspraken op de poli	JA	NEE	☐
Ik begrijp de verschillen tussen kinderzorg en volwassenenzorg	JA	NEE	☐
Ik weet welke mogelijkheden tot ondersteuning er zijn voor jongeren met mijn aandoening	JA	NEE	☐
Ik kan mijn vrienden uitleggen wat mijn aandoening inhoudt	JA	NEE	☐
Ik bel zelf met het ziekenhuis als ik een vraag heb of me zorgen maak over mijn aandoening of behandeling	JA	NEE	☐
OPMERKING:			

OPKOMEN VOOR JEZELF	JA	NEE	IK WIL MEER WETEN
Ik heb er vertrouwen in dat ik een (deel van de) afspraak bij de dokter of verpleegkundige alleen kan doen (zonder ouders) en dat ik zelf vragen kan stellen	JA	NEE	☐
Ik begrijp mijn recht op privacy in de zorg	JA	NEE	☐
Ik begrijp welke rechten ik heb in het nemen van de beslissingen over mijn gezondheid en ik gebruik daarbij de drie goede vragen (3goedevragen.nl)	JA	NEE	☐
OPMERKING:			

GEZONDHEID EN LEEFSTIJL	JA	NEE	IK WIL MEER WETEN
Ik doe regelmatig aan sport/ik heb een actieve leefstijl	JA	NEE	☐
Ik begrijp de gevaren van alcohol, drugs en roken voor mijn gezondheid	JA	NEE	☐
Ik begrijp wat gezond eten inhoudt en waarom het belangrijk is voor mijn gezondheid	JA	NEE	☐
Ik weet waar ik betrouwbare informatie kan vinden over seks en veilig vrijen	JA	NEE	☐
Ik begrijp wat de gevolgen van mijn aandoening/medicatie zijn op kinderen krijgen en zwangerschap	JA	NEE	☐
Ik weet dat mijn aandoening invloed kan hebben op mijn ontwikkeling, bijv. tijdens de puberteit	JA	NEE	☐
OPMERKING:			

www.opeigenbenen.nu/readysteadygo

Source: Opeigenbenen.nu

Kennis / Ervaring / Zorg

The Ready Steady Go transition programme - Go

The medical and nursing team aim to support you as you grow up and help you gradually develop the confidence and skills to take charge of your own healthcare.

Filling in this questionnaire will help the team create a programme to suit you.
Please answer all questions that are relevant to you and ask if you are unsure.

Ready Steady Go programme

Name: **Date:**

Knowledge and skills	Yes	I would like some extra advice/help with this	Comment
KNOWLEDGE			
I am confident in my knowledge about my condition and its management			
I understand what is likely to happen with my condition when I am an adult			
I look after my own medication			
I order and collect my repeat prescriptions and book my own appointments			
I call the hospital myself if there is a query about my condition and/or therapy			
SELF ADVOCACY (speaking up for yourself)			
I feel confident to be seen on my own in clinic			
I understand my right to confidentiality			
I understand my role in shared decision making			

TRANSITION PHASE

Practice in CEMA Antwerp

Preparation phase	
16 y/o	**First transition consultation**
17 y/o	Regular consultation with paediatrician + psychological consult
18 y/o	**Second transition consultation**
19 y/o	Regular consultation with paediatrician + psychological consult
Transition phase	
20 y/o	**Third and last transition consultation**
Evaluation phase	
20+ y/o	Regular consultation with adult metabolic specialist + evaluation

EVALUATION PHASE

Practice in CEMA Antwerp

Preparation phase	
16 y/o	**First transition consultation**
17 y/o	Regular consultation with paediatrician + psychological consult
18 y/o	**Second transition consultation**
19 y/o	Regular consultation with paediatrician + psychological consult
Transition phase	
20 y/o	**Third and last transition consultation**
Evaluation phase	
20+ y/o	Regular consultation with adult metabolic specialist + evaluation

Satisfaction survey

ON YOUR OWN FEET – TRANSFER EXPERIENCES SCALE (OYOF-TES)[1]

Antwoordcategorieën	score[2]
Helemaal oneens	1
Oneens	2
Niet oneens, niet eens	3
Eens	4
Helemaal eens	5

NEDERLANDS	ENGLISH
Subschaal A: Afstemming tussen kinder- en volwassenenzorg	**Subscale A: Alliance between pediatric and adult care**
Ik kan mijzelf goed redden in de spreekkamer bij mijn nieuwe behandelaar, ook zonder mijn ouders	I can manage well on my own during hospital consultations, also without my parents
Ik heb vertrouwen in mijn nieuwe behandelaars	I have confidence in my adult health care providers
Ik ben tevreden over de zorg die ik nu krijg in de volwassenenzorg	I am happy with the care I receive in the adult care setting

Source: Opeigenbenen.nu

Future challenges

- Patients with intellectual disability, physical disabilities or limited self-reliance

→ Common in metabolic care

→ Independence, self-management are unrealistic goals

→ **Continuity of family-centered care!**

Opportunities and practical problems encountered in the transition from pediatric to adult care: Everything from independent adults to multidisciplinary care for adults in childrens bodies and minds

Dr. Ann Verhaegen
Endocrinologist
Antwerp University Hospital
ZNA Jan Palfijn

Lydia, 28 y

Medical history:

- Galactosemia - well controlled and compliant with therapy
- Autism spectrum disorder

Transition at age 25 - no big problems encountered

Living with her parents who always join her at consultation

At 27 she wants to want to live on her own

Works as administrator in a police office

Jeff, 24 y

Spastic quadriplegia, visual disturbance, feeding problems (tube feeding) and therapy resistant epilepsy

(sub) acute medical problems:

- Epilepsy
- Recurrent pulmonary infections

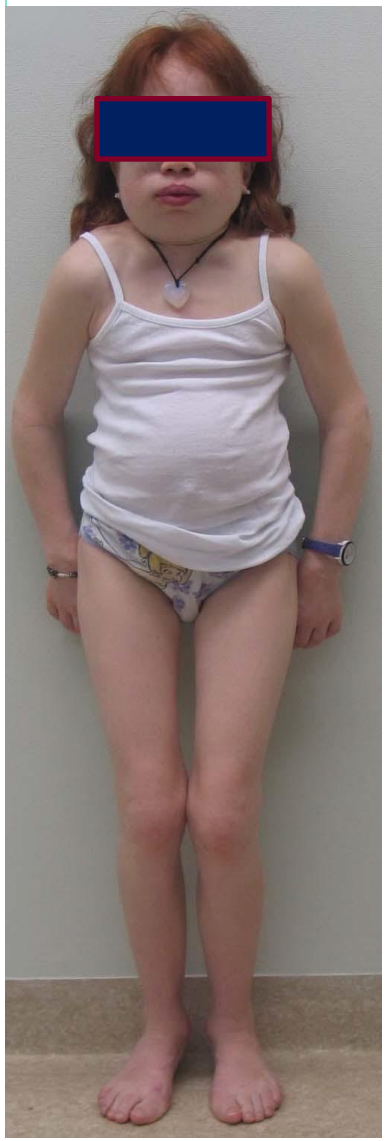
Transition at age 21y

Living with his parents who are primary care givers

MPS VI

short stature
122.4 cm

Underweight
BMI 17,7 kg/m²



Dysostosis multiplex
Bilateral limited abduction shoulder joint
camptobrachydactyly (claw hands)

Cervical medullar compression

Motoric decline: e.g. reduced walking endurance

Underdeveloped secondary sexual characteristics

Hepatomegaly

Sensorineural hearing loss

Low IQ
macrocephaly (head circumference 57 cm)

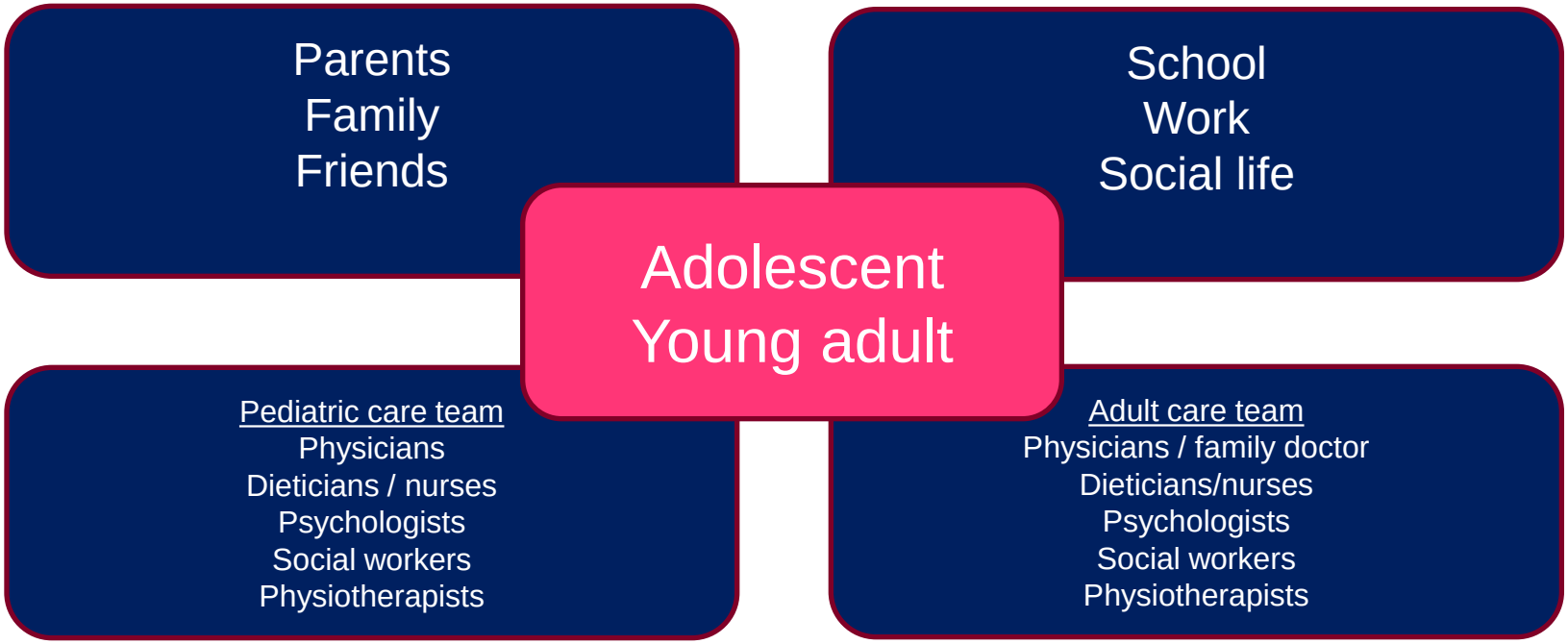
Visual disturbance
mild bilateral macular degenerative changes

Severe OSA

Mild valvular disease (thickening aortic, mitral)

Severe restrictive and obstructive lung disease (VC 39% pred. value)

Not for public use



Dependency on others

Independent life

Organisation of health care facilities
Social security
Reimbursement rules

Care models

Pediatric care

- Family centred
  - Parental involvement
- Protective/nurturing
- Prescriptive
- Focus on development and growth

Adult Care

- Independency (emotional and financial)
- Autonomy for health
- Collaborative
- Empowering

Contuinity in care

in particularly vulnerable time in the maturation of patients with IMD

Patient safety

Who's taking care of the patients with inherited metabolic diseases?

General Internal Medicine

Pneumology

Physiotherapist - Rehabilitative care

Nephrology

Ear nose throat

Gastroenterology

Ophtalmology

Cardiology

Inherited metabolic diseases

Transplant team

Hepatology

Rheumatology

Endocrinology

Psychiatry

Nutrition specialist

Orthopedic surgeon

Hematology

Clinical genetics

Neurology

Who's taking care of the patients with inherited metabolic diseases?

General Internal Medicine

Pneumology

Physiotherapist - Rehabilitative care

Nephrology

Ear nose throat

Gastroenterology

Ophtalmology

Cardiology

Transplant team

Hepatology

Rheumatology

Endocrinology

Psychiatry

Nutrition specialist

Orthopedic surgeon

Neurosurgeon

Hematology

Clinical genetics

Neurology

Adult caregivers concerns and barriers in taking care of patients with IMD

Many different (sub) specialties of adult medicine involved

Inadequate formal training in inherited metabolic diseases which still are considered as pediatric diseases

Multidisciplinary care in most patients

- Hard to organise in most adult care clinics
- Time consuming
- Lack of administrative support

Lack of skills in team (dietitians, nurses e.g. day clinic for specified therapy)

Adult caregivers concerns and barriers in transition of patients with IMD

Focus in adult care on self management of disease

Implies knowledge of their disease, treatment plan and prognosis

- (Re)-education of the patient

Can contrast with the potential of a patient

- Involvement of parents and other family care givers

  ←→ over protective parents can interfere with self-management

Supportive team of psychologists

- Assessment of cognitive functioning
- Follow up on coping skills
- Providing practice skills needed to participate in self-care
- Ensuring the patient is given a ‘voice’ and enable communication

Transition should focus on developmental level, not on chronological age

Specific needs for patients with progressive disease and/or physical or mentally inability to gain independency in live structural and organisational problems

Jeff needed to be hospitalized for pneumonia→ acute care

Multiple problems were encountered:

Emotional distress and discomfort when no family members were in his neighbourhood -> parents stayed with him

His body weight was 38 kg – adult dosing? -> training of nurses

Jeff is noisy – doesn't speak but produces sounds to express himself and he snores -> inform other patients

Due to illness of his mother, his parents needed a vacation and other family care givers were not in the possibility of taking care for him

Needed to be hospitalized since no rehabilitation centres could take care of him in meanwhile -> conflict with social security

Specific needs for patients with progressive disease and/or physical or mentally inability to gain independency in live structural and organisational problems

Progressive disease or acute deterioration can impede transition to adult care

- Instead of gaining independence, dependence on others can increase (e.g. for mobility, need of ventilatory assist, feeding assistance,…)

= bad moment for transition

Inadequate formal training in physical or intellectual disabilities in internal medicine

Specific needs for patients with progressive disease and/or physical or mentally inability to gain independency in live structural and organisational problems

Special needs during hospitalisation

- Dietary needs of patients with IMD not always compatible with regular hospital food
  - But also this can be an opportunity in re-education of patients
  - Collaboration with pediatric dieticians or education of adult dieticians
- Difficulties to handle with mentally ill patients or patients with psychiatric disorders

  Difficulties to handle with physically high demanding patients
  - Need for extra training of nursing staff
  - Support of psychologists and social workers is essential
- Nurses (day clinic, hospitalisation) training with IMD and therapies (enzyme replacement, other specific therapies)

Lydia, 28 y

Medical history:

- Galactosemia - well controlled and compliant with therapy
- Autism spectrum disorder

Transition at age 25 - no big problems encountered

Living with her parents who always join her at consultation

At 27 she wants to want to live on her own , doesn't get any support of her friend – less compliant –

deterioration of her liver function and mentally deterioration (concentration disturbance, motoric agitation)

increasing psychiatric problems – autistic behaviour

Works as administrator in a police office

uncapable of performing her tasks – partial invalidity requested

Financial and legal considerations of transition

Financial support can be hazardous in young adults willing to prepare for an independent life

- Chronic disease can impede educational achievements and/or impede working capacities-> will have an impact on earning
- Disease itself is costly

Social benefits are harder to get for adults than for families with children with a chronic disease

In Belgium social security is provided for young adults until 25y by the insurance of the parents, afterwards they will have to take care of it themselves except in cases of prolonged dependence where an administrator is indicated

Well trained social workers and
cooperation with social care organisation are essential

Opportunities to be taken into account

Close communication between pediatric and adult health care teams

- Staff meetings involving all members of both teams
- Transfer of the patient file
  - Medical history
  - Social history (adherence, distress situations,…)
- Organising shared ambulatory consultation

Timely preparation and information to patients and parents

- Timely getting to know each other – gradual transition and period of joint care
- Shared decision on moment of transition if possible and feasible

Meeting providers alone during consultations is often seen as a useful intervention to encourage self-efficacy and self-reliance in adolescents

Our experience

Adult care specialist

- UZA: formerly general internal medicine – shift to endocrinology for practical reasons
  - Familiar with transition care (Type 1 diabetes, obesity in youth, rare endocrine diseases manifesting in childhood,…)
  - Familiar with multidisciplinary approach (dietician, nurses/educators)

Other members of the team (psychiater, psychologists, dieticians, social workers) remain the same as in pediatric team, embedded in CEMA

- Patient and parents are familiar with them
- Well trained in inherited metabolic disease
- Affordable and accessible

- Can be a problem when patient is hospitalized
- Patient can be uncomfortable in his path to independence
- Distance between the wards – practical organisation

Needs to optimize care of adults with IMD in adult care setting

Formal training of internists in IMD including diagnostic procedures

Formal training of adult dieticians, psychologists and social workers

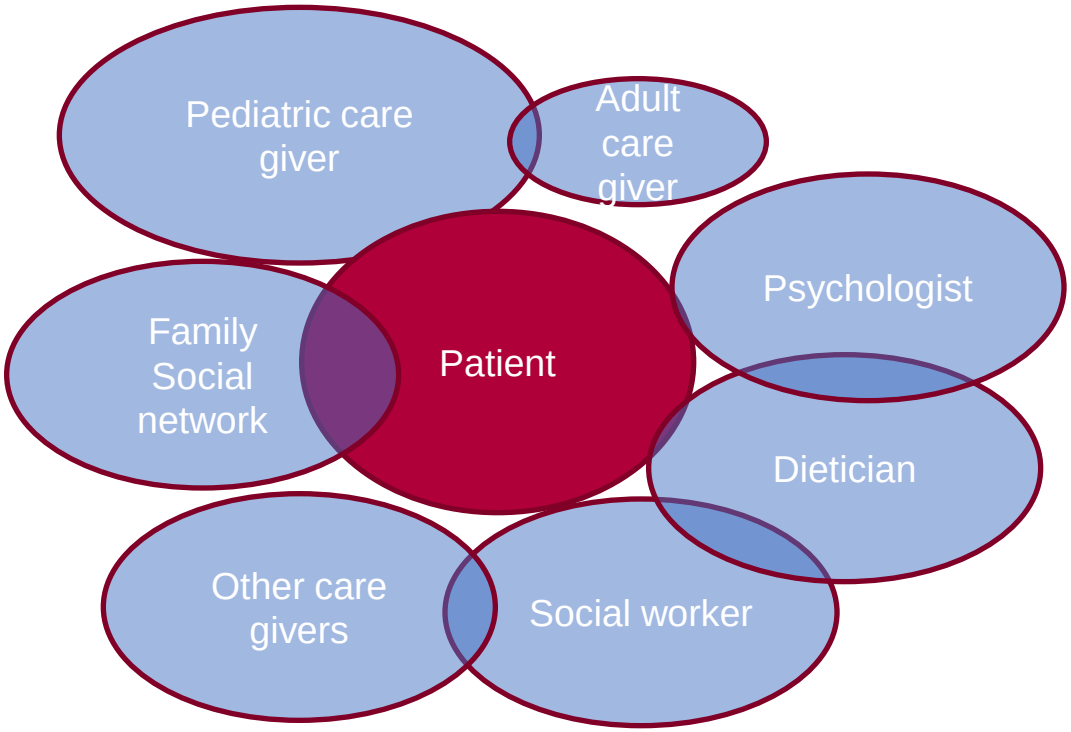
Multidisciplinarity should be encouraged

- Between specialists
- Other departments

Structural adaptations (e.g. possibilities for parent-child hospitalisation in adult care) for those that need it

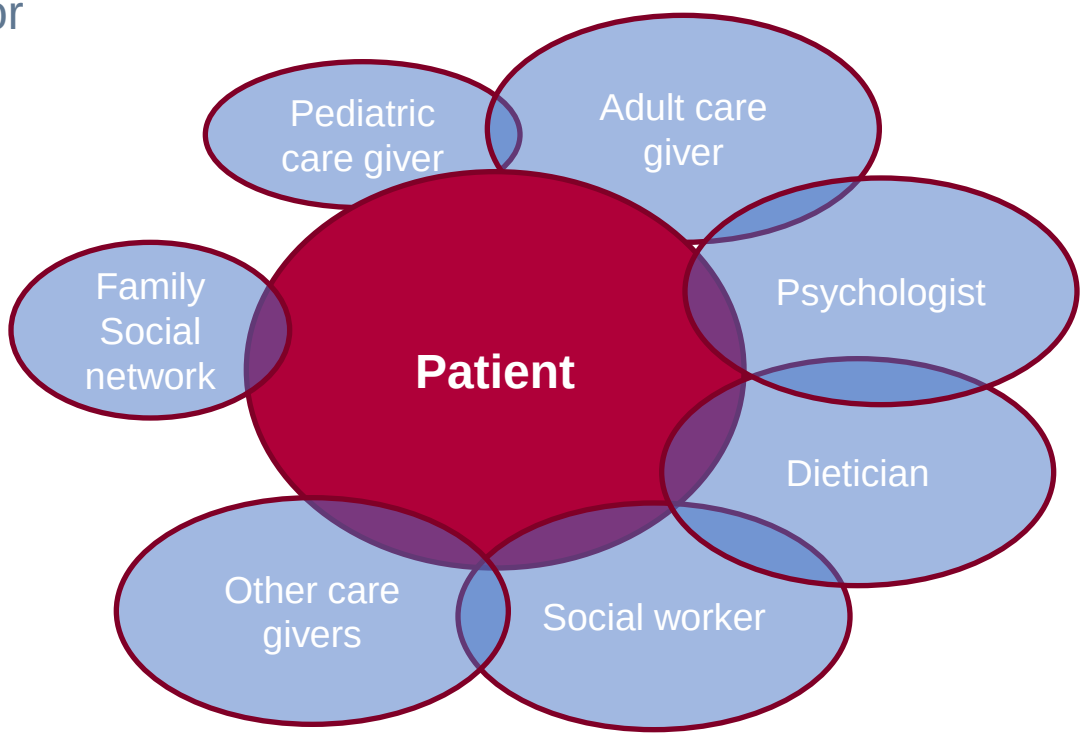
Close collaboration with general practitioner and first-line social workers

Transition is team work
Transition is an evolution, not a moment



Transition is team work
Transition is an evolution, not a moment

Transition plan
Transition coördinator



We all have still much to learn about best practice in transition of rare diseases
More emphasis on research in this field and exchanging experiences

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