Transition

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Grants or contracts from any entity	Nederlandse Hartstichting/ ZonMW	All payments to institution: Erasmus MC. Research project on Obesity
	ESPE (European Society for Paediatric Endocrinology) research unit	All payments to institution: Erasmus MC. Research project on CAH
	Stichting Erasmus Trustfonds	All payments to institution: Erasmus MC. Research project on Obesity
	NVK SKMS	All payments to institution: Erasmus MC. Guideline chair "treatment of children with obesity"
	Rhythm Pharmaceuticals Inc	All Payments to institution: Erasmus MC. Funding clinical trials: research personnel, research visits, diagnostics, treatment, provision of study materials, medical writing, article processing charges.
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	European Reference Network RareEndoERN member main thematic group growth&obesity	unpaid
	Partnership Obesity Netherlands (PON) – NVK representative	unpaid
	Rare EndoERN guideline pubertal induction and HRT	unpaid
	Rare EndoERN guideline Bardet Biedl syndrome	unpaid

OBESITY CENTER CGG

Children and Adults with obesity

Diagnostics of underlying causes

Personalized and innovative treatments

Research and Education

International collaboration

Societal impact

https://www.youtube.com/watch?v=uByJKC63apQ

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TRANSITION

EASO Masterclass July 12, 2022

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TRANSITION OF CARE FOR ADOLESCENTS WITH OBESITY

- Introduction/ definition
- What is the problem?
- Case example
- Stepwise approach
- Recommendations

Courtesy of EASO image bank
https://ecpomedia.org

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TRANSITION DEFINITION

Introduction

Transition is ‘the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-orientated health care systems’

Blum RW, Garell D, Hodgman CH, Jorissen TW, Okinow NA, Orr DP, Slap GB. Transition from child-centered to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. J Adolesc Health. 1993 Nov;14(7):570-6. doi: 10.1016/1054-139x(93)90143-d. PMID: 8312295.

intro

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MODEL OF CARE
introduction

Pediatric care

- Family centered
- Protective
- Prescriptive
- Focus on development and growth

Adult care

- Independence emotional and financial
- Autonomy for health
- Collaborative
- Empowering

ADOLESCENT OBESITY

What's the problem?

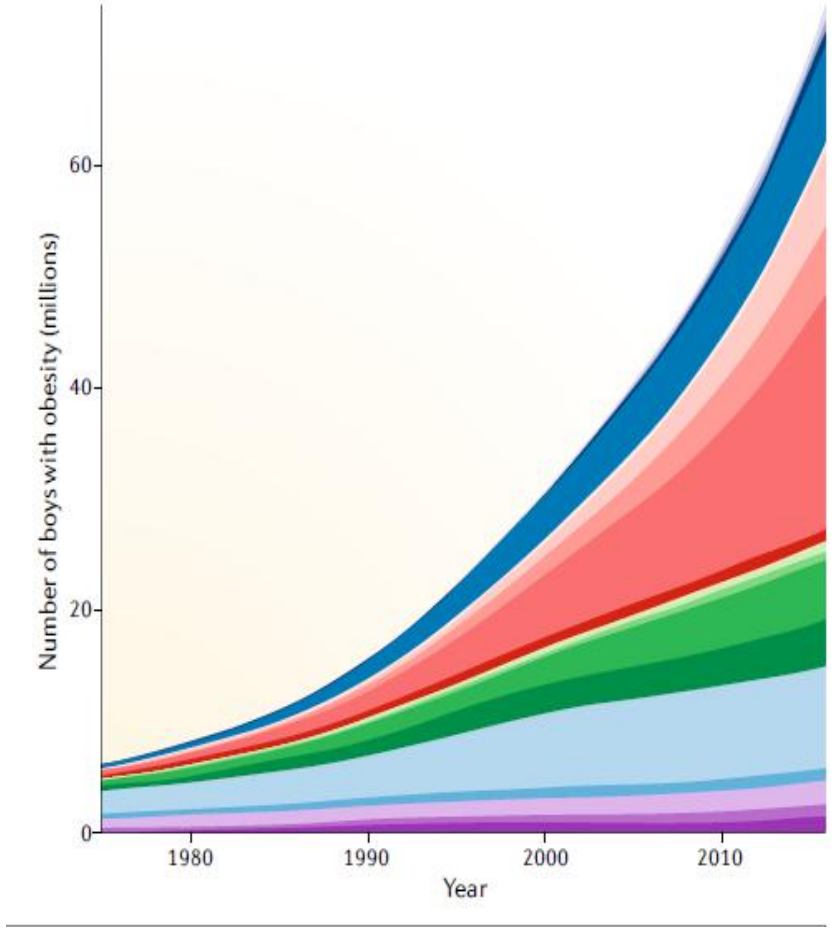
Prevalence high and rising: 124 million children <18

Health problems: emotional social and physical

Most become adults with obesity: 90%

Increased risk for cardiovasc disease and cancer in adulthood.

Care is challenging and requires special developmental approach



Cardel et al. Obesity Treatment Among Adolescents: A Review of Current Evidence and Future Directions.
Steinbeck et al Treatment of adol obesity. NatREv Endo2018
Juonala et al choildhood adiposity , adult adiposity and cardiovasc risk factors NEJM2011 and Twig et al NEJM 2016
Gordon-Larsen, P., Adair, L. S., Nelson, M. C. & Popkin, B. M. Five-year obesity incidence in the transition period between adolescence and adulthood: the national longitudinal study of adolescent health. Am. J. Clin. Nutr. 80, 569–575 (2004). 9. Patton, G. C. et al. Overweight and obesity between adolescence and young adulthood: a 10-year prospective cohort study. J. Adolesc. Health 48, 275–280 (2011)

TRANSITION

What is the problem?

Endocrine care transition study

Drop out rate 50%

- 25% from paediatric to adult endocrine care
- 25% dropped out within 2 years after transfer to adult care

11% missed first appointment in adult care

6% missed more than one appointment

Davidse K, van Staa A, Geilvoet W, van Eck JP, Pellikaan K, Baan J, Hokken-Koelega ACS, van den Akker ELT, Sas T, Hannema SE, van der Lely AJ, de Graaff LCG. We mind your step: understanding and preventing drop-out in the transfer from paediatric to adult tertiary endocrine healthcare. Endocr Connect. 2022 May 25;11(5):e220025. doi: 10.1530/EC-22-0025. PMID: 35521816; PMCID: PMC9175586

ADOLESCENT OBESITY SPECIFIC GAPS

What's the problem?

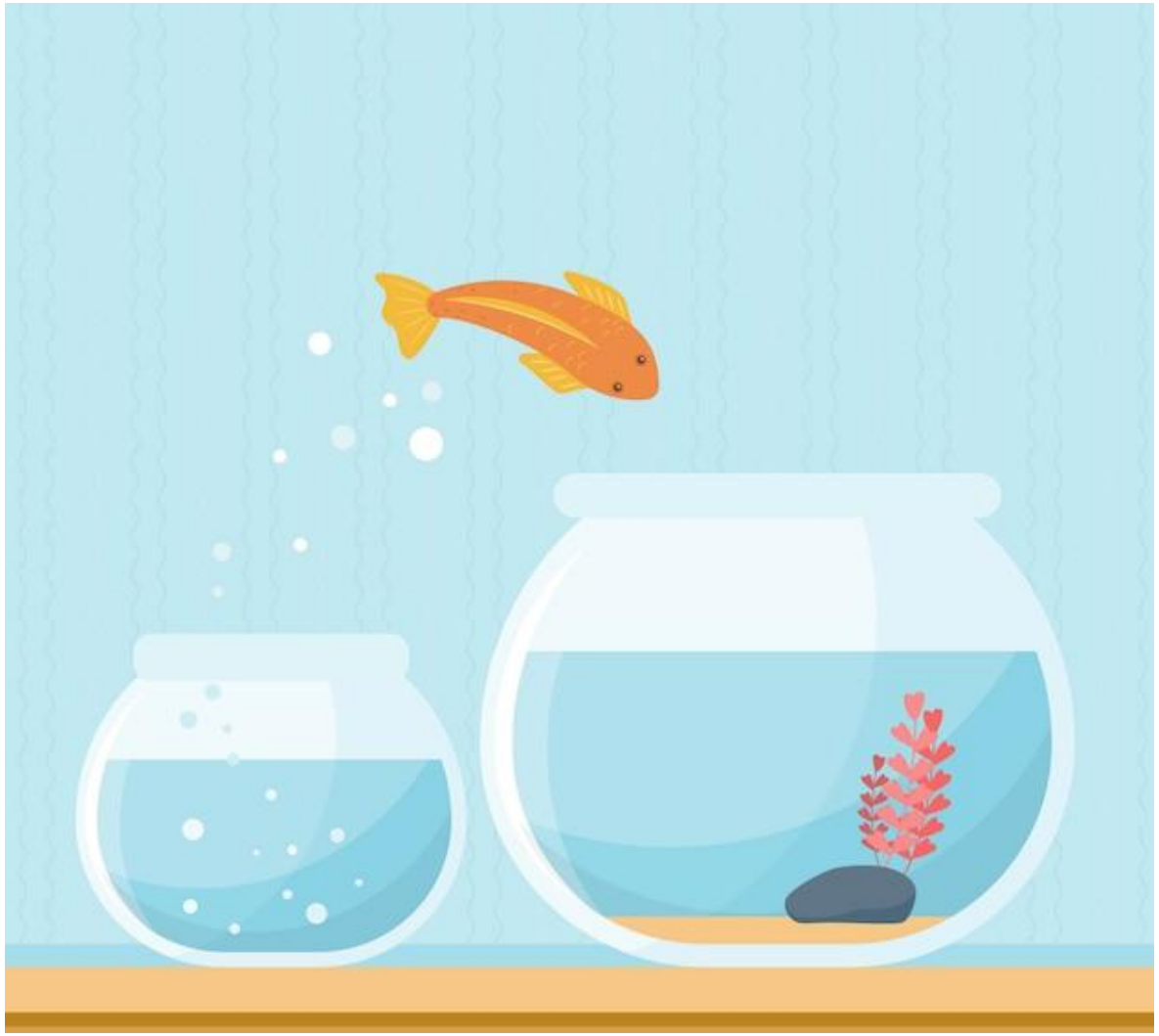
- Obesity is often not seen as a chronic illness
- Lower likelihood of it being included in national transition planning
- No obvious transition pathway.
- Limited specialist services, identification and treatment of pediatric obesity is low in primary and secondary care.
- Specialized pediatric obesity services are also not widely available
- Special developmental approach is required
- Paucity of health cost modeling around the impact of adolescent obesity on the costs of obesity in adulthood, which are likely to be significant over a lifetime
- Neglected topic : absence of published intervention programs/policies, and brevity of clinical guidance and expert opinion
- Obesity specific transition recommendations in guidelines is needed

CLINICAL PRACTICE GUIDELINE

Pediatric obesity. Styne et al jcem 2017

Adolescents undergoing lifestyle therapy, medication regimens, or bariatric surgery for obesity will need cohesive planning to help them effectively transition to adult care, such as continued necessary monitoring, support, and intervention. Transition programs for obesity are an uncharted area requiring further research for efficacy.

FROM THEORY TO PRACTICE



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CASE EXAMPLE

Jean 16 years old

History:

- Obesity grade 3
  - No hyperphagia
  - Normal development
  - Normal height
  - No medication
- Comorbidities: NASH, insulin resistance

Family history:

- weight differs from parents and siblings
- Father Dutch, Mother Italian, with extensive knowledge on different diets, “low carb fan”

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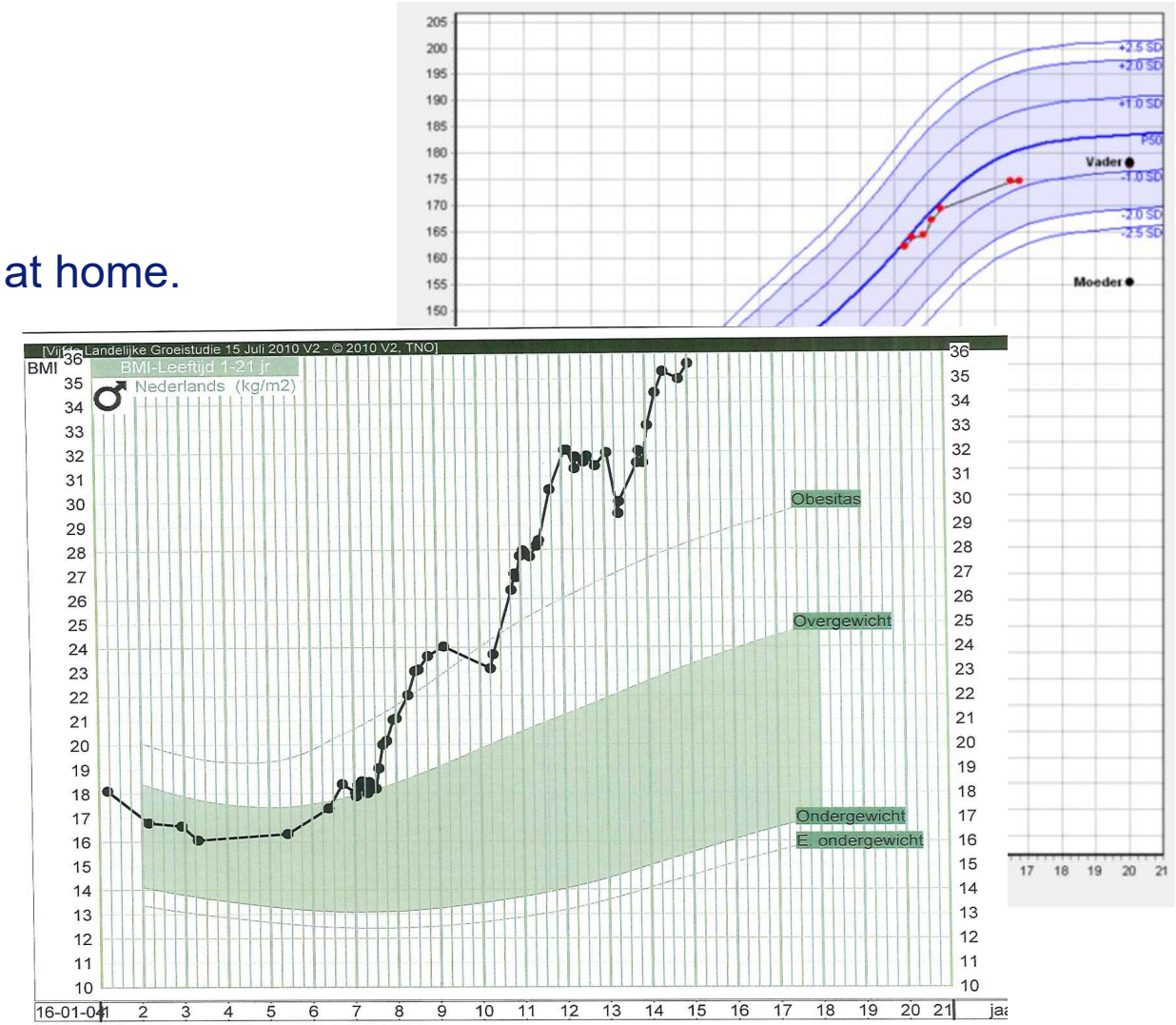
CASE EXAMPLE

Lifestyle:

- Healthy food: lots of focus on healthy lifestyle at home.
- Fysical activity >1h /day, screen time 4h/day
- No sleeping problems
- No stress or psychological problems

Growth charts



CASE EXAMPLE

Lifestyle:

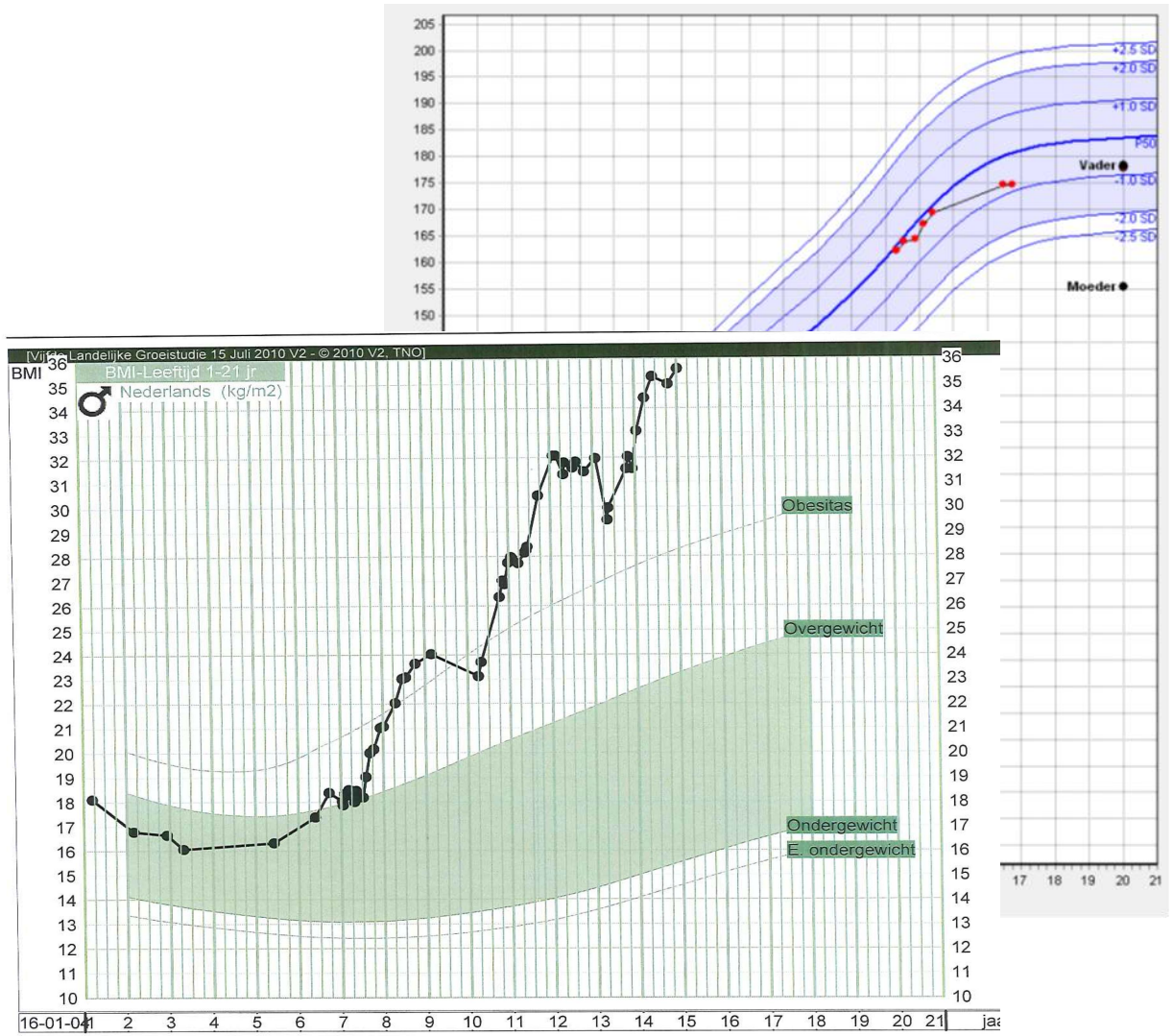
- Healthy food: lots of focus at home.
- Fysical activity >1h /day , screen time high
- No sleeping problems
- No stress or psychological problems

Growth charts

Interventions

Primary school: 1 year ‘LEFF’ program (CLI)

- Secondary school:
  - Dietician (“ no effect, had nothing to add”)
  - Own initiative: Several diets and sports



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QUESTION
case example

Q: When would you normally consider starting transition?

Anwer:

A. At 11-13 years of age

B. At 14-16 years of age

C. At 17- 18 years of age

D. At one year before transfer to adult service

GOALS

- To assess knowledge of their condition, their treatments and that they know who's who in their healthcare team.
- To support the development of self-advocacy (speaking up for yourself).
- To develop an understanding of the issues around a healthy lifestyle, sexual heath and where relevant pregnancy.
- To review educational and vocational issues to ensure the YP has high but also realistic expectations and has a plan to achieve their potential.
- To identify any psychosocial issues.
- To develop an understanding of the concept of transition.

GAPS TRANSITION READINESS

Knowledge of the disease

Being able to tell doctors how you feel

Ask questions

Take your medication

Pharmacy pick up prescriptions

Come to the hospital for lab tests

Come to the HCP for consultancy

TRANSITION PLAN 12-18 JR

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QUESTIONAIRRES

Knowledge on disease treatment and medication

Ik kan beschrijven wat mijn medische diagnose is en het aan anderen uitleggen
Ik weet waarom ik medicijnen gebruik
Ik weet wanneer ik mijn medicijnen moet innemen
Ik denk er zelf aan om mijn medicijnen te nemen
Ik haal zelf mij medicijnen bij de apotheek
Ik ken de bijwerkingen van mijn medicijnen
Ik weet waarom ik mijn medicatie consequent moet blijven gebruiken
Ik heb vertrouwen in mijn kennis over mijn aandoening en mijn behandeling
Ik weet wat ik moet doen als ik op reis of op vakantie ga
Ik weet welke medische controles en zorg in nodig heb als ik volwassen ben en waarom

Aanvullende opmerkingen:

Health literacy and skills

Ik stel zelf vragen aan de dokter of verpleegkundig specialist
Ik ken mijn rechten over toestemming, informatieverstrekking, besluitvorming en privacy
Ik weet wie mijn behandelaars op de polikliniek zijn (bijv dokter, verpleegkundig specialist)
Als ik vragen heb over mijn aandoening, mijn behandeling of mijn medicijnen kan ik zelf de polikliniek

Health and lifestyle

Ik weet dat ik op moet letten dat ik gezond blijf / dat ik niet te zwaar of te licht wordt
Ik weet wat gezonde voeding is
Ik ken de risico's van roken, alcohol en drugs in combinatie met mijn aandoening en de medicijnen die ik gebruik
Ik ben lid van een vereniging of sportclub
Ik begrijp dat bewegen en sporten belangrijk is voor mijn gezondheid

Aanvullende opmerkingen:

Social contacts and social skills

Ik heb vrienden en vriendinnen die ik buiten school of werk zie
Ik heb vrienden om mee te praten als ik me verdrietig voel of ergens van baal
Ik heb er vertrouwen in dat ik anderen, bijv. vrienden, familie en werkgevers, over mijn aandoening kan vertellen als ik dat wil

Aanvullende opmerkingen:

Love and sexuality

Ik weet waar ik informatie kan vinden over seks en veilig vrijen
Mijn vragen over seks kan ik met het behandelteam bespreken
Ik weet waar ik terecht kan met vragen over vruchtbaarheid en het hebben een kinderwens

Ouder/verzorger

Individueel Transitieplan voor Ouders kinderendocrinologie

Aanvullende opmerkingen:

School, future and independence

Het gaat goed op school, studie en/of werk

Ik denk na over wat ik later wil gaan doen als ik klaar ben met deze school

Ik maak mijn eigen lunch klaar en pak mijn schooltas in

Ik weet hoe ik met de trein, bus, tram of metro moet reizen

Ik ben verantwoordelijk voor één of meer huishoudelijke karweitjes

Ik heb al eens gewerkt

Ik weet dat ik vanaf mijn 18de verjaardag een eigen zorgverzekering afgesloten moet hebben

Ik weet waar ik terecht kan voor loopbaanadvies

Gebruik je glucocorticoïden?

Ik weet dat mijn lichaam een hogere dosis bijniermedicatie nodig heeft als ik ziek ben, langdurige stress heb o
geopereerd moet worden

Ik weet hoe ik mijn dosering moet veranderen als ik ziek ben, langdurige stress heb of een operatie moet ondergaan

Ik weet wat een (dreigende) bijniercrisis is

Ik weet wat de oorzaken voor het ontstaan van een bijniercrisis kunnen zijn

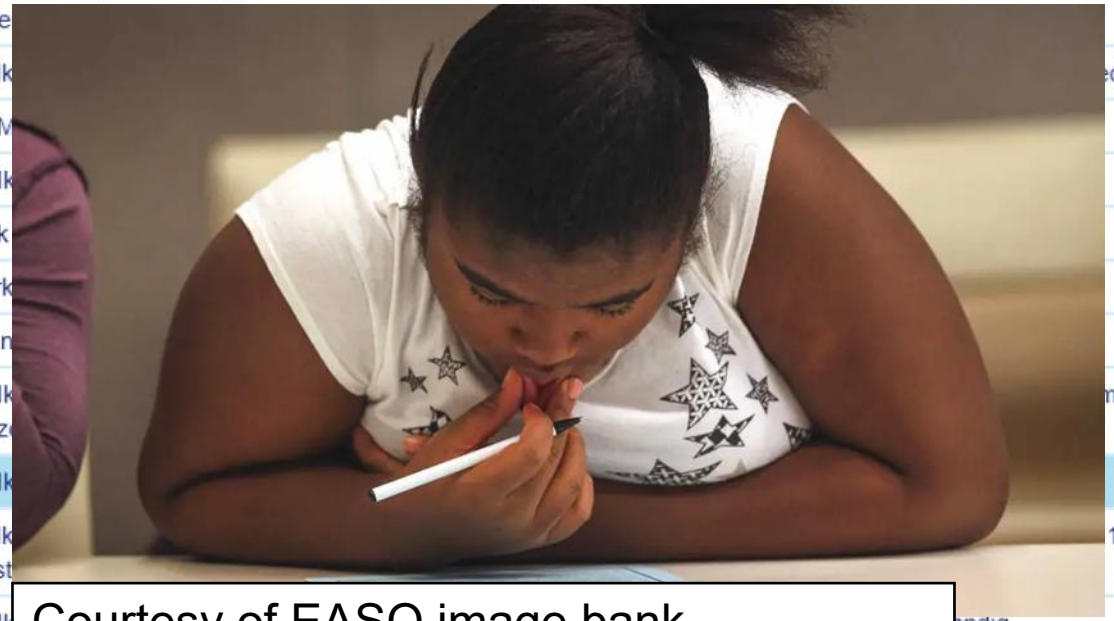
Ik weet hoe ik een (dreigende) bijniercrisis kan herkennen

A

Kennis over de aandoening, behandeling en medicatie

1a. Ik kan mijn kind uitleggen welke aandoening hij/zij heeft.

1b. Ik kan mijn kind uitleg geven over zijn/haar medicijnen, hoe en waarom deze gebruikt moeten worden en evt.



Courtesy of EASO image bank
https://ecpomedia.org

Opmerkingen:

Gezondheid en leefstijl

CASE EXAMPLE

• I know what obesity is	Yes
• I know why obesity is problem for my health	Yes
• I know which drugs i take	Yes
• I know what these drugs are for	No
• I know when I have to go to the doctor	Yes
• I know why I need check ups at the doctor	No
• I know why I need blood tests	No

Courtesy of EASO image bank
https://ecpomedia.org

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CASE EXAMPLE

- I know what obesity is — Yes
- I know why obesity is problem for my health — Yes

- I know which drugs i take — Yes
- I know what these drugs are for — No

- I know when I have to go to the doctor — Yes
- I know why I need check ups at the doctor — No
- I know why I need blood tests — N

Limited knowledge

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CASE EXAMPLE

- School: stress of exams
- Binge eating
- Unhealthy lifestyle: alcohol, smoking
- A lot of arguiing at home

CASE EXAMPLE

- School: stress of exams
- Binge eating
- Unhealthy lifestyle: alcohol

Health and lifestyle problems

CASE EXAMPLE

Interventions:

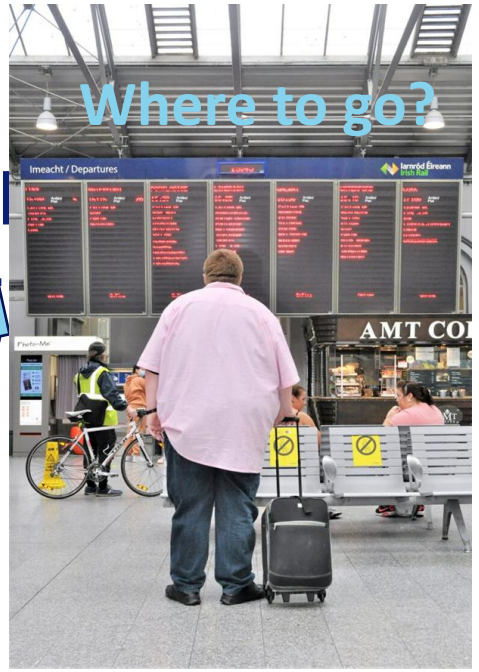
- Referred to psychology for Cognitive behavioral therapy (CLI plus)
- Farmacotherapy GLP-1 agonist subcutaneous injections
- Regular check every 3 months

CASE EXAMPLE

Interventions:

- Referred to psychology for Cognitive beh… th…
- Farmacotherapy GLP-1 a…
- Regular check…

Health literacy



….9 months later:

missed several checks

CBT never started, he never got the invitation to the appointment

Farmacotherapy: stopped because prescription was finished.

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RISK FACTORS FOR FAILURE OF TRANSITION

Patient level

lack of adherence to treatment and follow-up recommendations,

poor disease self-management

disengagement with clinical care

detrimental physical and psychosocial outcomes

perceived low readiness to transfer

hospitalization

Systematic narrative review of pediatric-to-adult care transition models for youth with pediatric-onset chronic conditions. Marani et al 2020
https://doi.org/10.1016/j.childyouth.2020.105415

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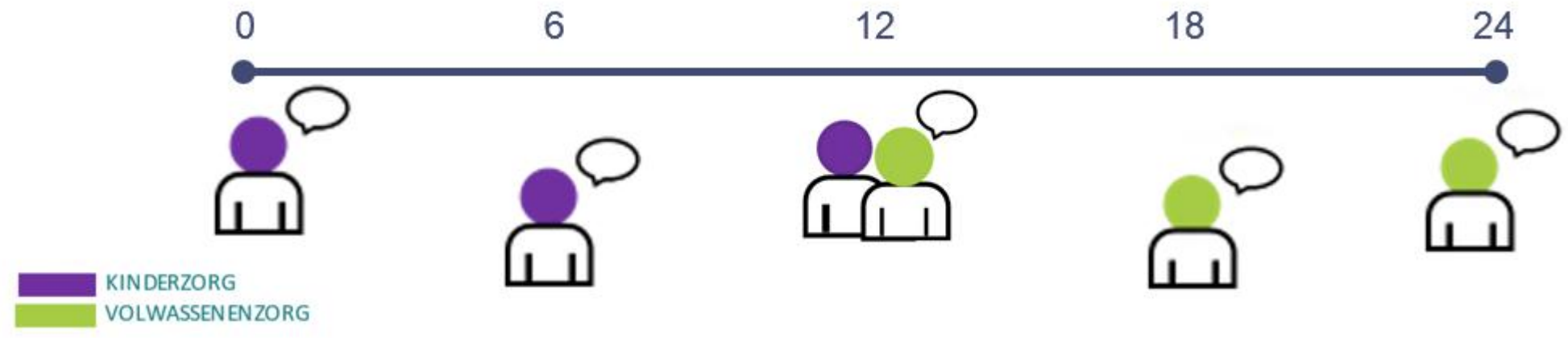
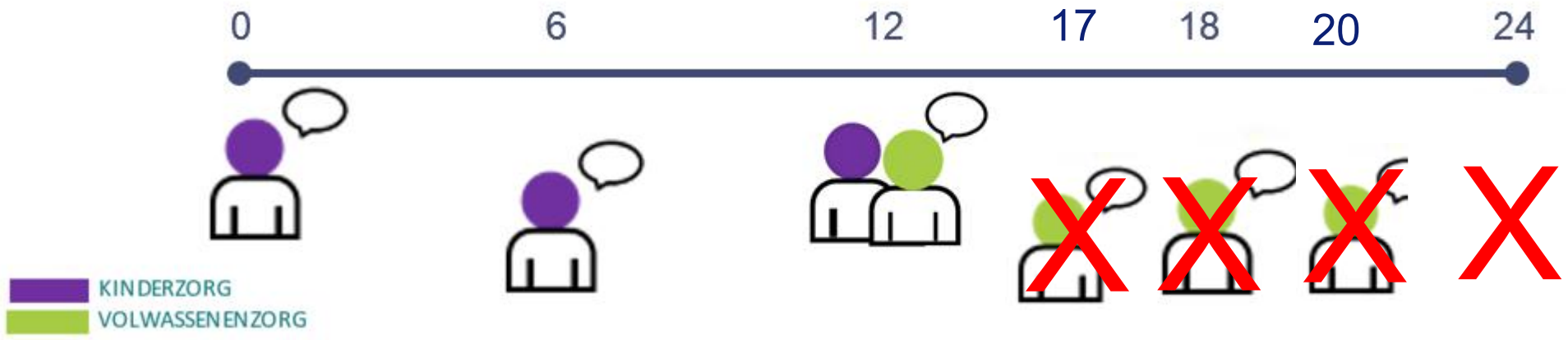
TRANSITION

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Drop out of care

RISK FACTORS FOR TRANSITION FAILURE

Physician level

lack of familiarity with the transition process

lack of time to coordinate

ineffective communication between pediatric and adult providers

irregular contact and monitoring of patient

lack of physician buy-in in the transition model of care

Systematic narrative review of pediatric-to-adult care transition models for youth with pediatric-onset chronic conditions. Marani et al 2020
https://doi.org/10.1016/j.childyouth.2020.105415

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RISK FACTORS FOR TRANSITION FAILURE

Health system level

Identifying an appropriate adult provider with expertise and interest in serving transition patients,

care that is not tailored to patients and their caregivers,

poor integration of transitional care services,

limited access to care

lack of collaboration within and beyond the facility delivering care

Systematic narrative review of pediatric-to-adult care transition models for youth with pediatric-onset chronic conditions. Marani et al 2020
https://doi.org/10.1016/j.childyouth.2020.105415

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TWO MODELS OF TRANSITION CARE:

Transition clinic with multidisc team

Transition program with facilitator

- ❑ educational interventions
- ❑ social programming
- ❑ peer support
- ❑ a transfer care summary
- ❑ transition-readiness interventions
- ❑ after-hours care
- ❑ communication modalities
- ❑ parental participation
- ❑ appointment reminders
- ❑ evaluation patient satisfaction and rates of attendance

Systematic narrative review of pediatric-to-adult care transition models for youth with pediatric-onset chronic conditions. Marani et al 2020
https://doi.org/10.1016/j.childyouth.2020.105415

STEPWISE APPROACH

YOUTH TRANSITIONING FROM PEDIATRIC TO ADULT HEALTH CARE

1
POLICY/GUIDE
Develop, discuss, and share transition and care policy/guide
AGE 12-14

2
TRACKING & MONITORING
Track progress using a flow sheet registry
AGE 14-18

3
READINESS
Assess self-care skills and offer education on identified needs
AGE 14-18

4
PLANNING
Develop HCT plan with medical summary
AGE 14-18

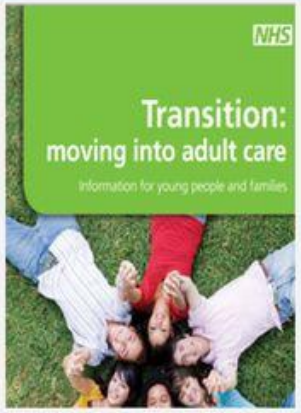
5
TRANSFER OF CARE
Transfer to adult-centered care and to an adult practice
AGE 18-21

6
TRANSITION COMPLETION
Confirm transfer completion and elicit consumer feedback
AGE 18-23

https://www.gottransition.org/six-core-elements/

Ready Steady Go: Moving through the programme

Ready Steady Go: Each Young person (YP) progresses at their own pace



11-12 yrs
YP and carer Introduced to Ready Steady Go programme with information leaflet + video
www.uhs.nhs.uk /readysteadygo

11 – 13 yrs
YP completes **Ready**
Issues addressed in bite sized pieces.
YP and carer introduced to concept of shared decision making and confidentiality
When ready YP seen on own for a few minutes during clinic.
Agree goals

14 – 16 yrs
YP completes **Steady**
Issues addressed in bite sized pieces
Aim to see YP for longer on own in clinic. Keep carer fully involved
Duplicate clinic letters offered to YP
Agree goals

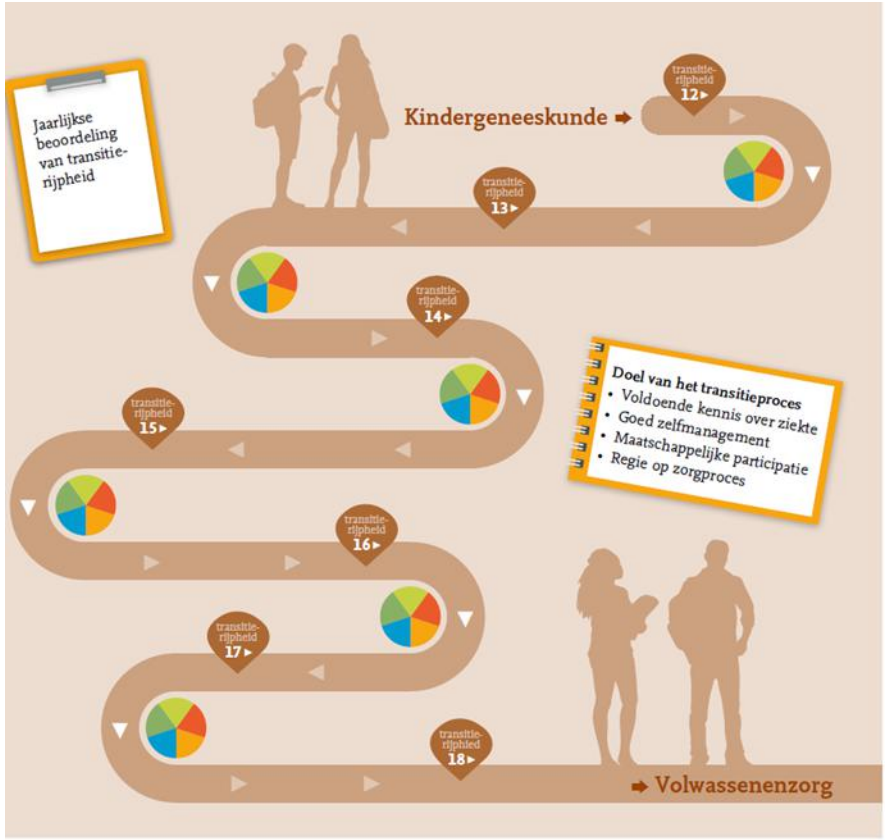
16 – 18 yrs
YP completes **Go**.
Issues addressed in bite sized pieces
Work towards YP conducting whole clinic on own. Keep carers involved
Referral letter to adult team.
YP meets adult team.
On-going issues highlighted to adult team. Ideally all issues addressed prior to transfer.
Write transfer letter
Agree goals

1st adult clinic
YP +/- carer completes **Hello**
Issues addressed in bite size pieces by HCP.
Clinic letters sent to YP
Periodically **Hello** completed again to ensure knowledge + skills maintained
Any issues addressed.
Agree goals

Arvind Nagra et al. Arch Dis Child Educ Pract Ed 2015;100:313-320

SUMMARY RECOMMENDATIONS

- ❑ Transition 12-18 years
- ❑ Use a transtion program
- ❑ Give adolescents the opportunity to be seen without their parents
- ❑ Needs of patient and needs of parents
- ❑ Involve adult physician prior to transfer
- ❑ Cooperation between pediatric and adult department (align!)
- ❑ Coördinator
- ❑ Evaluation



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