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Transition to adulthood in NMD

Background

- ***pediatric neurologists and other experts in pediatrics take care for chronically ill children and adolescents with variable NMDs***
- ***neurologists and other experts in adult medicine will see patients with complex phenotypes and variable handicap, with starting in childhood or a milder phenotype manifesting in adulthood***

Two definitions

- ***Transition*** *is the purposeful, planned transition of adolescents and young adults with chronic disabilities from child-centered to adult-centered health care systems, with the goal of ensuring coordinated, uninterrupted health care.*
- *The transition represents a challenge primarily for young people with special health care needs, especially people with a chronic illness. However, it is important because, especially in this phase of life, health care is subject to complex changes and often fails. It is neglected for various reasons. This has frequently a negative impact on the further course of the disease.*
- ***Transfer*** *is the direct transfer of the patient from pediatrics to adult medicine as a one-time event.*

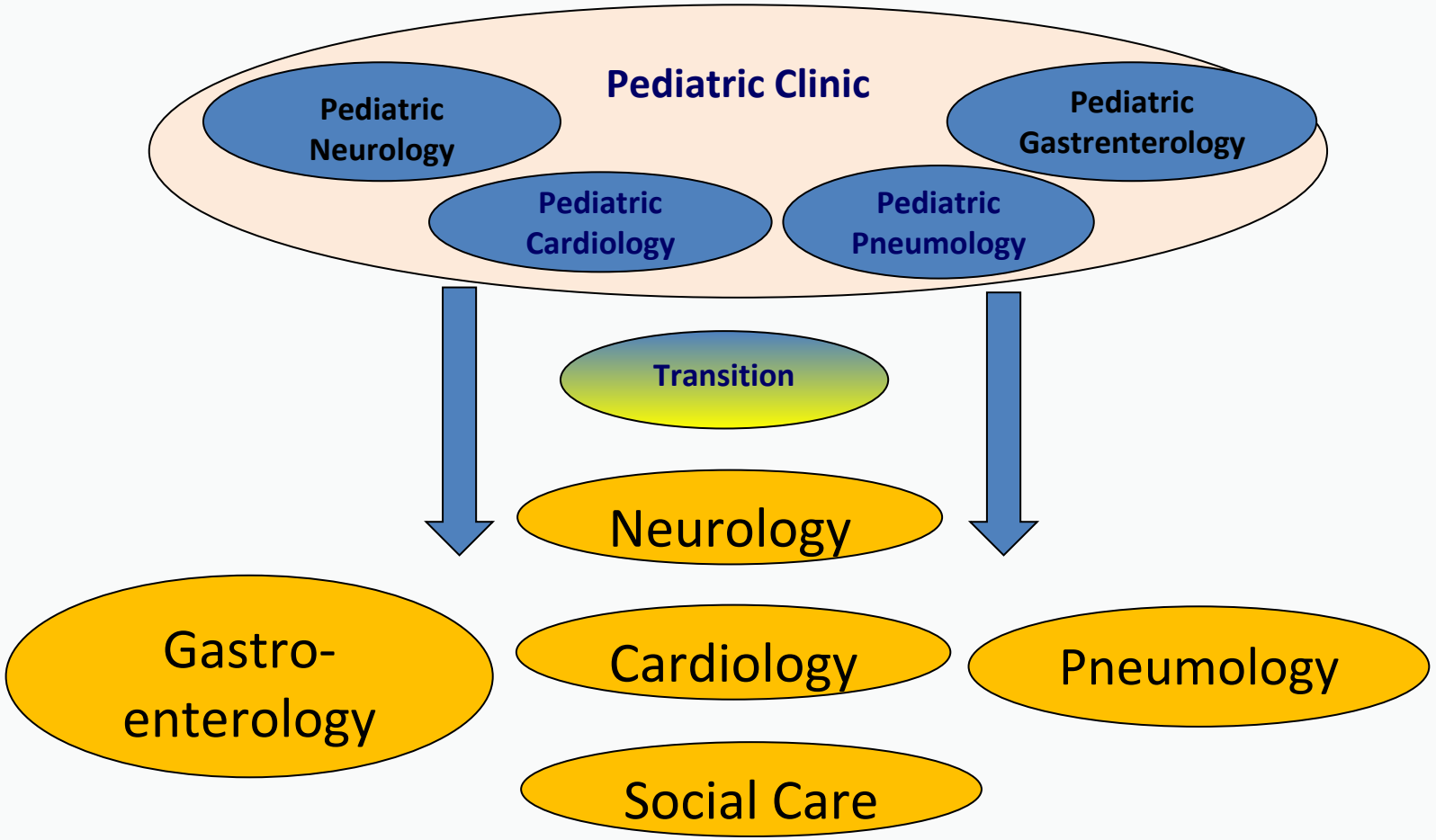
Background

- *transition is necessary in all chronic diseases, not only for neuromuscular disorders*
- *it is a politically addressed topic*
- *but, there are no general strategic plans in place, no financial ressources*
- *one S3 German guideline which addresses medical, psychological and social aspects in detail for patients and their families: a lot of recommendations, all helpful, but complex, a more realistic approach is starting step by step*
- *“Berliner Transitionsmodell”: a well organized transition plan, addressing structure and network of transition, independent of the affecting chronic disease, patients and families can subscribe into this program*
- *our local ”Essener Transitionsmodell”*
- *for single disorders recent recommendations are published, as an example: Transition of patients with Duchenne muscular dystrophy from paediatric to adult care: An international Delphi consensus study.*

Personal experience

- *Transition in Essen from Pediatric Neurology to Neurology started in 2018*
- *first with DMD patients, because of an urgent need*
- *now transition of all neuromuscular disorders from the age of 18 years*
- *Transition at UK Essen or to other Neurology Clinics with special expertise for NMD*
- *we started with single patients on an individual way*
- *currently we have a “transition day”, usually on Monday*
- *coming from the “network” in pediatrics we build up a “network” in adult medicine*
- *personal interest and activity as a motor*
- *local financial resources may be in place, but no general recommendations*
- *important is data sharing using our digital patient report*

Medical / organizational Challenges



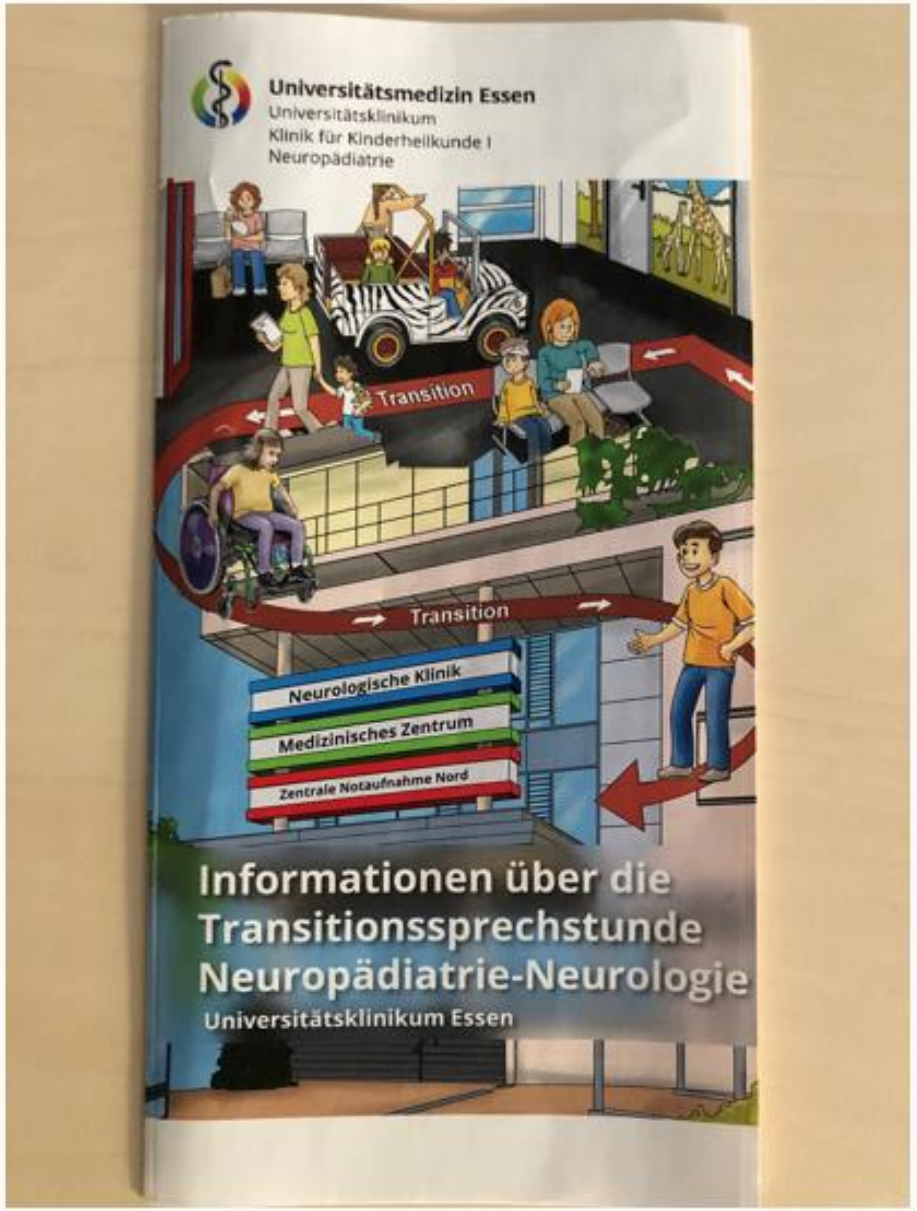


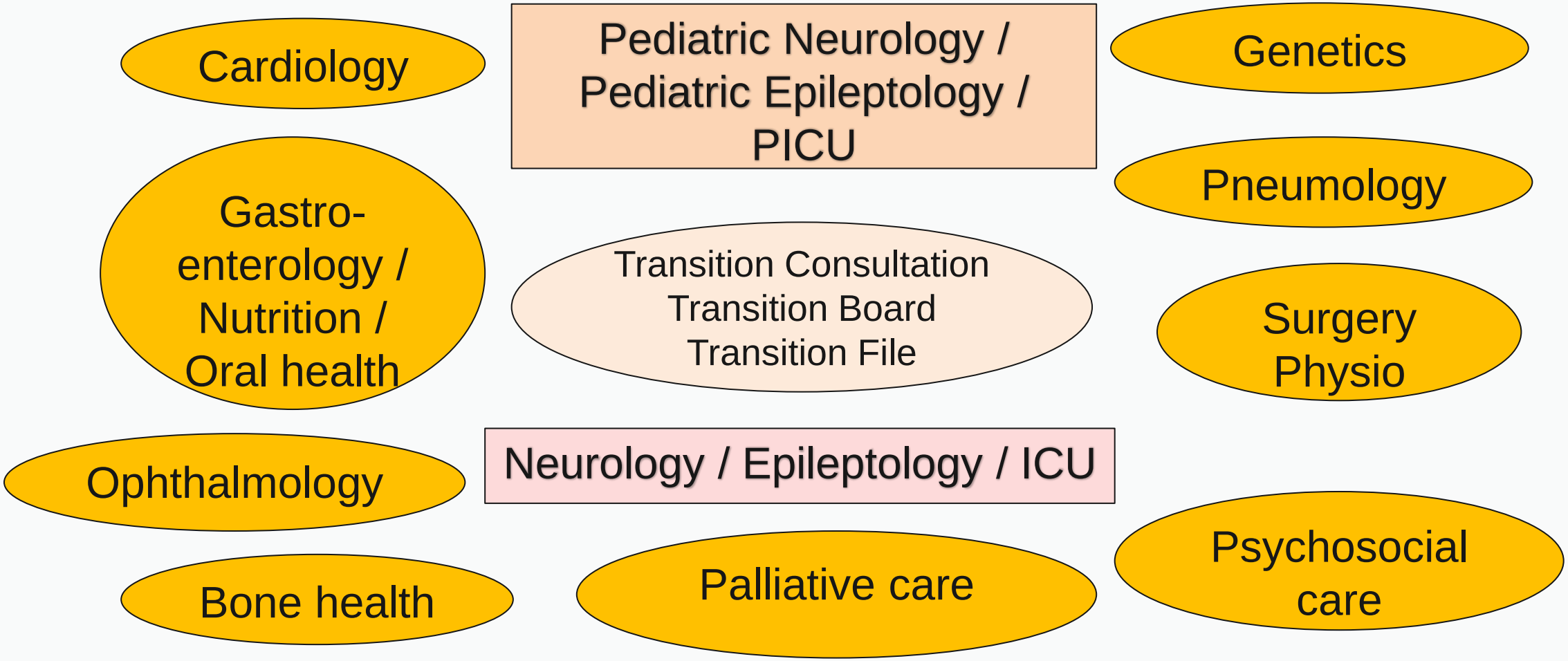
Image propriety of Prof. Ulrike Schara-Schmidt

Outpatient Clinic Pediatric Neurology

2 common clinical visits with specialists
Pediatric Neurology and Neurology

Outpatient Clinic Neurology

Facing challenges:
Transition at the “Transition board” – UK Essen



Gaps of knowledge

- *natural history data over a longer time span*

- *different phenotypes known by pediatric and adult neuromuscular experts*

→ *Who should be included in multidisciplinary care?*

specialities of other organ manifestations in NMDs

- *guidelines addressing all subtypes over the different life spans*

- *access to the multidisciplinary care in pediatric and adult patients*

→ *more / better cooperation of pediatric and adult experts*

Action points

- *collecting data in a natural history study and taking the different phenotypes into account*
- *defining and motivating experts necessary in general and on an individual basis*
- *cooperation, building networks, common guidelines*
- *education in different areas, e.g. phenotypes, diagnostics, supporting therapies, psychosocial aspects and counselling*
- *working for adequate financing*

- **outcome:** a patient centered multidisciplinary care kept up from adolescents to adults
- **action:** a structured plan for transition

References

- *Berliner Transitionsmodell; https://www.btp-ev.de/*
- Diana Castro …. Quinlivan R et al. Transition of patients with Duchenne muscular dystrophy from paediatric to adult care: An international Delphi consensus study. https://doi.org/10.1016/j.ejpn.2025.01.004
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Thank you!