

Online Guest Lecture  
Academy Joint Project „Transition in Rare Diseases“

***Lost in Transition - Young people in transition from  
pediatrics to adult medicine***

**Dr. Caroline Culen**  
(Austrian League for Child and Adolescent Health)

**Thursday 20 February 2025, 3:00-4:30pm CET online**  
Rare Disease Social Research Center  
Institute of Philosophy and Sociology, Polish Academy of Sciences

Join meeting:

<https://zoom.us/j/94278973444?pwd=O2w0jD3XeWZUfFwuiwXFCaTWm9ahJg.1>

Meeting ID: 942 7897 3444; Access code: 437424 LINK

The lecture deals with the health care transition (HTC) of young people with chronic and rare diseases from pediatric to adult medicine. Whereas a few decades ago only a few affected children reached adulthood, today around 90% survive thanks to medical advances. Nevertheless, this transition carries considerable risks: Adolescents miss follow-up appointments, their adherence to treatment decreases and some fall out of care (“lost in transition”), which can lead to deteriorating health. Challenges during the HTC include the loss of trusted doctors, structural differences between pediatric and adult medicine and a lack of independence and self-care on the part of young people. A successful HTC, on the other hand, reduces complications and improves medical outcomes and quality of life. The presentation will provide an overview of developments and efforts to improve transition in Austria along with best practice examples and HTC guidelines.



Dr. Caroline Culen studied psychology at the University of Vienna and completed her doctorate in public health at the Medical University of Vienna. She worked for *die möwe* child protection centers and at the children's clinic of the Vienna General Hospital (AKH Vienna) with chronically ill children and adolescents. Since 2019 she has headed the NGO Austrian League for Child and Adolescent Health. She publishes on the subject of young people with rare diseases, writes book contributions and specialist articles. She is committed to helping young people grow up in the best possible way through her lecturing activities, committee and umbrella organization work. She is the mother of 4 children.

