

# Experiences of UK-based adult transition services for Interstitial Lung Disease in childhood: “There’s a lot less cushioning”

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## Abstract

Interstitial Lung Disease in childhood (chILD) is rare and no longer solely a childhood issue. Many are surviving into adult life. Therefore, many affected with chILD need to transition from paediatric to adult healthcare services. Transition is a significant life event that has the potential to impact on physical and mental health outcomes and across Europe this is a haphazard process for chILD. This qualitative study explores how young people and parents in the United Kingdom experienced transition from paediatric to adult healthcare services for chILD. Participants (n = 7) were recruited from chILD patient organisations and online communities. We focused on the experience of transition and whether there were any information packs or support provided for the transition. The data was analysed by constructivist grounded theory. The study presents a lived experience of transition with themes of lack of transition preparation and planning, challenges of learning how to adapt to adult services and a changing healthcare scene. Due to the complexity of ChILD, parents discussed their need to remain, in part, as an advocate for the young person. Respondents provided recommendations for how transition could be improved along with tips for young people who are new to the transition process, which include educating oneself about the condition and learning medical terminology, being open if there are issues and reaching out for support.

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ChILD transition tables.docx available at <https://authorea.com/users/567073/articles/613591-experiences-of-uk-based-adult-transition-services-for-interstitial-lung-disease-in-childhood-there-s-a-lot-less-cushioning>