

Transition in care: from childhood to adulthood

By Anna Simon

Dr. Simon started by giving the definition of transition. It should address the medical, psychosocial, educational and vocational needs of adolescents and young adults. In real life experience, healthcare systems and hospitals are not really prepared for a smooth transition. Often, there is a lot of last-minute work and depending on the variabilities (i.e. is the disease controlled or not? Will the patient be going to the same or a different hospital?), it might get complicated.

She also mentioned that during consultation, it is usually the parents doing all the talking and not the patient. Literature shows that teenagers don't have enough experience or faith in their own knowledge and that they are dependent on their parents. As a result, follow up is lost, decreased compliance, decreased health and risk for complications.

At the Department of General Internal Medicine, Section Infectious Diseases of the Radboud University Nijmegen Medical Centre for PID (Primary Immunodeficiencies), the transition clinic has different phases.

From age 12, there is a yearly transition consultation at the paediatrics department.

For ages 16-17, there is a joint consultation (2 patients per clinic). The consultation takes place at the adult outpatient clinic but with their own paediatric clinician. Blood is taken by the nurse from the adult care department.

For ages 17 to 18, there is also a joint consultation (2 patients per clinic). They have their first appointment with the adult physician. Either the paediatric immunologist or the nurse practitioner joins the consultation.

Youngsters are taught about their disorder, how to be independent and responsible, as well as to collaborate with the clinician and their parents, resulting in better self-management.

Questionnaires are sent to youngsters in advance so that they have enough time to complete them. The purpose is to stimulate them and have them think about their priorities. They can talk about other topics than the usual ones, look for answers together with their family or friends. All this should help develop their training skills and gain confidence.

It is also important to include the parents in the transition plan because they are the ones supporting their youngsters. They can also help their youngster and the clinician to make the transition plan, especially handing over responsibility. In fact, parents might also need guidance during the transition process. A checklist for parents can also be useful.

At the transition clinic, the clinician speaks first alone with the youngster during the consultation. During this time, the youngster decides with the clinician what to tell the parents. Then the parent(s) are invited to join the consultation during the second half.