

Moving young people with rheumatic diseases from paediatric to adult care

This is the lay version of the EULAR recommendations for the transitional care of young people with juvenile-onset rheumatic diseases. The original publication can be downloaded from the EULAR website: www.eular.org.

Foster HE, et al. EULAR/PReS standards and recommendations for the transitional care of young people with juvenile-onset rheumatic diseases.

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Introduction

Recommendations give advice to doctors, other health professionals, patients and their families about the best way to treat and manage diseases. EULAR has written recommendations in partnership with Pediatric Rheumatology European Society (PReS) on the transitional care of young people with rheumatic diseases. Transitional care means moving young people from their childhood paediatric healthcare team into healthcare systems that look after adults.

The recommendations were written by adult and paediatric doctors from rheumatology, young people with rheumatic diseases as well as allied health professionals who are expert in transitional care. They looked at the evidence on the movement of young people with rheumatic diseases. They also discussed their expert opinion to achieve a level of agreement.

What do we already know?

Rheumatic diseases that start in childhood can continue into adulthood, and young people with continuing disease are at risk of ill health. Adolescence and young adulthood is an important time in a person's life. Moving from paediatric to adult care can be difficult for young people, and support and education is needed to make sure that they continue to receive the care they need.

What do the recommendations say?

Overall, there are 12 statements or recommendations. Each recommendation is based on available scientific evidence or expert opinion. The more stars a recommendation has the stronger the evidence is and the more important it is that you and your doctor should follow it.

One star (*) means it is a weak recommendation with limited evidence.

Two stars (**) means it is a weak recommendation with some evidence.

Three stars (***) means it is a strong recommendation with some evidence.

Four stars (****) means it is a strong recommendation with a lot of evidence.

- **Young people and their families should have access to high-quality, co-ordinated transitional care in partnership with their doctor in order to address individual needs.***

Care should be about more than just medical treatment, and should be tailored to each individual patient's present and future needs. Important factors to consider include your psychological and social wellbeing, as well as future educational and work desires.

- **Transition should start as early as possible, either in early adolescence or soon after diagnosis in disease that starts in adolescent.*****

For young people with childhood-onset diseases, the transition process should ideally start by the age of 11 years, and no later than 14 years. This allows you to develop self-care skills and optimise your education and work. If you are diagnosed after the age of 14, your transition to adult care should start as soon as possible after diagnosis..

- **There must be direct communication between everyone during transition. Before and after transfer, there should be direct contact between the paediatric and adult rheumatology teams.***

There should be a network of adult and paediatric rheumatologists who work together to ensure early and proactive transition. Ideally, there should be a meeting between you, your family and the team. If this is not possible, the minimum communication should be two telephone calls between the adult and paediatric rheumatology teams - one before and one after your transition. Written copies of the calls should be shared with you and your family.

- **Individual transition process and progress should be documented and planned with the young person and their family.***

Ideally, there should be a written transition plan for each individual young person with rheumatic disease. These documents should support you in managing your disease, and direct you to a tailored selection of local services that may be useful. The inclusion of any sensitive medical information should be discussed with you. At a minimum, transition should be recorded in your medical records.

- **Every rheumatology service and clinical network must have a written transition policy that is updated regularly.***

There should be a written policy that details how young people will be transitioned from paediatric to adult care. Policy documents on transition services within a hospital or clinic must be updated every five years.

- **It should be clear who is on the transition team, including a designated co-ordinator.***

The transition team may include doctors, nurses, physical therapists, occupational therapists, and youth or social workers. This is sometimes called a multidisciplinary team or MDT. It is essential that there is a nominated person on the team who takes responsibility for your team's co-ordination.

- **Transition services must be focused on and appropriate for the young person.***

Young people may need access to specialised healthcare. It is also important to tailor staff attitude and communication to ensure care is age-appropriate. Care should be organised to minimise the impact on your daily life. The aim of the service is to enable you to take control of the management of your disease, instead of relying on a parent or carer.

- **There must be a transfer document.***

The format of the transfer document should be agreed by paediatric and adult teams. As a minimum, it should include your diagnosis and a summary of past and current treatment, as well as your ability

to manage pain. The document should also include details of any complications or other diseases you may have. Finally, it should give an overview of your educational or work status.

- **Teams involved must have appropriate training in both rheumatic diseases in childhood, and generally how to look after adolescents.***

The people working on your transition team should know about rheumatic diseases in childhood, including how they are diagnosed and treated. They should also understand general health issues for adolescents, and how this might affect your rheumatic disease. Team members should be trained to address any emotional, mental or social issues you may have, and should be able to help you achieve a healthy lifestyle.

- **There must be secure funding for transition services for young people entering adult care.***

The transition care you receive should be decided based on your individual need, and not solely on your age or availability of funding. Health professionals and researchers should try to ensure that there is designated funding to support young people moving from paediatric to adult care.

- **There must be a freely accessible electronic platform where resources for transitional care can be found.***

Both you and your doctor can find useful resources and trustworthy information about transition on the EULAR (European League Against Rheumatism) and PReS (Paediatric Rheumatology European Society) websites. These resources are freely available and are endorsed by professional groups and charities.

- **Increased knowledge is needed to improve outcomes for young people with childhood-onset rheumatic diseases.***

Research is still needed to help improve the care of young people with rheumatic diseases. This includes transition, and how to measure the success of the process.

Summary

Overall, the recommendations say that it is important for young people and their families to work with their doctor and their wider healthcare team to minimise the impact of transition, and to get the best possible support and care. If you or someone in your family has a rheumatic disease from childhood, these recommendations will give you tips about what to expect through adolescence and early adulthood.

If you have any questions or concerns about your disease or your treatment, speak to your doctor.