

IMMUNOGLOBULIN REPLACEMENT THERAPY FOR PRIMARY IMMUNODEFICIENCY: RECOMMENDATIONS FOR MOVING FROM PAEDIATRIC TO ADULT CARE

The transition from paediatric to adult care is a big step for young adults. This is especially so if you have a chronic condition, such as a primary immunodeficiency (PID). Taking steps early on to prepare can go a long way to making the transition a smooth and positive experience, and ensuring you get the best care possible.

This fact sheet highlights important considerations as you prepare to take responsibility of your own care and provides helpful resources to navigate the transition.

PIDs and immunoglobulin replacement therapy

PIDs are a group of rare, chronic disorders that weaken the immune system and increase your chances of serious infections and other complications. They occur when components of your immune system called immunoglobulins (Ig, or antibodies) don't work properly.

Immunoglobulin replacement therapy (IRT) is the main treatment for PIDs and helps to protect you from infections and reduces some symptoms. IRT replaces the Ig (antibodies) – the proteins in the blood that your body should be making to help fight infections and diseases. Because the effect of IRT is temporary, it must be given regularly and is usually life-long.

Moving from child to adult care

The main difference between child and adult healthcare is that, as an adult, you are the main person communicating with your doctor and making your healthcare decisions. You will become responsible for:

- ▶ managing your own appointments,
- ▶ managing your own medications, and
- ▶ arranging Medicare, private health insurance and managing payments.

During the early months of the transition, you may feel overwhelmed by the amount of information and responsibility. Remember, you are always welcome to ask for help or bring a friend or family member to your appointments.

Finding a new doctor

Ask your current doctor if they have any suggestions for adult immunologists in your local area. Once you have picked someone, your doctor will send a referral and medical summary introducing you, and detailing your condition and treatment, to your new doctor. From there, all you need to do is call to set up your first appointment.

FAQs

When should I start thinking about the transition?

The best age to move to adult care is different for each person. The earlier you begin to think about the transition, the more prepared you will be for the changes in your care. Beginning to plan your transition in your early teens will give you time to become familiar with your condition and treatment, ask questions, and become confident managing your own healthcare.

Will I need to change doctors?

As a young person, you were most likely seen by a paediatrician, who is trained to care for infants and children. As you grow older, you are likely to have healthcare needs that you didn't have as a child. An immunologist who treats adults will be better equipped to understand your situation and provide you with the best care possible.

How can I manage my healthcare information?

This transfer guidance together with the NPS MedicineWise [Immunoglobulin management and wellbeing plan](#) provide a place for you to record key details about your condition and treatment. Store one copy of each plan in a safe place and carry another one with you to your appointments.

You can also use the NPS MedicineWise app to manage your appointments and other essential health information:

<https://www.nps.org.au/medicinewiseapp>

Healthcare skills checklist

Having a clear understanding of your condition and treatment and knowing how to independently manage your healthcare will make the transition from child to adult care smoother.

Think about how confident you are with the following items. Tick any that you are unsure about and make sure to discuss these with your family or healthcare team.

My health	My healthcare
<input type="checkbox"/> I understand what my condition is and can describe it to others	<input type="checkbox"/> I know what to do if I have a medical emergency
<input type="checkbox"/> I understand my treatment and treatment plan	<input type="checkbox"/> I know who to call if I have non-urgent medical questions or concerns
<input type="checkbox"/> I know the names of my medications, when to take them, and what they are used for	<input type="checkbox"/> I can complete medical forms
<input type="checkbox"/> I know the common and serious side effects from my treatments	<input type="checkbox"/> I know who my GP and immunologist are and can make my own medical appointments
<input type="checkbox"/> I know my allergies and actions to take if I have an allergic reaction	<input type="checkbox"/> I know when my next appointments are
<input type="checkbox"/> I am comfortable administering my own subcutaneous immunoglobulin (SCIg, if applicable)	<input type="checkbox"/> I know the details of my Medicare card and any private health insurance
	<input type="checkbox"/> I am comfortable discussing my health, asking questions, and communicating concerns

Record your questions or concerns in the space below:

Tips for preparing for the transition

- ▶ Ask your current doctor to explain information you do not understand
- ▶ Make your first appointment with your new doctor and note their location and contact details
- ▶ Ensure your referral and medical summary are current
- ▶ Keep a record of your treatments, medications, and allergies
- ▶ Write down a list of questions or concerns before seeing your new doctor
- ▶ Bring your Medicare card or card details to the appointment

Where to find support

Managing a chronic health condition can be challenging, but **you are not alone**. Local support groups can provide social, emotional, educational, and advocacy support, and can connect you to others with similar experiences.

- ▶ The Australian Society of Clinical Immunology and Allergy provides resources for patients, consumers, and carers: <https://www.allergy.org.au/patients/information>
- ▶ Immune Deficiencies Foundation Australia provides education, awareness, and advocacy on PIDs: <https://www.idfa.org.au/>
- ▶ AusPIPS provides advocacy and support for people living with PID: <https://www.auspips.org.au/>

More information

- ▶ NPS MedicineWise Immunoglobulin replacement therapy for PID: <https://www.nps.org.au/pdf-ig-immuno-factsheet-pid-and-role-of-ig>
- ▶ NPS MedicineWise Consumer Immunoglobulin management and wellbeing plan: <https://www.nps.org.au/pdf-ig-management-plan>
- ▶ NPS MedicineWise – Immunoglobulin consumer web hub: <https://www.nps.org.au/immunoglobulins#consumers>
- ▶ NPS MedicineWise - Immunoglobulins and me: Patient stories: <https://www.nps.org.au/immunoglobulins/communication-videos>
- ▶ National Blood Authority - Patient resources: <https://www.blood.gov.au/patient-factsheets-and-resources>

VALUE IN PRESCRIBING PROGRAM – IMMUNOGLOBULIN PRODUCTS

Increasing the awareness and understanding amongst health professionals of access to immunoglobulin products in Australia, and improving health outcomes for patients through access to better health information to manage their health conditions. Funded by the Australian Government Department of Health through the Value in Prescribing Program: Immunoglobulins Products Grant.

