A GUIDE TO TRANSITIONING FROM PAEDIATRIC TO ADULT CARE



TRANSITIONING FROM PAEDIATRIC TO ADULT CARE

The transition from paediatric to adult care is a significant milestone if you've been living with a pituitary condition from an early age. This fact sheet outlines key differences between paediatric and adult care systems and provides tips for a smooth transition.

KEY DIFFERENCES IN THE APPROACH TO CARE

Paediatric care

Paediatric care is typically family-centred, with parents or guardians heavily involved in decisionmaking and care coordination. In the paediatric setting, appointments often involve parents being present for most or all of the appointments. Health professionals will also usually direct most questions to the parents.

A paediatrician may coordinate multiple aspects of your healthcare and refer you to various healthcare providers. Parents or guardians usually make the appointments, help with day-to-day management of your condition, and advocate for you and your care.

Adult care

As you transition to adult care, you'll be expected to take charge of your own healthcare decisions and management. A General Practitioner (GP) will coordinate your care, but you will need to make the appointments with different healthcare providers yourself. Adult care adopts a patient-centred approach where you will be the prime person responsible for managing your care.

You can find health professionals for your needs by asking your Paediatric specialists, GP and researching yourself to find suitable health professionals. While you are still welcome to bring other people to your appointments, you will be expected to answer questions and explain your medical history yourself. If you have any questions about your condition or care, you will need to ask them yourself.

You may find that most adult specialists will only take over care after turning 18 years of age.

THE CARE TEAM: PAEDIATRIC VS ADULT

The types of health professionals you will see for your care are likely to change over the course of your life.

The main difference when you transition into adult care is that you will no longer see healthcare professionals who work with children (e.g. paediatric endocrinologist, paediatrician, paediatric nurse specialist or child psychologist). Instead, you will see practitioners who care for adults.

TIPS FOR A SMOOTH TRANSITION

Moving from paediatric care to adult care may feel overwhelming, but there are things you can do to make the transition as smooth as possible.

Start preparing early

When you're around 14-16 years, gradually take more responsibility for your healthcare. You can do this by booking your own appointments and managing your medications.

Ask about transition services

Check with your paediatric team whether they have a transition coordinator or service that can help you to move to adult services. Many hospitals have access to these types of services and they can be very helpful.

Find a good GP

Having a positive relationship with a General Practitioner (GP) is crucial for managing your overall health as an adult, particularly if you have a pituitary condition. You can ask for a referral to a GP or check local directories. If you're not comfortable with one GP you have the right to change doctors and find one you're happy with.

Find a good specialist if needed

There are many specialists, but you may want to seek one that has some experience in your type of condition. Having a positive relationship with a GP and a specialist is important for your future health journey. Talk to your current paediatric team and GP to gather information about specialists they may be familiar with. You can also search the internet to find information about health professionals bios and medical interests.

Practice solo appointments

Practice having solo or partial solo appointments with your doctor to build confidence in communicating with healthcare providers without your parents in the room.

Keep medical records

Take responsibility for your own medical records such as medical history, medications, and allergies. This information will be crucial when transitioning to new healthcare providers.

Familiarise yourself

If you'll be seeing doctors in a different healthcare clinic, familiarise yourself with the service before your first appointment. This may involve visiting the clinic, working out how to get there, where to park, and where you need to check in.

Understand your condition

It's important you fully understand your pituitary condition and any specific needs you may have as an adult. This knowledge will help you manage your condition and advocate for yourself in the adult healthcare system.

Learn symptoms to be aware of

Ask your paediatric endocrinologist, or endocrinology nurse if you have one, to go through each of your diagnosis or hormone deficiencies and the medication you take for each one. Discuss the signs and symptoms you may experience if you need a dose adjustment, so you know to report these to your adult endocrinologist once you have transitioned.

Manage your medications

Learn how to take medicines on your own and what to do when you run out. In adult care, you'll be expected to manage your own treatment, including getting your medication from the pharmacy.

Get financial

Once you move into adult care, you'll need to know how to pay for your appointments. You'll also need your own Medicare card and private health insurance card if you have insurance.

Ask questions

Talk to your paediatric team about the transition process and what you can expect. Some hospitals may have specific transition clinics or services to support this process.

Don't be afraid to ask questions if you don't understand something or want further information. After all, it is your health. All healthcare providers should explain information in a way you can understand, no matter how old you are.

Remember, you don't have to transition in one go. A successful transition process is gradual and should be tailored to your individual needs. Your new adult healthcare team should have expertise in managing pituitary conditions in adults, so don't hesitate to ask about their experience with your specific condition.

MORE INFORMATION

The Australian Pituitary Foundation provides social support for patients and carers, and has published a range of patient resources on pituitary conditions and treatments.

For more information, please visit our website: www.pituitary.asn.au

Email: support@pituitary.asn.au

Phone: 1300 331 807

Acknowledgement – We are grateful to the members of the Australian Pituitary Foundation for reviewing this information.

Disclaimer – The information in this guide, whether provided by the Australian Pituitary Foundation or a third party, is provided as a general guide and is not intended to replace professional health advice. Please consult your endocrinologist if you have any concern about your treatment or are experiencing side effects. The Australian Pituitary Foundation, nor a third party, does not accept liability for any injury, loss or damage incurred using or relying on the information in this production.

This fact sheet is proudly endorsed by:



E N S A Endocrine Nurses' Society of Australasia Inc.