

# Moving on to Royal Perth Hospital

## A guide for young adults with metabolic disorders transitioning from Perth Children's Hospital (PCH)

This Health Fact is designed to help you with your transition to the metabolic team at Royal Perth Hospital (RPH).

While transition is an important step, some young people may find it daunting to leave what is familiar, getting to know a new team and hospital as well as taking responsibility for their own care.

Most young people will transition to RPH towards the end of Year 12 or equivalent. The RPH team is dedicated to providing you with continued high quality care. Before you transition, you will be introduced to the RPH team at least once at PCH.

### What can I expect when I first visit RPH?

The clinics are held weekly on a Monday afternoon in the Outpatient Clinic on Goderich Street, East Perth. The nearest train station is McIver Station and the Red Cat bus stops just outside the entrance. Parking is available in the multistorey car park at the back of RPH (access is from Lord Street).

Your appointment time will be mailed to you and you will receive a text message reminder. Please bring your Medicare card to every appointment. If you are unable to attend, please call the Outpatient Clinic direct on 1300 855 275.

It is your responsibility to inform the clinic if you cannot attend or need to reschedule your appointment.

The metabolic team at RPH consists of Associate Professor Damon Bell, Dr Kharis Burns, Catherine Manolikos and Bianca Vescovo, Senior Dietitians. It is helpful for the team to see you on your own initially and then with your parents, as we do at PCH. Over time, we find that most young people prefer to be seen alone. However parents, partners and friends are always welcome to attend, for as long as you wish.

### How do I get my medications?

Most medications, including specialised metabolic nutritional supplements, are available from your local pharmacy. The doctor can supply you with a prescription at your appointment; however, your GP will supply you with most prescriptions.

### What happens if I get sick?

If you feel unwell, follow your personalised sick day plan. If you continue to feel unwell and think you may need an admission, present to the Emergency Department at your nearest hospital. The hospital you visit can contact PCH or RPH for advice on



management of your condition if necessary. Make sure to take your personalised sick day plan and specialised nutritional supplements if possible. Once you have been seen at RPH they will take over your care and you will be provided with a new Sick Day Management Plan and information about what to do if you are unwell.

## Transition information

It is important that you:

- start to make your own appointments
- see the clinic doctor on your own
- obtain your own Medicare card
- know the name of your metabolic condition and how it affects you
- recognise when you are sick and know what to do
- have a group of friends who know you have a metabolic condition and know what to do if you are sick
- Carry a copy of your sick day plan at all times, you may consider saving it on your phone or email it to yourself for easy access, or carry a hard copy
- know about your medications or supplements – what they do, how they work and why you need to take them
- organise to get more medications or supplements
- have a GP that you visit who knows about your metabolic condition
- have someone to talk to if you are worried or feeling down
- make plans for future education and employment
- Understand that leaving PCH is part of your journey into adulthood.
- You may continue to call the on call metabolic physician at PCH until your first appointment at RPH.

## Information for parents

The teenage years are a time of exciting challenges and changes. Part of your teenager's journey to becoming a healthy and independent young adult will involve them learning to take responsibility and mastering the tasks that build independence. Every teenager will achieve this at a different pace; there is no one time frame that suits everyone.

We hope this information can support you and your teenager during the transition period. You may struggle with 'letting go' and promoting your teenager's independence – this is understandable. Please feel free to discuss the transition at depth at your appointments with PCH metabolic team.

The PCH Metabolic team wishes you and your teenager the best of health for the future.



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