

Tips for people with cerebral palsy and those who support them in healthcare

To stay healthy, it is important to take a proactive approach to healthcare wherever possible. The following are some ideas to ensure the time and information is available at your appointment with your doctor to enable provision of the best health care.

Time

Doctors' appointments are usually booked every 10 minutes or so. This is often not enough time if you have:

- Complex multiple or health issues to discuss;
- Paperwork that needs to be filled out; and/or
- Difficulty communicating.

It is therefore helpful to book a **double appointment** with your General Practitioner (GP) to allow for the extra time required.

It is often hard to remember everything at the time of an appointment. So prepare for the appointment by **writing down the points to be covered** during the visit, including any prescriptions that are required so you make the best use of the time available.

Your doctor

- **We are all individuals** with different personalities, priorities, support networks, interests, abilities and disabilities. Likewise, cerebral palsy impacts on everybody differently and individuals have a different range of health issues, both related and unrelated to cerebral palsy.
- **It takes time for your health professionals to get to know you**, particularly if you have difficulty communicating. That's why it's important to build a relationship with one doctor or medical practice and stay with them over time (when possible) to enable them to know you and work with you to achieve and maintain your best possible health.
 - Stay with one GP or at least in the same GP practice whenever possible.
 - Arrange regular medical reviews – perhaps every one to six months, depending on your health. This ensures you and your doctor have the time to talk about how to avoid disease and stay well, rather than just treating illness when you are sick.
 - Sign privacy forms to enable your GP to be notified if you are admitted to hospital.
 - Request that your GP is sent a Discharge Summary outlining the details of what you were in hospital for and what treatments were given, whenever you go into hospital – even for a day procedure.
 - Ask other doctors and health professionals that you see to write to your GP, to keep your GP up-to-date with information about your health and healthcare.
 - Ask that copies of any test results are sent to your GP (e.g. blood tests, X-rays etc).

Your medications

- **Keep an up-to-date list** of current medications in paper form or on your smart phone and share this with all the doctors involved in your care.
- **Keep a record of prescriptions** with the numbers of repeats remaining so you don't run out.
- **Useful apps** for keeping your medication list up to date include:
 - www.nps.org.au/medical-info/consumer-info/keeping-a-medicines-list
 - www.medadvisor.com.au/Home/Landing

Your pharmacist

Using one pharmacy enables the pharmacist to have a list of your medications and inform you of medication effects and possible interactions, so use one community-based or hospital-based pharmacy whenever possible.

Your medical history

Most people with cerebral palsy see many different doctors, therapists and other health professionals over their lifetime. Your doctors will change over time and you may move to a different area. It is therefore really important that you have a copy of all important information and reports about your health so you know what's going on, and so you can share it with your current healthcare team.

- When you see a doctor or other health professional, **ask for a copy** of the letter or report that is sent to the GP.
- **Request copies of any test results**, including blood tests or X-rays.
- **Keep an up-to-date list** of all significant medical and surgical procedures or consider keeping a brief medical history. This saves a lot of time if you are admitted to hospital or if you are seeing a new specialist (could be as easy as a Word document stored on your computer or on a USB).
- If you have a complex medical history, **write a few notes after each appointment** and keep it on your smart phone or in a folder. You can also share this with your health care professional. Include details such as date, who you saw, one or two dot points about the appointment, what treatment or test was recommended, and what the next step is (for example: Sep 30, saw GP - Dr Walsh, discussed back pain, MRI ordered, I need to book appointment for MRI and see Dr Walsh for results one week later).

These resources are designed to support General Practitioners in the care of their patients with cerebral palsy. They were developed in partnership by The Royal Children's Hospital; the Centre for Developmental Disability, Monash Health; and Murdoch Children's Research Institute. The project was funded by an Avant Quality Improvement Grant 2017.