

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.

Your appointments

The importance of keeping in touch regularly with your healthcare practitioner cannot be overemphasized and is an important aspect of the whole management of cerebral palsy. It is a condition which requires regular monitoring and timely intervention throughout life.

Never miss an appointment. If you do, be sure to book the next appointment as soon as you can.

Always inform the healthcare practitioner about any changes in your contact details including address, email address and telephone number, so that you can keep in contact with all of your health professionals and receive copies of reports and correspondence. Request a copy for yourself also.

If you are moving to a new area let your healthcare practitioner know so they can arrange for your care and management to be transferred to professionals in the new area and forward the necessary records.



Cerebral palsy is a condition which requires regular monitoring throughout life. Build a strong relationship with your healthcare professionals.

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 healthcare practitioner 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 and function.

- Stay with one healthcare practitioner 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 healthcare practitioner to be notified if you are admitted to hospital.
- Request that your healthcare practitioner 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 healthcare practitioner, to keep your healthcare practitioner up-to-date with information about your health and healthcare.

These resources are designed to support healthcare practitioners in the care of their patients with cerebral palsy in Australia. They were developed in partnership by The Royal Children's Hospital; the Centre for Developmental Disability, Monash Health; and Murdoch Children's Research Institute. They have been amended for use by healthcare workers globally in partnership with IAACD. The initial project was funded by an Avant Quality Improvement Grant 2017.



Keep an up-to-date list of the medications that you take, and all significant medical and surgical procedures.

Your therapist

Your physiotherapist is probably your most frequently encountered healthcare professional. Time spent with your physiotherapist provides an opportunity for you to discuss your health condition on a regular basis

- Be sure to inform your therapist about any difficulties or pain that you may have while in the session or at home
- Keep a notebook or ask for a copy of exercises or activities to be followed at home lest you should forget them
- Therapists usually have goal oriented objectives. You should agree to any short or long term goals and you should feel free to suggest them yourself. Remember it is always teamwork which achieves the best results.

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

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 healthcare practitioner.
- **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 healthcare practitioner - Dr Walsh, discussed back pain, MRI ordered, I need to book appointment for MRI and see Dr Walsh for results one week later).