Welcome

Welcome to the *Family Handbook for Neurosciences* – a resource designed to assist patients and their families at the Lady Cilento Children's Hospital.

You are probably reading this handbook because your child has been diagnosed with a serious neurological condition. You are not alone. Our hospital provides care for more than 2,500 children and young people with neurological conditions every year. These patients may be diagnosed with epilepsy, neuromuscular disorders or other serious conditions affecting the brain or nervous system. Many of these cases are complex and will require multiple hospital visits over many years with the involvement of medical, allied health and other staff from across Children's Health Queensland.

Visiting the hospital can initially feel overwhelming, however as you start to understand more about your child's condition, meet with clinicians and find your way around wards, outpatient clinics and service areas everything will seem less daunting. This publication is designed to help you navigate hospital processes, understand your child's treatment and, most importantly, learn more about the support, help and services we provide. It will also empower you through providing information so you can work collaboratively with our specialist staff to ensure the best health outcomes for your child.

I encourage you to read this handbook and discuss its contents with your consultant neurologist, nurse or any other member of your child's health care team. You can also add any extra fact sheets or other helpful information into this handbook.

This publication was developed in partnership with families who use the neurology service and demonstrates our commitment to the values of respect, integrity, care and imagination. We hope you find it useful and that your family feel supported and informed throughout your child's health care journey at the Lady Cilento Children's Hospital.

Fionnagh Dougan
Chief Executive
Children's Health Queensland

Acknowledgements

Consumers: Mel Gourley, Sue Hogan, Hazel Lloyd, Gillian Ruddell and Kirsty Wardle.

Children's Health Queensland acknowledges and pays respect to the traditional custodians of the lands on which we walk, work, talk and live. We also acknowledge and pay our respect to Aboriginal and Torres Strait Islander Elders both past and present.

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Section 2: Patient records

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Section 1

Patient information

Family information

Patient's details

Child's name:

Nickname:
Date of birth:

Medicare number:

Heathcare card:
Hospital UR:

Legal guardian details

Legal guardian/s:

Family/carer details

Mother's name:

Address:

Home phone:
Work phone:

Father's name:

Address:

Home phone:
Work phone:

Carer's name:

Address:

Home phone:
Work phone:

Sibling 1 name:
Date of birth:

Sibling 2 name:
Date of birth:

Sibling 3 name:
Date of birth:

Key diagnoses

After hours and emergencies

After hours

If you are worried about your child's medical condition after hours please call the hospital switchboard on 3068 1111 and you will be transferred to the appropriate medical officer.

In emergencies call for an ambulance on 000.

Regional centre contact details

Home town general practitioner (GP) or local paediatrician

Name: Phone:

Services provided/current shared care arrangements:

Closest medical facility

Phone:

Services provided/current shared care arrangements:

Regional hospital

Contact: Phone:

Services provided/current shared care arrangements:

Clinical nurse consultant (CNC) or clinical nurse (CN)

Name: Phone:

Interpreter information

Please point to your language and we will arrange an interpreter for you, free of charge.

العربية *Arabic*

الرجاء أن تشير إلى لغتك التي تتحدثها. وسوف نرتب لك لحضور مترجم فوري مجانا.

বাংলা *Bangla (Bengali)*

অনুগ্রহ করে আপনার ভাষা উলেখ করুন । আমরা বিনামুল্যে একজন দোভাষীর ব্যবস্থা করব ।

မြန်မာ *Burmese*

သင်ပြောသည့်စကားကို လက်ညှိုးထိုးပြီး ညွှန်ပြပါ။ အခကြေးငွေ မယူဘဲ စကားပြန် တစ်ယောက် ခေါ်ပေးပါမည်။

廣東話 *Cantonese*

請指出您的語言。我們將免費為您安排口譯員。

دری *Dari*

لطفاً نشان دهید لسان شما کدام است. ما برای شما یک ترجمان بطور رایگان تهیه میکنیم

Thoŋ muɔnyjääŋ *Dinka*

Nyoth thuɔŋdu.ok abï ran war yï thok guir tënë yïn ke cïn guruc (wëu) täu piny.

فا رسی *Farsi (Persian)*

لطفا زبا نی را که به آ ن صحبت میکنید با انگشت نشا ن دهید. ما بطور را یگا ن ترتیب حضور مترجم میدهیم

Vaka Viti *Fijian*

Dusia na nomu vosa ena nomui qaqalo. Ketou na vakarautaka edua na daunivakadewa ena sega ni saumi.

Filipino *Filipino*

Paki-turo mo kung alin ang iyong wika. Mag-aayos kami ng walang bayad na tagapagsalin sa wika.

Français *French*

Désignez-nous votre langue. Nous vous fournirons gratuitement un interprète.

हिन्दी *Hindi*

कृपया अपनी भाषा इंगित करें। हम एक दुभाषिए का बंदोबस्त करेंगे और आपको इसका कोई शुल्क भी नहीं देना पड़ेगा।

Hmoob *Hmong*

Thov taw tes rau koj yam lus. Peb mam li nrhiav neeg pes lus rau koj, tsis raug nqi dab tsi li.

Bahasa Indonesia *Indonesian*

Silahkan menunjuk ke bahasa Anda. Kami akan memanggil seorang penerjemah bagi Anda secara cuma-cuma.

日本語 *Japanese*

スタッフにあなたの母国語を知らせてください。通訳を無料で手配いたします。

ភាសាខ្មែរ *Khmer*

សូមចង្អុលទៅភាសារបស់លោកអ្នក។ យើងខ្ញុំនឹងរៀបចំចាត់ចែងរកអ្នកបកប្រែជូន ដោយឥតគិតថ្លៃ។

한국어 *Korean*

여러분의 해당 언어를 손가락으로 지적해 주십시오. 무료로 통역사를 예약해 드리겠습니다.

Bahasa Melayu/Malaysia *Malay*

Sila pilih bahasa anda. Kami akan menyediakan perkhidmatan penterjemah secara percuma.

中文 *Mandarin*

请指出您的语言。我们将免费为您安排口译员。

Kuki Airani Maori *Maori*

Tou mai i toou reo, ka tuku atu matou i tetai tangata uri reo noou, kare e tutaki.

Tok Pisin *PNG Pidgin*

Plis soim tokples blong yu. Bai mipela i painim wanpela man o meri long halipim yu. Dispela em i fri sevis.

Português *Portuguese*

Favor indicar seu idioma. Nós arranjaremos um intérprete de graça.

Gagana Samoa *Samoan*

Faamolemole faasino mai lau gagana. Ole a matou sailia se faamatalaupu mo oe e aunoa ma se totogi.

Српски *Serbian*

Молим вас покажите ми свој језик. Организоваћемо вам бесплатно тумача.

සිංහල *Sinhalese*

කරුණාකර ඔබගේ භාෂාව පෙන්වන්න. අපි ඔබ සඳහා අය කිරීමකින් තොරව, භාෂා පරිවර්තකයෙකු ලබා දෙන්නෙමු

Español *Spanish*

Indique por favor su idioma. Le conseguiremos un intérprete sin coste.

Kiswahili *Swahili*

Tafadhali onyesha lugha yako kwa kidole. Tutakuandalia mkalimani wa kukusaidia bure (yaani bila malipo).

தமிழ் *Tamil*

உங்கள் மொழியைக் குறிப்பிடவும். நாம் இலவசமாக உரைபெயர்ப்பாளரை ஒழுங்கு செய்வோம்.

ไทย *Thai*

โปรดชี้ไปที่ภาษาของท่าน เราจะจัดหาล่ามให้ท่านโดยไม่ คิดมูลค่า

Faka-Tonga *Tongan*

Kataki ‘o tuhu ki he Lea Faka-Tonga. Te mau lava ‘o ‘omai ha fakatonulea pea ‘e ‘ikai totongi.

Türkçe *Turkish*

Lutfen kendi dilinizi belirtiniz. Sizin için ücretsiz bir tercüman temin edeceğiz.

اردو *Urdu*

مہربانی کرکے اپنی زبان کی طرف اشارہ کیجیے۔ ہم آپ کے لیے ترجمان کا مفت انتظام کریں گے۔

Tiếng Việt *Vietnamese*

Hãy chỉ ngôn ngữ của quý vị. Chúng tôi sẽ sắp xếp một thông dịch viên miễn phí.

Medical records

A confidential record will be kept of your child's medical treatment while they are under the care of Children's Health Queensland at the Lady Cilento Children's Hospital. This record is identified by a unique number that is assigned to your child. Only Children's Health Queensland employees who are directly involved in your child's treatment will have access to this record. You have the right to apply for access to your child's medical record under the *Information Privacy Act 2009* and the *Right to Information Act 2009*. If you would like to access your child's medical record after discharge, please contact our Health Information Access team on 07 3068 5935.

Patient privacy

Queensland Health is committed to protecting the privacy of patients, and Children's Health Queensland and the Lady Cilento Children's Hospital is required by law to protect personal information. For more information or a copy of the *Respecting Your Privacy* brochure, contact the Health Information Access team on 07 3068 4842 or email CHQ_HIA@health.qld.gov.au

Parents/carers also have a role to play in respecting the privacy of other children and families in the hospital. Please be conscious of other parents' wishes and whether they wish to talk about their child's condition.

Tell us if you think something is wrong

Your child's safety is our top priority. If at any stage you feel their clinical condition is getting worse or they are not improving as expected, speak to a staff member immediately. Please do not hesitate to speak to us if you have any concerns or questions. You know your child better than anyone else and we value that knowledge and your involvement as a member of their care team. If, after raising your concerns with our staff, you're still not satisfied with the answers or response we've provided, you can choose to use Ryan's Rule.

Ryan's Rule is a simple three-step process that gives patients, parents, family members and carers a way to escalate any concerns they have about a child's clinical condition while they are in hospital.

Ryan's story

Ryan Saunders was nearly three years old when he tragically died in hospital. His death was found to be in all likelihood preventable. Staff did not know Ryan as well as his mum and dad knew him.

When Ryan's parents were worried he was getting worse they didn't feel their concerns were acted on in time. In memory of Ryan, and to reduce the chance of something like this happening again to any patient, the Department of Health introduced Ryan's Rule to hospitals throughout Queensland.

Ryan's Rule – three steps to follow

1: Talk to your child's treating nurse or doctor about your concerns.

2: If you are not satisfied with the response, ask to speak with the nurse in charge of the shift.

3: If you are still concerned, call a Ryan's Rule – dial **13 HEALTH** (13 432 584). Give your name, ward and bed number.

Patient rights

The Australian Charter of Healthcare Rights lists seven basic healthcare rights:

1. **Access –** You have a right to healthcare
2. **Safety –** You have a right to safe and high quality care
3. **Respect –** You have a right to respect, dignity and consideration
4. **Communication –** You have a right to be informed about services, treatment, options and costs in a clear and open way
5. **Participation –** You have a right to be included in decisions and choices about your/your child's care
6. **Privacy –** You have a right to privacy and confidentiality of your personal information
7. **Comment –** You have a right to comment on your care and have your concerns addressed

Please ask staff if you have any questions about your rights in hospital.

Patient-centred care is our priority

The Lady Cilento Children's Hospital places children and their families at the centre of everything we do. As part of this holistic and patient-centred approach, our hospital has adopted the internationally-recognised Planetree model of health care. The model emphasises personalising, demystifying and humanising the patient experience and prioritises making information available to health care consumers.

The Planetree philosophy involves caring for each person as an individual and recognises their unique mental, social, emotional, spiritual and physical care needs. Research shows that organisations using this patient-centred approach deliver improved clinical outcomes such as:

- reduced length of stay
- improved patient satisfaction
- decreased infection rates
- decreased readmission rates
- decreased mortality.

Our hospital is implementing the Planetree model as we continue to focus on providing the best possible health care experience for our patients, and their carers and loved ones.

Tell us how we’re doing

We welcome feedback from families and are committed to working with you to continually improve the care and services we provide. Your feedback, both good and bad, is important because it helps us deliver the best possible healthcare experience not only for you and your child, but for all the patients and families we care for. You can provide feedback by:

- speaking directly to the staff member who is caring for your child.
- asking a staff member for one of our ‘Tell us how we’re doing’ feedback forms. You can complete the form online or download it at **www.childrens.health.qld.gov.au/chq/get-involved/feedback**
- contacting our Patient Experience Improvement Officers by phone on 07 3068 1120 or by emailing CHQ_PatientExperience@health.qld.gov.au

Our patient experience improvement officers will work with you to address any concerns you have and whenever possible they will try to fix the situation immediately. If it requires further action, an investigation will be conducted and we will contact you to let you know what we have done to resolve the matter.

If you are not satisfied with our management of your complaint, you may contact the Office of the Health Ombudsman on 133 646 (133 OHO) or email info@oho.qld.gov.au

Section 2

Patient records

Please use the templates in this section to record your child's medical history. Copies of these templates can also be found on the Children's Health Queensland website, at **www.childrens.health.qld.gov.au/neurosciences**

Health care professionals – key contacts

Please use the spaces below to keep a record of the key health care professionals involved in your child's care such as your consultant neurologist, your GP, paeditrician, etc.

Name/job title:

Organisation: Phone:

Address:

Email:

Name/job title:

Organisation: Phone:

Address:

Email:

Name/job title:

Organisation: Phone:

Address:

Email:

Name/job title:

Organisation: Phone:

Address:

Email:

Name/job title:

Organisation: Phone:

Address:

Email:

Health care professionals *continued*

Please use the spaces below to keep a record of the key health care professionals involved in your child's care such as your consultant neurologist, your GP, paeditrician, etc.

Name/job title:

Organisation: Phone:

Address:

Email:

Name/job title:

Organisation: Phone:

Address:

Email:

Name/job title:

Organisation: Phone:

Address:

Email:

Name/job title:

Organisation: Phone:

Address:

Email:

Name/job title:

Organisation: Phone:

Address:

Email:

Health care professionals *continued*

Please use the spaces below to keep a record of the key health care professionals involved in your child's care such as your consultant neurologist, your GP, paeditrician, etc.

Name/job title:

Organisation: Phone:

Address:

Email:

Name/job title:

Organisation: Phone:

Address:

Email:

Name/job title:

Organisation: Phone:

Address:

Email:

Name/job title:

Organisation: Phone:

Address:

Email:

Name/job title:

Organisation: Phone:

Address:

Email:

Therapists

Please use the spaces below to keep a record of the therapists involved in your child's care such as your physiotherapist, occupational therapist, etc.

Name/job title:
Organisation:
Address:
Start date: Phone:
Email:

Name/job title:
Organisation:
Address:
Start date: Phone:
Email:

Name/job title:
Organisation:
Address:
Start date: Phone:
Email:

Name/job title:
Organisation:
Address:
Start date: Phone:
Email:

Therapists *continued*

Please use the spaces below to keep a record of the therapists involved in your child’s care such as your physiotherapist, occupational therapist, etc.

Name/job title:

Organisation:

Address:

Start date: Phone:

Email:

Name/job title:

Organisation:

Address:

Start date: Phone:

Email:

Name/job title:

Organisation:

Address:

Start date: Phone:

Email:

Name/job title:

Organisation:

Address:

Start date: Phone:

Email:

Service providers

Please use the spaces below to keep a record of community contacts and service providers involved in your child's care such as the school, respite agency, etc.

Contact person:
Organisation:
Address:
Phone:
Email:

Contact person:
Organisation:
Address:
Phone:
Email:

Contact person:
Organisation:
Address:
Phone:
Email:

Contact person:
Organisation:
Address:
Phone:
Email:

Service providers *continued*

Please use the spaces below to keep a record of community contacts and service providers involved in your child's care such as the school, respite agency, etc.

Contact person:
Organisation:
Address:
Phone:
Email:

Contact person:
Organisation:
Address:
Phone:
Email:

Contact person:
Organisation:
Address:
Phone:
Email:

Contact person:
Organisation:
Address:
Phone:
Email:

Appointment log

Date: Provider:

Reason seen/care provided:

Next appointment:

Date: Provider:

Reason seen/care provided:

Next appointment:

Date: Provider:

Reason seen/care provided:

Next appointment:

Date: Provider:

Reason seen/care provided:

Next appointment:

Appointment log *continued*

Date: Provider:

Reason seen/care provided:

Next appointment:

Date: Provider:

Reason seen/care provided:

Next appointment:

Date: Provider:

Reason seen/care provided:

Next appointment:

Date: Provider:

Reason seen/care provided:

Next appointment:

Appointment log *continued*

Date: Provider:

Reason seen/care provided:

Next appointment:

Date: Provider:

Reason seen/care provided:

Next appointment:

Date: Provider:

Reason seen/care provided:

Next appointment:

Date: Provider:

Reason seen/care provided:

Next appointment:

Appointment log *continued*

Date: Provider:

Reason seen/care provided:

Next appointment:

Date: Provider:

Reason seen/care provided:

Next appointment:

Date: Provider:

Reason seen/care provided:

Next appointment:

Date: Provider:

Reason seen/care provided:

Next appointment:

Clinics

Clinic name:
Specialist:
Address:
Phone:
Email:

Clinic name:
Specialist:
Address:
Phone:
Email:

Clinic name:
Specialist:
Address:
Phone:
Email:

Clinic name:
Specialist:
Address:
Phone:
Email:

Clinics *continued*

Clinic name:
Specialist:
Address:
Phone:
Email:

Clinic name:
Specialist:
Address:
Phone:
Email:

Clinic name:
Specialist:
Address:
Phone:
Email:

Clinic name:
Specialist:
Address:
Phone:
Email:

Medication log

Make a new entry when a medication is started, increased, decreased or discontinued.

Date	Current weight	Medication	Dosage	Frequency	mg/mcg/ concentration	Status			Reason for change/discontinuing	Response	Physician name and speciality
						Increase	Decrease	Discont.			

Medication log *continued*

Make a new entry when a medication is started, increased, decreased or discontinued.

Date	Current weight	Medication	Dosage	Frequency	mg/mcg/ concentration	Status			Reason for change/discontinuing	Response	Physician name and speciality
						Increase	Decrease	Discont.			

Monitoring – height, weight, blood pressure

Wheelchair weight:

Date: Height: Weight:

BP: Comments:

Date: Height: Weight:

BP: Comments:

Date: Height: Weight:

BP: Comments:

Date: Height: Weight:

BP: Comments:

Date: Height: Weight:

BP: Comments:

Date: Height: Weight:

BP: Comments:

Date: Height: Weight:

BP: Comments:

Date: Height: Weight:

BP: Comments:

Date: Height: Weight:

BP: Comments:

Date: Height: Weight:

BP: Comments:

Monitoring – height, weight, blood pressure

Wheelchair weight:

Date: Height: Weight:
BP: Comments:

Date: Height: Weight:
BP: Comments:

Date: Height: Weight:
BP: Comments:

Date: Height: Weight:
BP: Comments:

Date: Height: Weight:
BP: Comments:

Date: Height: Weight:
BP: Comments:

Date: Height: Weight:
BP: Comments:

Date: Height: Weight:
BP: Comments:

Date: Height: Weight:
BP: Comments:

Date: Height: Weight:
BP: Comments:

Tests

Date:
Procedure:
Reason for test:
Results expected by:
Results:

Date:
Procedure:
Reason for test:
Results expected by:
Results:

Date:
Procedure:
Reason for test:
Results expected by:
Results:

Date:
Procedure:
Reason for test:
Results expected by:
Results:

Date:
Procedure:
Reason for test:
Results expected by:
Results:

Tests *continued*

Date:
Procedure:
Reason for test:
Results expected by:
Results:

Date:
Procedure:
Reason for test:
Results expected by:
Results:

Date:
Procedure:
Reason for test:
Results expected by:
Results:

Date:
Procedure:
Reason for test:
Results expected by:
Results:

Date:
Procedure:
Reason for test:
Results expected by:
Results:

Medical/surgical procedures

Date: Procedure:

Results:

Comments:

Date: Procedure:

Results:

Comments:

Date: Procedure:

Results:

Comments:

Date: Procedure:

Results:

Comments:

Medical/surgical procedures *continued*

Date: Procedure:

Results:

Comments:

Date: Procedure:

Results:

Comments:

Date: Procedure:

Results:

Comments:

Date: Procedure:

Results:

Comments:

Bone health monitoring

Date: Result:

Comments:

Date: Result:

Comments:

Date: Result:

Comments:

Date: Result:

Comments:

Date: Result:

Comments:

Date: Result:

Comments:

Date: Result:

Comments:

Date: Result:

Comments:

Date: Result:

Comments:

Date: Result:

Comments:

Date: Result:

Comments:

Bone health monitoring *continued*

Date: Result:

Comments:

Date: Result:

Comments:

Date: Result:

Comments:

Date: Result:

Comments:

Date: Result:

Comments:

Date: Result:

Comments:

Date: Result:

Comments:

Date: Result:

Comments:

Date: Result:

Comments:

Date: Result:

Comments:

Date: Result:

Comments:

Behaviour diary

Date	Behavior *physical/verbal*	Eating changes	Sleeping changes	Potential triggers	Current medications	Comments

Behaviour diary *continued*

Date	Behavior *physical/verbal*	Eating changes	Sleeping changes	Potential triggers	Current medications	Comments

Seizure diary

Date	Time	Awake or asleep	How long	Triggers	Seizure description
				☐ illness ☐ missed medication ☐ other:________________	
				☐ illness ☐ missed medication ☐ other:________________	
				☐ illness ☐ missed medication ☐ other:________________	
				☐ illness ☐ missed medication ☐ other:________________	
				☐ illness ☐ missed medication ☐ other:________________	
				☐ illness ☐ missed medication ☐ other:________________	
				☐ illness ☐ missed medication ☐ other:________________	
				☐ illness ☐ missed medication ☐ other:________________	
				☐ illness ☐ missed medication ☐ other:________________	

Seizure diary *continued*

Date	Time	Awake or asleep	How long	Triggers	Seizure description
				☐ illness ☐ missed medication ☐ other:________	
				☐ illness ☐ missed medication ☐ other:________	
				☐ illness ☐ missed medication ☐ other:________	
				☐ illness ☐ missed medication ☐ other:________	
				☐ illness ☐ missed medication ☐ other:________	
				☐ illness ☐ missed medication ☐ other:________	
				☐ illness ☐ missed medication ☐ other:________	
				☐ illness ☐ missed medication ☐ other:________	
				☐ illness ☐ missed medication ☐ other:________	

Equipment suppliers/vendors

Please use the spaces below to keep a record of the vendors who provide equipment and supplies to assist in the care of your child.

Type of equipment/supplies:

Description: *(e.g. brand, size etc)*

Date obtained: Vendor:

Phone: Contact name:

Email:

Type of equipment/supplies:

Description: *(e.g. brand, size etc)*

Date obtained: Vendor:

Phone: Contact name:

Email:

Type of equipment/supplies:

Description: *(e.g. brand, size etc)*

Date obtained: Vendor:

Phone: Contact name:

Email:

Equipment suppliers/vendors *continued*

Please use the spaces below to keep a record of the vendors who provide equipment and supplies to assist in the care of your child.

Type of equipment/supplies:

Description: *(e.g. brand, size etc)*

Date obtained:	**Vendor:**
Phone:	**Contact name:**

Email:

Type of equipment/supplies:

Description: *(e.g. brand, size etc)*

Date obtained:	**Vendor:**
Phone:	**Contact name:**

Email:

Type of equipment/supplies:

Description: *(e.g. brand, size etc)*

Date obtained:	**Vendor:**
Phone:	**Contact name:**

Email:

Health summary

Date of birth:	Health issue/s:
Date of birth:	Health issue/s:
Date of birth:	Health issue/s:
Date of birth:	Health issue/s:
Date of birth:	Health issue/s:
Date of birth:	Health issue/s:
Date of birth:	Health issue/s:
Date of birth:	Health issue/s:

Health summary *continued*

Date of birth:	Health issue/s:
Date of birth:	Health issue/s:
Date of birth:	Health issue/s:
Date of birth:	Health issue/s:
Date of birth:	Health issue/s:
Date of birth:	Health issue/s:
Date of birth:	Health issue/s:
Date of birth:	Health issue/s:

Things I want to discuss

Use this sheet to list the things you want to discuss with your health care team at your next appointment.

Appointment with:

Date: Time: Phone:

Reminders:

☐ Results
☐ Concerns
☐ Forms
☐ Side effects
☐ Symptoms
☐ Prescriptions
☐ Referral
☐ Care plan
☐ Family needs
☐ Next appointment
☐ Travel insurance
☐ Appointment summary plan

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- ☐ Appointment summary plan

Section 3

Lady Cilento Children's Hospital

About our hospital

The Lady Cilento Children's Hospital in South Brisbane is the major specialist paediatric hospital for families in Queensland and northern New South Wales and is a centre for teaching and research.

At Children's Health Queensland, we're committed to providing safe, high-quality, family-centred care for children, young people and their families.

Our staff will help you and your child feel welcome, comfortable and safe during your stay.

We believe parents and carers play a vital role in the care of children and we aim to work in partnership with families. We acknowledge you know your child best and this knowledge is invaluable to staff.

Please don't hesitate to ask staff for information or help during your visit.

Patient and family services

Our partners

Children's Health Queensland has many charity and volunteer partners who provide fantastic support for patients and families. Learn more about partners at **www.childrens.health.qld.gov.au/partners** or, if you're looking for some on-site support for your child, check out our *Fun stuff for patients* page **www.childrens.health.qld.gov.au/lcch-fun**

Children's Hospital Foundation

The Children's Hospital Foundation and its dedicated volunteers (in green shirts or aprons) provide patient and family support, care programs, and fun activities and entertainment for children in hospital. This includes bedside play, pet therapy, special events and Juiced TV (check it out on the Patient Entertainment System or see **www.juicedtv.com.au**).

Foundation volunteers can help families find their way around the hospital, support parents and carers while their child is in theatre, and look after young babies so parents can have a break (ask about the Cuddle Carers program). For more information see **www.childrens.org.au**

All foundation volunteers wear identification badges.

Find out what's on at **www.childrens.health.qld.gov.au/lcch-events**

Family Resource Centre

The Family Resource Centre on Level 2, managed by the Children's Hospital Foundation, offers families computer and internet access, printing, phones, faxes, information on local support groups and services, health information resources, laptop and mobile charging points, an iPad loan service and a stroller loan service. The centre includes a lounge and play area.

A supervised play service is available for children up to the age of eight. Please note, parents and carers must remain on site at the hospital (if their child is aged three to eight) or stay at the Family Resource Centre (if their child is under three years). Capacity is limited to 10 children.

If the centre is unattended and you require assistance, please call 07 3068 1662 Monday to Friday, 8am-7.30pm and weekends, 9am-4pm.

Family Resource Centre (2a)

- Level 2 (near main reception)
- t 07 3068 4730
- 6am-8pm, seven days a week. Supervised play service: Monday to Friday, 9.30am-12noon and 3pm-5pm (subject to volunteer availability)

Clown Doctors

Clown Doctors roam around the hospital, visiting wards, outpatients and other areas to play and tell jokes. The clown doctors generally have fun with children, parents and staff, and inject some laughter and lighter moments into the usual hospital routines. Some of their procedures include 'laughectomies', red-nose transplants and, in severe cases, knock-knock therapy.

Ronald McDonald House Family Room

This room provides a quiet retreat for families to relax and eat, and is located next to 6c Neurosciences and Metabolic Outpatients. Services include lockers, a beverage bay with free tea and coffee, a microwave and sandwich toaster for preparing snacks, and a children's play area.

Ronald McDonald House Family Room

Monday to Friday, 8am-6pm
Weekends, 10.30am-5pm

Starlight Express Room

The Starlight Express Room on Level 6 provides an escape from the hospital environment for children and families. Captain Starlights offer fun and mayhem, alongside the latest computer games, movies, crafts and activities. If your child is an inpatient, please ask your nurse if it is safe for your child to leave the ward to visit the Starlight Express Room. Children under eight must be accompanied by a parent/carer at all times.

Starlight Express Room

Monday to Friday, 9am-4.30pm
Saturday, 11am-4pm
Sunday, 10am-4pm

Radio Lollipop

Our in-house Radio Lollipop studio on Level 6 broadcasts a live show daily between 5.30pm and 7.30pm, Monday to Friday, and 9.30am-11.30am on Saturdays. Patients can tune in via the Patient Entertainment System.

Chaplaincy and spiritual support

A team of chaplains are on hand to offer understanding and support to families of all religions and faiths. The chaplains can be paged through the hospital switchboard on 07 3068 1111 or you can ask staff to do this for you. The Multi-faith Centre offers a quiet place for prayer and congregational fellowship.

Multi-faith Centre

📍 Level 5 (near B lifts)

🕒 24 hours, seven days a week

Interpreter services

Queensland Health provides interpreters in more than 130 languages at no cost to families. You can request an interpreter at any time during your stay by asking our staff for assistance.

Indigenous services

Indigenous liaison officers are available to provide assistance and support to Aboriginal and Torres Strait Islander patients and their families. Please ask hospital staff if you would like to access this service or call the liaison officer on 0411 654 079, Monday to Friday, 8am-4.30pm.

Lady Cilento Children's Hospital School

Education Queensland runs the Lady Cilento Children's Hospital School for children from prep to year 12 with the same term dates as all state schools. Early Years education (prep to year four) is taught in the Junior Campus on Stanley Street (located right beside the hospital). Students from years five to 12 are taught in the classrooms on Level 8 of the hospital. Lessons are also delivered at the bedside for children who are unable to leave the wards. The school is also available to siblings of patients.

For more information on education and learning support, contact the school on 07 3004 7888 or ask ward nursing staff to contact the teacher if your child is an inpatient.

Food and retail

Meal vouchers

Parents/carers staying overnight in a ward may purchase meal vouchers which can be used in a number of hospital food outlets and to access the ward meal trolleys if your child is an inpatient. Please refer to page 80 for more information.

Inside the hospital

Asian

The Asian rice and noodle bar offers a selection of rice dishes, noodles, sushi and dim sims.

📍 Level 2 (in the food court)
🕓 11am-3pm, seven days

Convenience store

The Amigo Shop to Go convenience store offers a selection of foods, drinks, gifts, newspapers, magazines, and postal and dry cleaning services.

📍 Level 2 (near the escalator)
🕓 7:30am-7:30pm, seven days

Hudsons Coffee

Hudsons Coffee provides hot and cold beverages as well as a selection of cakes, pastries and sandwiches.

📍 Outside the hospital on Level 1 (cnr of Stanley and Graham Sts)
🕓 6am-5pm, Monday to Friday

Juice

Juice offers a selection of fresh fruit, juices, smoothies, yoghurt and fruit salad pots.

📍 Level 2 (in the food court)
🕓 7am-2.30pm, Monday to Friday

Mr Pickles

Mr Pickles café offers a selection of hot and cold food, and beverages including tea, coffee, cakes, sandwiches, toasted sandwiches, muffins, pies and sausage rolls.

📍 Level 2 in the food court
🕓 6.30am-8pm, seven days

Sumo Salad

Sumo Salad offers a selection of salads, wraps and cold beverages.

📍 Level 2 (outside the food court)
🕓 6.30am-5.30pm, Monday to Friday

Vending machines

A vending machine offering fresh fruit is located on Level 2 near the food court.

Vending machines stocked with drinks and snack items are located on:

- Level 1 – in Department of Emergency foyer, and between B Lifts and parent lounge
- Level 2 – behind B lifts (across from the Pharmacy)
- Level 5 – near 5a
- Level 6 – between B lifts and 6d Outpatients (near toilets)
- Levels 9, 10 and 11 – in the main foyer areas.

Outside the hospital

A number of supermarkets, cafes, gourmet eateries and takeaway restaurants are located within walking distance of the hospital, including:

Coles Woolloongabba

A 15-minute walk or five minute bus ride from the hospital and located across the road from the South-East Busway Woolloongabba stop (the shopping centre is inside the arcade).

📍 Woolloongabba Shopping Centre,
795 Stanley St, Woolloongabba
🕒 Monday to Saturday, 7am-9pm
Sunday, 9am-6pm

IGA X-press Woolloongabba

A five-minute drive or a 20-minute walk from the hospital.

📍 679 Main St, Kangaroo Point
🕒 24-hours, seven days per week

One Stop Express Mart

A five-minute walk from the hospital (opposite Woolworths).

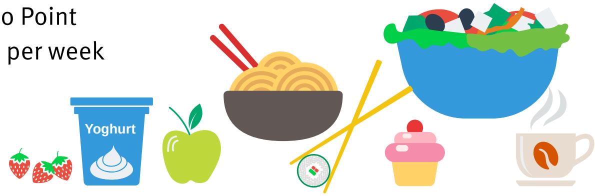
📍 Shop 7/15 Tribune St,
South Brisbane
🕒 Monday to Friday, 6am-8pm
Saturday, 7am-8pm
Sunday, 8am -7pm.

Woolworths Southpoint

A five minute walk from the hospital and located next to South Bank Train Station.

📍 217 Grey St, Brisbane
🕒 Monday to Saturday, 7am-9pm
Sunday, 9am-6pm

Please visit **www.childrens.health.qld.gov.au/lcch/visiting-staying/food-shopping** for more information.



Amenities

ATMs

An ATM is located on Level 2, opposite the Family Resource Centre, off the Raymond Terrace entrance. There is also an ATM in the Mater's Hancock Street car park, next to the Car Park Customer Service Centre on Level 1.

Bathrooms

Public toilets are available on every level of the hospital. Hoist equipment is available for families visiting the hospital in the unisex toilet/shower next to the Ronald McDonald Family Room on Level 6. Families can use their own sling (loop-style compatible) or ask to borrow one from an allied health assistant.

Mobile charging stations

Mobile charging stations are located throughout the hospital. The charging cables provided are compatible with Apple, Android and Windows devices and allow for multiple devices to be connected at a time. Please ensure your mobile device is supervised at all times during charging. Mobile charging stations are available at:

- Level 1 – Emergency main waiting room, Emergency Short Stay Family Room, 1b Orthopaedics
- Level 2 – Family Resource Centre, food court area, 2e General Medicine
- Level 3 – 3b Surgical
- Level 4 – Day Surgery Unit
- Level 5 – 5c Oncology.

Outdoor areas

Rooftop gardens and terraces are located on Level 5 (for the public) and on levels 6, 8 and 9 (for inpatients). The George Gregan playground is located on Level 2 near the main entrance on Raymond Terrace.

Parenting facilities

Parent rooms are located throughout the hospital and include changing facilities, sinks, seating and areas for breastfeeding.

Personal care rooms

Personal care rooms are available for parents and carers to attend to the toileting and showering needs of older children with disabilities who are visiting the hospital as outpatients. Locations: Levels 2 and 6.

Telephones

Mobile phones and other wireless devices can interfere with hospital equipment such as ventilators and monitors and are not permitted in some areas. Ask your child's nurse for advice on where it's safe to use your phone or device. A phone is also located in the parents' lounge for families to use. Lift the handset to be connected to the hospital switchboard.

Public telephones are located on Levels 1 and 2.

Wi-Fi

A free Wi-Fi service is available for patients, families and visitors. The network 'QH-Free WiFi' operates on most Wi-Fi enabled devices and does not require a password to connect. To activate the network, simply read and accept the terms and conditions. Users will be asked to re-accept the terms and conditions after 12 hours of continuous use, or if your device is inactive for more than 30 minutes.

Resources

Children's Health Queensland has a range of online resources to assist parents, carers and families including:

- a comprehensive website with detailed information about services, processes and facilities **www.childrens.health.qld.gov.au/lcch**
- Children's Health Queensland fact sheets **www.childrens.health.qld.gov.au/fact-sheets**
- the LCCH family newsletter, *Connections* **www.childrens.health.qld.gov.au/connections**
- Facebook, Instagram and Twitter provide updates on current events.

Government websites

Better Start Funding
www.betterstart.net.au

Carer's allowance
www.humanservices.gov.au/customer/services/centrelink/carer-allowance

Carer's payment
www.humanservices.gov.au/customer/services/centrelink/carer-payment

Commonwealth Respite and Carelink Centres
www.dss.gov.au/disability-and-carers/programmes-services/for-carers/commonwealth-respite-and-carelink-centres

Companion Card
www.qld.gov.au/disability/out-and-about/companion-card

Continence Aids Payment Scheme
www.humanservices.gov.au/customer/services/medicare/continence-aids-payment-scheme

Department of Communities, Child Safety and Disability Services
www.communities.qld.gov.au/disability/disability-community-care

Disability parking permits
www.qld.gov.au/disability/out-and-about/parking-permits

Isolated Patients Travel and Accommodation Assistance Scheme – for families living in New South Wales
www.enable.health.nsw.gov.au/home/iptaas

Medical Aids Subsidy Scheme
www.health.qld.gov.au/mass

Medical Cooling and Heating Electricity Concession Scheme
www.qld.gov.au/community/cost-of-living-support/medical-cooling-heating-electricity-concession-scheme

National Disability Insurance Scheme
www.ndis.gov.au

Patient Travel Subsidy Scheme – for families living in Queensland
www.qld.gov.au/health/services/travel/subsidies

Taxi Subsidy Scheme
www.qld.gov.au/disability/out-and-about/taxi-subsidy

Community organisations

Angel Flight
www.angelflight.org.au

Autism Queensland
www.autismqld.com.au

Carer's Queensland
www.carersqld.asn.au

Cerebral Palsy League
www.cpl.org.au

Charcot-Marie-Tooth Association Australia Inc.
www.cmt.org.au

Epilepsy Action Australia
www.epilepsy.org.au

Epilepsy Australia
www.epilepsyaustralia.net

Epilepsy Queensland
www.epilepsyqueensland.com.au

Infocus Disability Services
www.infocusdisability.org

Make a Wish Foundation
www.makeawish.org.au

Montrose Therapy and Respite Services
www.montrose.org.au

Muscular Dystrophy Queensland
www.mdqld.org.au

Muscular Dystrophy Foundation Australia
www.mdaustralia.org.au

Myasthenia Gravis Association of Queensland Inc.
www.mgaq.org.au

National Stroke Association
www.stroke.org

Ronald McDonald Learning Program
www.learningprogram.rmhc.org.au

Save our Sons Duchenne Foundation
www.saveoursons.org.au

Spinal Muscular Atrophy Australia Inc.
www.smaaustralia.org.au

Starlight Children's Foundation
www.starlight.org

Stroke Association of Queensland Inc
www.strokeqld.org.aulanding

Stroke Foundation
www.strokefoundation.org.au

Tourette’s Syndrome Association of Australia Inc.
www.tourette.org.au

Transverse Myelitis Association
www.myelitis.org

Tuberous Sclerosis Australia
www.tsa.org.au

Useful Apps

EpApp
Migraine Buddy
My MG
Track it
Parent Project Muscular Dystrophy

Financial assistance

You may be eligible for a subsidy for some of the costs of travel or accommodation if you are travelling more than 50 kilometres from your local hospital to attend an appointment or if your child is being admitted to the LCCH. Enquiries about eligibility for the Patient Travel Subsidy Scheme (PTSS) should be made at your nearest public hospital.

Please refer to the information in the Government support and information section of this handbook for more information or call 13HEALTH (13 43 25 84). Accommodation and travel support fact sheet **www.childrens.health.qld.gov.au/lcch/patientsfamilies/assistance**

Social Work and welfare staff can provide advice on PTSS (see p. 73)

Parking assistance

Families experiencing financial hardship may be eligible for parking assistance. For further information contact Social Work and Welfare on 07 3068 2940 or visit the team on Level 6 (6f) of the hospital, Monday to Friday from 8am to 4.30pm.

Your child's health care team

Your child’s health care team may include medical, nursing and allied health staff who will work together to ensure the best possible outcomes for your child. Some staff may not wear a formal uniform however, they will have an identification card visible at all times.

Medical staff
(in alphabetical order)

Consultant neurologists

Consultant neurologists are doctors who specialise in caring for children with neurological conditions. Your child will have his/her own consultant neurologist who will be the person in charge of their neurological care. They will be the person who advises you of your child’s diagnosis and his/her treatment plan. They will also advise you of test results and make changes to your child’s treatment if necessary.

Each week a consultant neurologist (with his/her team) is rostered ‘on call’ to respond to urgent care needs for all neurology inpatients. If your child’s consultant neurologist is not rostered on they will be advised of your child’s condition and they will also see your child as needed.

Fellows

A fellow is a senior doctor who is training to become a specialist in their chosen field. Within neurosciences, the fellows have a special interest in neurosciences and are in a training program. These doctors work under the direction of consultant neurologists. Fellows in the neurosciences team generally work at the LCCH for one to two years.

Registrars

A registrar is a senior doctor who is enrolled in a specialist training program and working towards becoming a paediatrician. These doctors work under the direction of consultants and fellows, and rotate through different services in the hospital approximately every three months to gain experience in caring for children with different diseases and conditions.

Residents

A resident is a qualified junior doctor who is gaining more experience in the treatment and management of children. Resident doctors work under the direction of the registrars and move to a different hospital area approximately every three months to gain experience in all areas of medicine.

Nurses
(in alphabetical order)

Clinical nurses

A clinical nurse (CN) has knowledge and experience in the conditions and disease treated within a specialty area. Within the neurosciences team, CNs work under the direction of the clinical nurse consultant. Clinical nurses also work in the inpatient wards and provide care for patients under the direction of a ward nurse unit manager.

Clinical nurse consultants

The clinical nurse consultant (CNC) is an advanced practice registered nurse who has the expertise and skills to provide expert clinical advice to patients, carers and other health care professionals within a defined specialty area. Many CNCs have post graduate qualifications and/or credentials within a specialist area. Within the Neurosciences team we have two CNCs who work within defined specialty areas.

Nurse practitioners

A nurse practitioner is an advanced practice nurse who has obtained a Masters in Nursing Sciences. They are able to independently diagnose, prescribe medications and treat health conditions within their scope of practice.

Nurses

Inpatient and outpatient care is provided by a team of registered nurses (RNs), enrolled nurses (ENs) and assistants in nursing (AINs).

These nurses record your child's vital sign, height and weight, etc. when they arrive for outpatient appointments and also work in partnerships to provide care for your child during inpatient admissions.

Nursing shift coordinators

A nursing shift coordinator is allocated to each inpatient ward shift and is the nurse responsible for the coordination of all aspects of care during that shift.

Nurse unit managers

The nurse unit manager (NUM) is the clinical manager responsible for overseeing and coordinating patient care and nursing staff on their inpatient ward. There is a NUM for each inpatient ward and each day unit.

Allied health

(in alphabetical order)

During your child's inpatient admission or as part of their outpatient care, they may receive treatment from one or more allied health professionals. These include physiotherapists, occupational therapists, dietitians, etc. These staff will work as part of a team to support your child's care and management. Your health care team will refer your child to allied health professionals, when required. Parents can also request a referral from their consultation neurologist.

Dietitians

The dietitian provides nutrition support for babies and children with eating and swallowing difficulties, slow or excessive weight gain, bone health, constipation, poor appetite, tube feeding devices and specialised diets. They will conduct an assessment of your child's growth and nutritional intake, and tailor a nutrition care plan to meet their specific needs.

Music therapists

Music therapy provides familiar, safe, positive and non-threatening musical experiences for children during their hospitalisation.

A music therapist can support your child with settling, relaxation, appropriate stimulation (for their age and health), emotional validation and social interaction. Music therapy sessions can involve instrumental playing, singing and song writing.

Neuropsychologists

Clinical neuropsychologists provide specialist assessment and intervention for children who are experiencing cognitive (thinking) or behavioural changes, or struggling at school due to an actual or suspected neurological condition or disease. They may assess your child for verbal and non-verbal reasoning, attention/concentration, memory/learning, thinking, problem-solving, and planning and organisation skills. They may also evaluate your child's ability to manage their emotions and emotional issues such as depression or anxiety.

The neuropsychology assessment will provide information about your child's cognitive strengths and weaknesses, help guide decision-making around intervention (e.g. surgery) and recommend management strategies.

Neuroscientists

Neuroscientists study the development and function of the nervous system including the brain, spinal cord and nerve cells in the body. They may perform various neurophysiology tests to help diagnose and manage neurological conditions such as epilepsy, disorders of the retina, and orthopaedic and neuro-spinal related disorders such as spinal cord tumours and scoliosis. Tests include electroencephalography (EEG), electroretinography (ERG), and motor (MEP) and sensory-evoked potentials (SEP).

Respiratory scientists

Respiratory scientists perform specialised breathing tests to measure how effectively the lungs are working. This is particularly important for patients with neuromuscular disorders as these conditions can cause a loss of respiratory function. Generally, the first test is spirometry which measures how much air can be blown out of the lungs (this indicates how big the lungs are) and how fast air can be blown out (this indicates how open or narrow the airways are). More detailed measurements of lung volumes and the strength of breathing muscles may also be performed.

Occupational therapists

The occupational therapist (OT) helps children engage in everyday activities (occupations) such as play, school and self-care. Your child's ability to do these activities may be affected by their disease or condition. OTs will help your child participate more fully in everyday life by helping them cope with hospital stays and returning home, manage changes such as returning to school, and do daily tasks such as brushing their teeth, dressing and feeding themselves.

Pharmacists

The hospital pharmacist will look after all drug (medication) related matters while your child is in hospital. A pharmacist will visit the ward to confirm your child's medication history and ask about medicines taken prior to hospital admission, review the medications prescribed by your doctor and provide appropriate advice. They will also organise the most suitable form of medicine for your child (e.g. tablets, capsules, mixtures, injections or creams) and provide you and your child with information about different medications, their purpose, how to take them, possible side effects and other important details you may need to know. The pharmacist will also facilitate the supply of medications your child requires when discharged and provide a list of your child's current medications and doses.

Physiotherapists

Physiotherapists work collaboratively with parents and carers to help children achieve optimum motor development, mobility and participation in family, school and community life. A physiotherapist may assess and work with your child to address the developmental or movement difficulties caused by their neurological or neuromuscular condition, or neurosurgery. They can also provide advice regarding equipment such as wheelchairs, mobility aids and orthotics.

Social workers

Social workers help families cope with their child's diagnosis, changes in the way the family functions and the treatment process. This can involve providing emotional support and counselling for family members, and advice on how to support your child and other children. The social worker also helps your family use its own strengths to adapt to the ongoing treatment process. They also provide post-discharge psychological and emotional support, bereavement support and referrals to community organisations.

Speech pathologists

Speech pathologists provide support for children with communication, eating and swallowing difficulties which may be present from birth, infancy or acquired later in childhood. This may include the assessment and treatment of speech, language, voice, literacy and stuttering disorders. Children with verbal communication difficulties may be supported with tools such as signing, picture/symbol/alphabet boards or electronic devices. Speech pathologists also help manage eating and swallowing problems associated with breast and bottle feeding, chewing skills, texture progression, choking on foods, food or liquids going into the lungs, and transitioning from tube to oral feeding.

Welfare workers

Welfare workers can provide practical and solution-focused advice for your family regarding the Patient Travel Subsidy Scheme (PTSS), Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS), accommodation and travel bookings. They can also help complete forms and navigate Centrelink requirements. Additionally, the welfare worker can help you understand the financial impacts of your child's hospitalisation and in some cases may be able to provide support such as meal vouchers if you are experiencing financial hardship while your child is in hospital. More information is available at **www.childrens.health.qld.gov.au/lcch/visiting-staying/accommodation**

Note, our allied health professionals may also refer you to local services for ongoing support near your home.

Connected Care and Nurse Navigator Programs

The Connected Care and Nurse Navigator Programs helps families of children with chronic and complex health care needs.

Nurse navigators and connected care coordinators work together to improve access to specialist paediatric services and support for children. By improving communication between health care providers, these staff help ensure a child's care is managed seamlessly across the acute, community and primary healthcare sectors.

Connected care coordinators are located throughout the state and assist families across Queensland and northern New South Wales. These nurses coordinate access to health care providers and the support services families need for their child, both within the hospital and health service where they live. Connected care coordinators provide a single point of contact for families for support and assistance in their local/region.

Nurse navigators are based at the hospital and work with families and hospital doctors to identify and monitor the health care requirements of children with high needs, develop tailored care plans and facilitate timely access to appropriate services. These specialist nurses provide support for families with children who require intravenous feeding, home ventilation, or whose care is transferring to adult services or alternate health service providers in the community.

Find out more about Connected Care at **www.childrens.health.qld.gov.au/lcch/patients-families/connected-care**

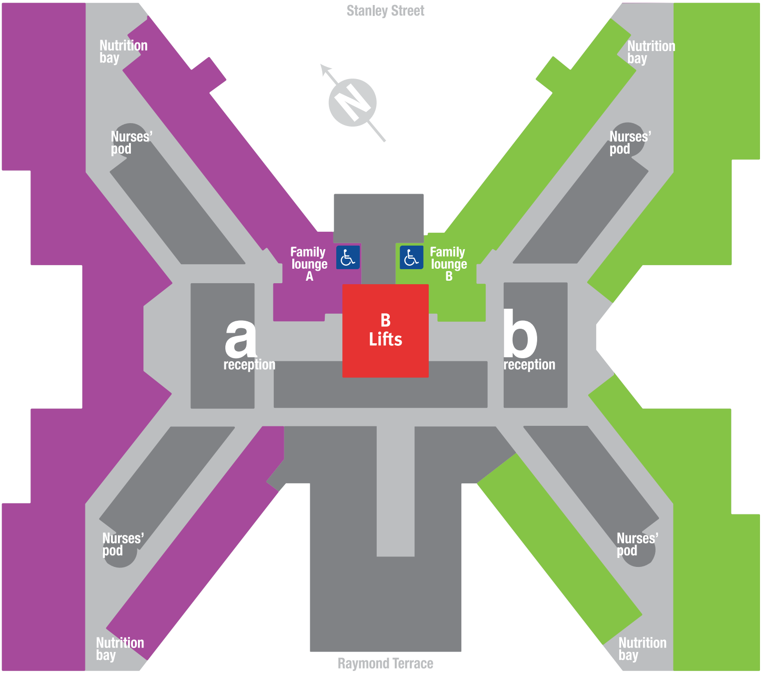
Inpatient wards

Children with neurological disorders will be admitted to a specific ward in the hospital depending on their current condition or treatment needs. If your child is not admitted under Neurology, please advise the admitting team that your child is under the care of a consultant neurologist at the LCCH. The Neurology team will continue to review your child during their admission.

Each inpatient ward is open 24 hours, seven days a week and has a range of single rooms, and two- and four-bed bays. Children are located within the ward in accordance with their infection status and the level of observation required:

- children with contagious infections will be placed in single rooms or co-located with a child with the same infection
- children who are very unwell or require close supervision may be co-located with other children requiring increased nursing support in a two- or four-bed bay.

Wards are divided into two ends with 12 beds at each end. A circular nurses' pod is located at the end of each ward and in some of the high-observation rooms.



Inpatient wards footprint

What to expect during your inpatient stay

During your child's stay, there will be regular routines, tests and records taken to monitor their health.

Medications

Please provide your nurse with a list of all medications your child is currently taking and the actual medications, where possible. This will help ensure your health care team has the most up-to-date details for your child.

Vital signs

Your child's blood pressure, temperature, heart rate and breathing rate will be checked regularly during their inpatient stay. The frequency of these checks will depend on your child's condition. In certain situations, such as when your child has a fever or is receiving particular medications or an infusion, the vital signs will be checked more often. Vital signs tell the health care team how your child's body is responding to treatment.

Weight

Your child's weight will be checked in the Emergency Department (if they are admitted through Emergency), on admission to a ward, and weekly for children who are in hospital for an extended period. Some children require more frequent weight checks. Weight provides information about your child's nutritional and hydration status, and growth.

Medications for children are calculated using their weight. Therefore, it's important to have an accurate measure of your child's current weight. During the admission weight check, please advise staff if your child has lost or gained weight.

If your child has a mobility device, please ask nursing staff to record the wheelchair weight in your child's medical notes for future reference. You may also like to note this information for your own records.

Intake and output

Your child's fluid input and output may be monitored during your inpatient stay.

Intake means how much fluid your child is taking in by mouth, feeding tube or device and via the intravenous (IV) drip. Output means how much fluid your child is losing (urine, vomit and stool). Fluid balance may be measured twice daily to keep track of what your child drinks and how much your child puts out. If you change your child's nappy, please advise the nurse caring for your child. In some situations, the nappy will need to be weighed to provide an accurate output measurement for your child. Your nurse will advise if this is needed. If your child uses a urinal or bedpan or attends the toilet, please advise your nurse. If your child has passed urine or used their bowels, this will be recorded on their chart.

Blood tests

Your child may need blood tests during their hospital stay. These tests are usually performed early in the morning (if pre-planned) or throughout the day as needed. The phlebotomist (blood collector) will attend the ward to take these bloods or they may be taken by the nursing or medical staff. Where possible, blood collection is grouped together with other procedures to reduce the amount of needles your child experiences.

Rounds and handovers

The on-call consultant neurologist and the fellow, registrar and resident rostered on for inpatients meet each morning to review the after-hours calls and discuss the plan of care for all children admitted by, or needing input from, the Neurology team.

Ward rounds commence from 9am each day and can take several hours. On Mondays and Tuesdays the ward rounds start later in the morning to allow for handover between the on-call neurologists and the weekly handover meeting with the neurology team.

The neurology nursing team work closely with the on call consultant neurologist and inpatient teams and will be present at ward rounds as required. A member of the neurology team will review your child's treatment and progress each day.

The following tips will help you get the most out of ward rounds:

- Use the patient whiteboard near the bed to record key questions/ notes and if necessary remind the nurse to update their name at the start of the shift as well as the key medical team/doctor names.
- Ask who people are if you need to. It's also a good idea to introduce yourself by name and state your relationship with the patient (e.g. mum, dad, grandparent, etc.).
- Keep a list of your questions or concerns. Bring pen and paper to take notes, use a note-taking app on your phone, or use the patient whiteboard. Be as prepared as possible, as the team will need to move on to the next patient in a timely manner.
- Ask for more details if you don't understand something and, if required, ask the medical team to draw a picture or write down any medical terms or key information you need. Please speak up if any incorrect information is accidentally given or key information is missed during ward rounds.
- Understand any tests/scans that your child requires including:
  - why the tests are being conducted (e.g. blood test to check for iron levels)
  - the timing (e.g. as soon as possible or later that day or week)
  - when the results will be available (two hours, two days, etc.).

- Know the frequency of any regular medications, medical observations or tests that have been prescribed, and the frequency that your child requires them (e.g. four-hourly check of blood pressure/breathing rate, Panadol every six to eight hours). The patient whiteboard is a handy place for you to record this information.
- Talk to the pharmacist when they visit the ward about your child's current medications and any changes that are made. Always ask questions if you need to.

Private health insurance

If your family is Medicare eligible and covered by private health insurance, you can choose to have your child treated as an insured (private) inpatient at the Lady Cilento Children's Hospital.

Simply let our admissions staff know you would like your child treated as an insured inpatient. We can then liaise with your health fund and help you complete any paperwork.

When you use your health insurance at the Lady Cilento Children's Hospital, Children's Health Queensland receives additional funding which helps us deliver more services to children in our communities.

We respect your right to decide what is best for your child and family. No matter what your choice, you can be certain that your child will receive the best health care we can provide.

For more information **www.childrens.health.qld.gov.au/lcch/patients-families/public-or-private**

Bed allocation

Single rooms are allocated based on clinical need (not private health coverage). If a room is available and it is clinically appropriate, a single room may be provided. The majority of the hospital's beds are in single rooms.

Meals

The hospital provides a choice of meals for patients and will meet special dietary requirements including those required to support your child's medical care or religious needs. If your child is not on a restricted diet they will be offered a selection of dishes at mealtime.

Ward mealtimes

Note, meal service times run for approximately 20 minutes.

Ward	Breakfast	Lunch	Dinner
4a	7.25am	11.45am (cold lunch)	4.45pm
5d	7.30am	12.05pm	5.05pm
8a	8am	12noon	5.45pm
8b	7.30am	11.45am	5pm
8c	7.15am	11.45am	4.45pm
9a	7am	11.30am	4.30pm
9b	7.30am	12noon	5.10pm
10a	7.30am	12noon	5pm
10b	8am	12.30pm	5.35pm
11a	7.20am	11.30am	4.30pm
11b	8am	12noon	5pm
11b (BMT)	8.20am	12.30pm	5.30pm

Nurse call system

The nurse call system is located on the same handset as the Patient Entertainment System. There are three types of call buttons in patient rooms: green, yellow and red.

The silent nurse system means that when you press a call button, instead of sounding a tone throughout the unit, the alarm sounds on the nurses' portable phone. There is also an indicator outside the room and a screen in the corridor that transmits your call to the nursing team.

Green nurse call button

The green nurse call button is for patients, parents and carers. These buttons are located in three places:

- The handset on a cord by the bed
- A fixed white panel above the bed
- A fixed white panel in the bathroom.

The yellow staff assist and red emergency buttons are for staff use only.

Visitors

Parents and carers can visit anytime (day or night) and are encouraged to spend as much time with their child as possible. Visiting hours for other family members and friends are between 10am and 8pm. The main lights will be switched off by 8pm to encourage children to settle. Please ensure young visitors are supervised by an adult at all times.

All visitors are asked to wash their hands as soon as they enter the ward and must also check in with reception or nursing staff. If a family member, friend or other visitor has a fever, rash, diarrhoea, vomiting or any other illness, they must not visit your child.

As a courtesy, we will check to ensure you and your child are happy to have visitors before they enter the patient areas. We do not wish your child to be placed at risk and the status of other patients in your room will also be considered.

Keeping your child safe

The following hospital procedures are designed to help keep your child safe during their stay:

- Patient identification bands must be worn at all times. The band confirms your child's name and essential details, and ensures he/she receives the right treatment. It also assists with patient identification when parents/carers are not present to confirm the identity of their child.
- Bedside curtains must remain open so nursing staff can carry out observations and assessments of your child. Curtains may be closed for privacy for procedures, toileting and breastfeeding.
- Whiteboards are located next to most beds in the Lady Cilento Children's Hospital. They are there to help families communicate with their child's health care team. Families and clinicians are encouraged to update the whiteboards regularly.
- Footwear must be worn at all times.
- All hot drinks (e.g. tea and coffee) must be covered with a lid before they are brought into the ward.
- Fresh flowers and latex balloons are not permitted in the hospital because they can trigger allergic reactions in some patients.
- All inpatient wards are nut-free due to the risk of allergies. Please do not bring nuts or products containing nuts (including peanut butter) into the ward.
- Wash your hands at every opportunity to protect yourself, your child and other patients. It is particularly important to clean your hands when you enter and leave the ward. If you are unsure when to wash your hands, or whether to use hand rub or soap and water, please ask the nurse caring for your child. See further information about hand wash and hand rub procedure on pages 65 and 66.

Patient Entertainment System

The Patient Entertainment System touchscreen at each inpatient bedside allows children to access a range of television stations, the radio, games, internet, movies and general hospital information. Please be mindful of volume levels.

Many of our patients require a quiet environment for their recovery and we ask that everyone respect the comfort of others. Headphones should be used for all televisions and portable electronic devices.

Staying overnight with your child

One parent or carer can stay overnight with their child in his/her room. Single bed rooms have an ensuite and built-in bed for a parent or carer. Shared rooms also have an ensuite and a place at each bedside for a parent or carer to stay. If your child is in a single patient room, you can use the bathroom in that room. If you are in a double room, you will need to use the bathroom facilities in the parent lounge area. Parents are also welcome to use towels from our linen trolley for showering but must provide their own toiletries.

Meals

Meals are provided for all patients and bread, condiments, tea and coffee are available in the parent lounge/nutrition bay for parents who stay overnight with their child. Alternatively, parents can purchase meals from inpatient food trolleys using meal vouchers. Each voucher entitles the holder to one meal from the food trolley. Vouchers can be used in all overnight inpatient wards. The vouchers can also be redeemed at the Amigo to Go convenience store and some outlets in the food court on Level 2. They cannot be redeemed at Hudsons Coffee or Sumo Salad.

Meal vouchers are sold at the Cashier's Office on Level 2 of the hospital (opposite the Family Room) on weekdays from 8am to 5pm. On weekends and public holidays, vouchers can be purchased from the Amigo to Go convenience store on Level 2. Cash, EFTPOS and credit cards are accepted. Please note, payment cannot be accepted in the ward.

Meal vouchers have no expiry date and can be refunded by the Cashier's Office. Meal vouchers distributed by Welfare cannot be exchanged for money or refunded.

See pages 63 and 64 for other meal and snack options for parents and visitors.

Family facilities

Nutrition bay

A nutrition bay is located at each end of the ward and includes facilities such as a microwave, sandwich press, cold-filtered water and sink. Due to fire regulations, cooking appliances that release fumes and smoke (e.g. toasters and cooktops) are not permitted. Some nutrition bays also include tea, coffee, bread, milk and condiments for parents/ carers who stay overnight with their child. Two fridges are often located in the nutrition bay. If available, one will be labelled 'bread, milk and condiments' and can be accessed by parents/carers. The second fridge will be labelled 'hospital supplied patient food' and can only be accessed by staff. Both fridges are for hospital-supplied food only.

Family lounge

A family lounge is located in all wards. It includes a fridge, microwave, a television, tea and coffee-making facilities, and (in some wards) a shower and toilet. Please label all items you place in the fridge using the labels provided in the ward and throw out any unwanted food when your child is discharged. Note, products containing nuts will be removed. There is a small dining table for families to eat meals together, and couches and armchairs. Small children must be supervised at all times in the family lounge.

Laundry facilities

Laundries are located on levels 8 (for all inpatient families) and 11 (oncology patients only) for parents and carers. These facilities are open 24 hours, seven days and are free of charge for inpatient families.

After hours

For the security of patients, visitors and staff, all external entrance doors (except Emergency) to the hospital are locked between 8pm and 6am. Entry to the hospital during these hours is through the Emergency Department on Stanley Street. You can exit from any door at any time.To enter the ward during these hours, you will need to use the intercom located by the entry doors. You will be asked to identify yourself to nursing staff and provide the name of your child. Please keep in mind that our nurses are caring for patients and you may have to wait until someone is available to admit you.

All parents/carers are asked to wear an identification band if they are in the hospital after hours. These bands enable security staff to easily identify you as a parent/carer. The wrist bands can be obtained from the nurses' station in your ward and must be worn between 8pm and 6am.

Medical Day Unit (5b)

The Medical Day Unit (5b) provides care for children who require admission for a day procedure or a treatment that doesn't require an overnight stay. These may include infusions, medical reviews and investigations.

Location and access

The Medical Day Unit (5b) is open Monday to Friday from 7am to 4.30pm and is located on Level 5 of the hospital. View the virtual tour of Level 5 **www.childrens.health.qld.gov.au/lcch/about-us/virtual-tour**

The unit can be accessed via the A or B lifts. When you exit the lifts on Level 5, walk past 5c (on your right) towards the Oncology Waiting Area. Then turn left immediately after the glassed-in play area. The Medical Day Unit is located through the glass doors at the end of the corridor.

On arrival

When you arrive, please go to reception (located inside the unit) where staff will begin the process of admitting your child. Our staff will attend to your child's care as soon as possible after you arrive. Please note, delays may be due to other patient emergencies or consultants may be attending to other very sick patients.

Waiting area

There is a waiting area with a television and a play area for smaller children outside the ward. While you are waiting, you may want to visit the outdoor garden near 5b (go along the corridor past the 5a Respiratory and Sleep Studies Unit and the entrance hall is on the right). Please inform reception or nursing staff if you are going outside.

During the procedure or treatment

You and your child must remain in the ward while your child is receiving treatment. This will enable our staff to monitor your child's progress.

Morning tea and lunch will be provided for your child during their day admission.

Kitchenette

A kitchenette for parents/carers is located outside the Medical Day Unit. This includes a fridge, microwave and tea- and coffee-making facilities.

Paediatric Intensive Care Unit

In some instances, your child might require intensive nursing and medical care and will admitted to the Paediatric Intensive Care Unit (PICU). This is located on Level 4 of the hospital. While in the unit, you will have regular contact with your neurology team and your child will be closely monitored.

Explore PICU in 360 degree views in our online virtual tour. You will be able to go to particular points of interest and journey as if you are actually there!

Epilepsy Monitoring Unit

The Epilepsy Monitoring Unit (EMU) is the inpatient section of the Department of Neurosciences specifically involved in long-term video EEG monitoring. Monitoring is a very important part of caring for children with epilepsy. Patients are usually admitted to ward 11a for monitoring periods lasting from 24 hours to six days. Long-term monitoring is similar to routine EEGs but the electrodes are attached to the head more securely using a water-soluble paste. Prolonged monitoring captures seizures and events, and is used as a diagnostic tool, as an aid to medication management or for detailed assessment before to epilepsy surgery. EMU staff also assist with monitoring patients during epilepsy-related surgical procedures.

Neurosciences and Metabolic Outpatients (6c)

Neurology and Metabolic Outpatients (6c) is located on level 6 of the hospital and manages:

- neurology outpatients
- neurophysiology testing (e.g. EEGs, VERs, ERGs)
- metabolic outpatients
- clinics for neuromuscular, complex headache, tuberose sclerosis and neurovascular conditions, and ketogenic diet.

Neurosciences enquiries

🕓 Monday to Friday, 8am-4.30pm

t 07 3068 2880

e CHQ_Neurosciences@health.qld.gov.au (general)

e CHQ-NEUROMUSCULAR@health.qld.gov.au (neuromuscular patients)

Enquiries

If you have any questions, are delayed or cannot attend an appointment, please call 07 3068 2880 during business hours.

For all calls, emails or messages please provide the name of the clinic, enquiry details and your child's:

- full name
- date of birth
- hospital ur number
- treating consultant
- neurology nurse (if allocated).

This will help us direct your call to the right person and ensure you are provided with the correct information.

Phone messages and emails

If you call Neurosciences and Metabolic Outpatients (6c) during business hours, administrative staff will answer your enquiry, take a message or transfer you to a staff member who can assist you.

If the line is busy, please leave a message. Phone messages are checked by administration staff regularly. Messages received after 4.30pm will be checked on the next business day and we will call you then to provide an update on the progress of your enquiry.

The CHQ Neurosciences email account is checked twice daily. Please note, the email is checked by administration staff who are not clinically trained. The CHQ Neuromuscular email account (for neuromuscular patients only) is checked regularly by the clinical nurse consultant or one of the clinical nurses.

If your child is unwell

Infectious diseases

Your outpatient appointment may need to be rescheduled if your child is unwell. Please call Neurosciences and Metabolic Outpatients (6c) for advice if you have an appointment in the next two days and:

- your child or a family member has an infectious disease such as chicken pox
- your child is unwell with other illnesses such as the common cold, flu, vomiting or diarrhoea.

Medical condition

If you are concerned about your child's medical condition, please call 07 3068 2880, outline your concern and you will be transferred to one of our clinically trained staff, when possible. In some cases, our clinical staff will be busy with other patients and you will be asked to leave a message. We will get back to you as soon as possible. Please don't hesitate to take further action such as contacting your GP or paediatrician if your child's condition worsens before we are able to return your call. **Please call 000 for all emergencies.**

Cancellations

Please provide at least 48 hours notice if you need to cancel your appointment. This will enable us to offer the appointment to another patient. Please note, clinics are heavily booked so there may be a lengthy delay (four to six months) before the next available appointment.

Earlier appointments

Please speak to your GP or paediatrician if you believe your child needs an earlier appointment. They will review your child's condition and liaise with our medical staff to establish if an earlier appointment is needed. Please ensure your GP knows about any changes to your child's condition and communicates this information to our medical staff.

Referrals

Your child will initially require a current, valid referral to access our neurology clinics.

Specialist referrals: Any referral written by a specialist will be valid for three months from your first outpatient appointment. This includes referrals by LCCH specialists.

GP referrals (ongoing care): Any referral written by a GP is valid for 12 months from your first outpatient appointment unless otherwise stated by the referring doctor.

Indefinite referrals: These can only be completed by a GP for a chronic condition. These referrals will remain in place indefinitely or until the patient is discharged from the care of the consultant neurologist.

You will receive a reminder letter if you need a new referral for your upcoming appointment. Please ask the administrative staff at reception in Neurosciences and Metabolic Outpatients (6c) if a new referral is required for your next appointment.

Preparing for your appointment

What to bring

Please bring the following items to your appointment:

- Any relevant medical information, e.g. results, X-rays and scans, letters from other specialists, diaries and videos that may assist the health care team to assess your child.
- Your Medicare card.
- Referrals – if your previous referral is out of date.
- Any questions you or your child would like to ask the consultant neurologist.
- Entertainment such as books and/or toys for the waiting room. Allow plenty of time for the appointment (including waiting time) as there can be delays due to complications with other patients.
- Snacks. You are welcome to bring snacks and a drink to consume while you are waiting for your appointment. There are a number of cafes/vending machines in or near the hospital where you can buy food and drinks. The food court and convenience store are located on Level 2.
- Chargers for your phone and other electronic devices.

Your child may require additional tests before their clinic appointment. If so, you will receive a separate, detailed letter advising you what time to arrive and where the tests will be conducted.

Preparing your child

It often helps to show children where they will be going, who they will meet and some of the fun things to do and see while you're at the hospital.

- Visit our website for more information **www.childrens.health.qld.gov.au**
- View the My Trip to Hospital videos **www.childrens.health.qld.gov.au/lcch/my-trip-to-hospital**
- Take the hospital virtual tour **www.childrens.health.qld.gov.au/lcch/about-us/virtual-tour**

Travelling to your appointment

A set-down area is located at the main entrance on Raymond Terrace. There are also several car parks close to the hospital.

Parking

The Lady Cilento Children's Hospital is located in a busy area in South Brisbane. Please allow plenty of time for parking if you are attending an outpatient appointment. In emergencies, cars may pull up outside the Emergency Department located at the Stanley Street entrance.

Families experiencing financial hardship may be eligible for parking assistance. For further information contact Social Work and Welfare on 07 3068 2940 or visit the team on Level 6 (6f) of the hospital, Monday to Friday from 8am to 4.30pm.

Read more about parking at **www.childrens.health.qld.gov.au/lcch/visiting-staying/parking**

LCCH car park

Entry to the hospital basement car park is via Raymond Terrace (corner of Graham Street). Height clearance at the entry is 2.2 metres. A total of 22 car parks for people with wheelchair accessible vehicles are located on Level B1. These spaces have a height clearance of up to 2.5 metres to allow lifts and hoists to be operated once your car/van is parked.

If your vehicle's height exceeds the hospital's basement car park entry clearance of 2.2 metres, contact hospital security on 07 3068 5128 before your visit to arrange alternative parking. You can park your car in the drop-off area on Raymond Terrace but you will require a security permit. Security is located on Level 2 beside the escalators.

Hancock Street car park

Entry via Hancock Street (height clearance 2.25 metres).

Mater Hill West car park

Entry via Stanley Street (height clearance 2.1 metres) and Water Street (height clearance 2.1 metres).

Mater Hill East car park

Entry via Allen Street (height clearance 2.3 metres).

Car parking is also available at South Bank Parklands. Buses and trains stop within 100-200m of the hospital and exits are wheelchair accessible.

Information about public transport options can be found at **www.childrens.health.qld.gov.au/lcch/visiting-staying/travelling-to-hospital**

A helping hand while collecting your car

Volunteers in the Family Resource Centre on Level 2 can watch your child for up to 15 minutes while you collect your vehicle from one of the hospital car parks. This assistance is available from 9.30am to 12noon and 3pm to 5pm, Monday to Friday. This service is provided by the Children's Hospital Foundation and depends on the availability of volunteers.

Mobility assistance

A limited number of wheelchairs are available at the front desk on Level 2 for patients who need to be escorted somewhere in the hospital or to the car park. Volunteer staff will escort the patient but a parent/guardian must also be in attendance.

Your outpatient appointment

Your outpatient appointment letter will tell you where to go when you come to the hospital.

When you arrive

Step 1: Reception

Administrative staff at the reception desk will confirm your arrival and prepare the paperwork for your appointment while you wait and ensure your address and contact details are up to date. Please provide our administrative staff with:

- all updated referrals
- the updated details for your child's GP and any other specialists, schools, therapists, etc. who should be copied into hospital correspondence.

Step 2: Assessment

The outpatient nurse will measure your child's height, weight and vital signs. Please arrive 15 minutes before your appointment to enable nursing staff enough time to review your child.

6c Neurosciences and Metabolic Outpatients caters for patients in wheelchairs, and a hoist and wheelchair scales are available.

Please tell the outpatient nurse if your child has any individual needs or if you have concerns about their wellbeing on the day of their appointment, e.g. your child will become distressed in the waiting room or has become unwell on the way to the appointment.

Step 3: Appointment

Your child may have several medical appointments on the same day. These details will be outlined in your clinic letter/s or schedule.

Our consultant neurologists aim to be on time for all their appointments. However, delays may occur as the result of medical emergencies, patients arriving late, or when appointments take longer than expected. We appreciate your patience if your appointment is later than scheduled. Please speak with our administrative staff at the front desk if you are concerned about your waiting time.

You can ask the consultant neurologist for a written summary (Appointment Summary Plan) of your child's care plan at the end of the appointment, if needed. This form can also be uploaded to your child's file for future reference. Summary information will also be included in the letter sent to your local doctor and copied to you if clinically appropriate.

Step 4: Back to reception

Please visit reception before you leave to ensure your child's future appointments have been made and all required paperwork has been completed. Please also check if you need an updated referral for your next appointment.

How to get the most out of your appointment

Outpatient appointments work best when there is a partnership and sharing of information between you and your child's health care team. The following actions will help you get the most out of your appointment.

- Prepare a list of your questions. You might ask if there are any community organisations you can access for support or if a follow-up appointment is required. Bring a pen and paper to take notes or use a note-taking app on your phone.
- Prepare a list of any significant events that happened to your child before coming to your first appointment or since your child's last appointment.
- Take your phone or iPad if you've recorded videos of significant events so you can show the health care team.
- Write down your child's current medications, doses and any changes.
- Advise the consultant neurologist of any other specialist appointments your child has attended (when and which speciality/consultant) and any medical tests/scans, etc. that occurred before your first or since your last appointment.
- Bring any forms you need the consultant neurologist to complete for your child's school, day care etc.
- Review your child's scripts to see if any repeat scripts are required.
- Write down any tests if you are waiting for results.
- Bring a support person if you need to, particularly for complex appointments. They can help listen and take notes, or look after your child/children so you can listen and take notes more easily.
- Check your list of questions again before the appointment is finished and make sure you have answers that you understand. If not, ask for further clarification from the consultant neurologist e.g. ask them to draw a picture or get them to write down any new medical terms or key information.

Central Resource Service

The Central Resource Service provides outpatients with the specialist clinical consumables (e.g. dressings, bandages, etc.) they need for ongoing care at home. Your health care team will arrange these items for your child before discharge and provide you with instructions when needed.

Central Resource Service

📍 Level 2 (opposite Pharmacy)

🕓 Monday to Friday, 7am-3.30pm (excluding public holidays)

Other clinics

In some cases, your child may need to visit other outpatient clinics in the hospital. The processes and requirements for these clinics will be outlined in your appointment letter/s.

Clinic	Level
Allied Health – 6a (dietetics, occupational therapy, physiotherapy, psychology, music therapy, speech pathology)	6
Audiology – 3a (including childhood hearing clinic)	3
Burns – 5e	5
Cardiac – 3d	3
Child Development – 6d)	6
Child Protection – 2f)	2
General Medicine – 2e) (genetics, haematology, pain, palliative care, psychiatry, renal, rheumatology)	2
Oncology (5c)	5
Ophthalmology – 2d	2
Oral Health – 6b	6
Orthopaedics – 1b	1
Otolaryngology Head and Neck Surgery (OHNS) and Ear, Nose and Throat (ENT) – 3a	3
Medical – 3c (allergy, diabetes, dermatology, endocrinology, immunology, infectious diseases)	3
Medical Imaging – 1a	1
Neurology/Metabolic/EEG – 6c	6
Pathology collections	3
Rehabilitation – 6g	6
Respiratory/Sleep Medicine – 5a	5
Social Work and Welfare – 6f	6
Surgical – 3b (gastroenterology and hepatology, paediatric surgery, plastics and reconstructive, maxillofacial and neurosurgery)	3

Medical Imaging and Nuclear Medicine

Medical Imaging and Nuclear Medicine provides a range of services to help diagnose, monitor and treat children suffering from neurological diseases or conditions. These inpatient and outpatient services include:

- X-ray e.g. fluoroscopy, radiography, angiography
- bone mineral densitometry (BMD)
- ultrasound (US)
- computed tomography (CT)
- magnetic resonance imaging (MRI) (including mock and intra-operative)
- nuclear medicine (NM) – some services are also delivered at the Royal Brisbane and Women's Hospital)
- single-photon emission computed tomography (SPECT)
- OPG (dental X-ray)
- positron emission tomography (PET) scanning.

A "mock" MRI and CT service (see p. 97 and 101) is also run by occupational therapists (if needed) to assess if children over four years of age can undergo these procedures without a general anaesthetic. This enables children to become familiar with the noisy and confined environment of the scanners and/or the process and to practise the tasks expected of them.

Please note, a referral is required to access this service.

Medical Imaging and Nuclear Medicine

Level 1 (1a near A lifts)
and Level 4 (4d)

Monday to Friday, 8am-5pm
MRIs: Monday to Friday, 7am-7pm
After hours: 24-hour emergency X-ray service and on call services

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Phlebotomy (blood collection)

Phlebotomy is the practice of drawing blood from patients for laboratory testing. Phlebotomy Outpatients provides blood test services for LCCH outpatients.

Phlebotomy

Level 3 (behind A lifts)

Monday to Friday, 7.30am-5pm
(no appointment necessary)
Weekends, 7.30am-3.15pm
(please call 3068 3505 to schedule an appointment)

Pharmacy

The Pharmacy looks after all medication-related matters while your child is in hospital and our pharmacists will visit your child regularly (Monday to Friday) in the ward. The Pharmacy can also assist with other prescription-related matters for outpatients, as needed. Please see page 115 of the Medications and Supplements section for more information.

Pharmacy

Level 2 (beside B lifts)

Monday to Friday, 8am-5.30pm
(no appointment necessary)
Weekends and public holidays
9am-5pm

Section 4

Disease and treatment information

The Department of Neurosciences provides specialist care for children with neurological conditions and diseases from across Queensland and northern New South Wales. Neurological conditions affect the nervous system (brain, spinal cord, muscle and nerves) and may be due to inherited, auto-immune or acquired conditions.

Many of these conditions are complex and your multidisciplinary care team (a team of specialists) will work with you and your family to ensure your child receives the best possible care. The team will include your GP, paediatrician and specialist hospital staff including doctors, nurses and allied health practitioners, and external care providers. Children treated by the department may have:

- undiagnosed neurological conditions requiring diagnostic evaluation, treatment and management advice
- epilepsy with underlying structural, metabolic, genetic or unknown causes
- neuromuscular disorders such as Duchenne muscular dystrophy, spinal muscular atrophy, congenital myopathies, congenital muscular dystrophies, congenital myasthenic syndromes, myasthenia gravis or neuropathies such as Charcot-Marie-Tooth
- neurovascular conditions such as stroke and Moyamoya disease
- complex headaches including chronic migraine, atypical migraine and cluster headaches
- neuroinflammatory conditions, demyelinating conditions and immune-mediated encephalopathies
- movement disorders.

The department provides care to children and young people through:

- general neurology clinics
- a comprehensive epilepsy service which can include medical management, surgery, vagus nerve stimulation therapy, and ketogenic diet (a low-carbohydrate, high-fat diet that may help control seizures in some children) and tuberous sclerosis clinics
- a comprehensive neuromuscular service which can include neurology, respiratory, cardiology, dietetics and physiotherapy clinics, and specialist CNC
- neurovascular clinics
- complex headache clinics.

These services are provided until your child transitions to adult services when they turn 18.

Working with your health care team

We pride ourselves on placing the needs of children and their families at the heart of everything we do. We also acknowledge that a child's family knows them best and can provide an important perspective for health professionals when they are involved as members of their child's health care team.

Through partnering with parents and carers, staff can better understand a patient's individual needs and make more informed care decisions. Likewise, parents can make better decisions for their children when they have all the information and support they require.

Staff will provide you with comprehensive details about your child's diagnosis, treatment options and progress, and assist you to make informed choices about your child's care. Please don't hesitate to ask questions or raise concerns with your health care team as a constructive two-way dialogue between you and specialists will ensure the best outcomes are achieved for your child.

Doctors, nurses and allied health professionals also rely on parents and carers to share information about their child's progress, medication side-effects, and significant health events such as seizures. By keeping records such as a diary or filming events (where possible), you will be able to provide your health care team with current information. This will help ensure also staff have the 'full picture' when making any diagnosis or treatment recommendation.

Tests

Your child may need tests to determine the cause of their neurological condition and identify the best treatment. If tests are needed, your consultant neurologist will explain:

- the reason for the test
- when the test is needed e.g. urgently or at the next available appointment
- when the results will be available
- how results will be provided to you e.g. during an outpatient appointment, over the phone, via telehealth or in a clinic letter.

If your consultant neurologist says they need to see you in person after the tests have been completed please **call Neurosciences and Metabolic Outpatients (6c) on 07 3068 2880** and tell them when the test will be done and ask for a follow-up appointment after the test results are available.

Please call Neurosciences and Metabolic Outpatients (6c) if your child's test date is changed as this may affect scheduling of the follow-up appointment.

The following tests are commonly used to help diagnose, treat and manage neurological conditions. Your consultant neurologist will refer your child for one or more of these tests, if required.

Blood tests

Blood tests will be frequently used to monitor your child's progress and treatment. The electronic form for the blood test will be forwarded directly to pathology by your consultant neurologist or you will be given a hard copy form to take to Pathology.

Hard copy forms are also available if you choose to have the blood tests performed by a private pathology laboratory. Please note, some of these tests may not be bulk billed and you will need to pay a fee.

Blood tests are conducted on Level 3, LCCH and standard blood test results will usually be available in one week.

Bone mineral density test

See dual-energy X-ray absorptiometry (DXA) test.

Computerised tomography scan

A computerised tomography (CT or CAT) scan uses X-rays to take a three-dimensional picture of the inside of the body. The scan is conducted in Medical Imaging and Nuclear Medicine.

The CT machine looks like a large doughnut. Your child will need to lie still while the CT bed moves in and out of the hole in the middle and takes pictures of the body.

Your child may be given an X-ray contrast (dye) via a vein for some examinations. They won't feel any pain during the scan however, if they require the X-ray contrast, your child may experience a warm feeling or funny taste/smell. This should only last for two to three minutes.

One parent/carer may remain in the room during the scan only when absolutely necessary. If you are pregnant you will not be able to stay in the room for the safety of your baby.

It's very important that your child lies still during the CT scan so the images are clear. Where appropriate, children who find it difficult to lie still or follow instructions will be considered for a mock CT. This will involve practising with one of our occupational therapists to determine if your child will be able to complete the scan without a general anaesthetic. If urgent, results will be available within one day.

Routine test results will usually be available in one week.

Dual-energy X-ray absorptiometry test

A dual-energy X-ray absorptiometry (DXA) test, also known as a bone mineral density (BMD) scan, uses very low doses of X-rays to measure the density of the bones. The test involves scanning the hips, spine and/or whole body and only takes a few minutes. Your child will need to lie still during this test. For some conditions, this test will be performed annually as part of your child's routine care. It may also be performed if your clinician would like more information about your child's bone health.

Results will usually be available in one week.

Echocardiogram

An echocardiogram (ECHO) is an ultrasound that provides information on the structure, function and strength of the heart. A clear jelly will be placed on your child's chest and the technician or cardiologist will use a small "camera" on the chest and abdomen to send sound waves to the heart. These will create a picture of the heart. An ECHO does not hurt but your child will need to lie still for this test.

Results will usually be available at the time of the scan.

Electrocardiogram

An electrocardiogram (ECG) looks at the electrical activity of the heart. Small sticky plastic dots with leads will be placed on different parts of your child's chest, ankles and wrists. The leads will be attached to a monitor or machine that creates a picture of the electrical activity that causes each heartbeat.

Your child will need to lie still for this test and results will usually be available at the time of the test.

Electrocorticography

Electrocorticography (ECoG) may be performed during some epilepsy surgical procedures. This is similar to electroencephalogram (EEG) monitoring but special sterile electrodes will be placed directly onto the brain to help define the areas of abnormality.

Electroencephalogram

An electroencephalogram (EEG) evaluates and records the electrical activity in the brain. Brain cells communicate with each other through electrical impulses and an EEG can be used to help detect potential problems associated with this activity including seizures.

The EEG involves applying numerous electrodes to the scalp with paste at specific positions on the head. These electrodes record the electricity of the brain. The procedure can include hyperventilation (blowing a pinwheel) and photic stimulation where your child looks at a flashing light. Your child's movements will be recorded on video and matched to any corresponding clinical events captured on the EEG (if they occur).

An EEG with sleep deprivation (where your child's sleep is reduced the night before the test) or an EEG with sleep (to capture seizures and events while your child sleeps) can also be conducted, if needed. We know this is stressful for children and this is only performed when absolutely necessary.

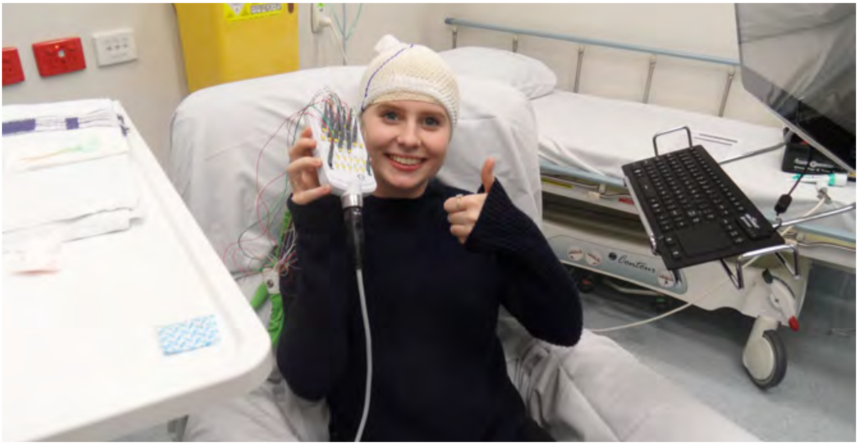
EEGs are completed in Neurosciences and Metabolic Outpatients (6c) and in various inpatient wards as part of planned and emergency admissions.

Standard EEG results will usually be available in four weeks.

EEG (24-hour ambulatory)

Some children may require a 24-hour ambulatory EEG. This is performed while your child is an outpatient on a take-home device. The brain activity is recorded onto a data card and there is no video with this type of monitoring.

Results will usually be available within four to six weeks.



EEG (long-term/prolonged)

Some EEGs are performed over prolonged periods from one to five days. Your child will be an inpatient during this period. Long-term EEGs are similar to routine EEGs but the electrodes are attached to the head more securely using a water soluble paste. This type of video-monitoring is requested to capture seizures and events, and is used as a diagnostic tool, as an aid for medication management or for detailed assessment before epilepsy surgery.

Please speak to your consultant neurologist about result timeframes.

Electromyography

See nerve conduction studies.

Electroretinography

An electroretinography (ERG) test, also known as an electroretinogram, measures the electrical response of the light-sensitive cells in your child's eyes. These cells are known as rods and cones, and are part of the retina (back of the eye). This test is conducted as an outpatient procedure or under a general anaesthetic during an inpatient stay.

Results will usually be available in four to six weeks.

Genetic tests

Genetic tests are used to identify if your child's neurological condition is caused by an underlying inherited (genetic) problem. These detailed tests will usually involve taking a blood sample. Some rarer conditions may require the collection of additional tissue samples such as skin or muscle.

The tests may be analysed by specialist laboratories that are located interstate or overseas. Please speak to your consultant neurologist about result timeframes as these will depend on the laboratory and type of testing being conducted.

If a genetic cause is identified, your consultant neurologist may refer your family for genetic counselling with Genetic Health Queensland. Patients living in New South Wales will be referred to the nearest genetics service in their state.

Sometimes we may suspect your child's condition is caused by a genetic problem but current tests will be unable to identify the cause. As further information about genetics becomes available, your consultant neurologist will consider whether new tests are appropriate for your child.

Lumbar puncture

A lumbar puncture involves using a needle to obtain a small sample of cerebrospinal fluid (CSF) from the base of your child's spine. CSF is a clear, colourless liquid that delivers nutrients and 'cushions' the brain, spinal cord and central nervous system.

This common medical procedure may be used to show if abnormal cells are present. These cells indicate specific diseases in the central nervous system.

A lumbar puncture may also be used to measure specific chemicals and cerebrospinal fluid (CSF) pressure. This test will assist with the diagnosis of your child's condition.

Your child may be lightly sedated for the procedure. Alternatively, it may be coordinated with other procedures if your child is having a general anaesthetic.

Please speak to your consultant neurologist about result timeframes as these will depend on what is being tested.

Magnetic resonance imaging

Magnetic resonance imaging (MRI) uses magnetic waves to create a picture of the inside of the body. This type of scan does not use radiation.

A special dye (a gadolinium-based contrast) may be injected into a vein during the procedure to give further information during the scan. Your child will need to lie still on the table inside the MRI machine while the pictures are taken or may be given a general anaesthetic if your doctor decides this approach is needed.

Your child cannot wear anything metal (jewellery, belt, etc.) because the machine attracts metal. If your child has a ventriculoperitoneal (VP) shunt, vagus nerve stimulation (VNS) device, cardiac pacemaker or any other implantable device it is very important for your child's safety that you advise:

- your consultant neurologist at the time the MRI test is discussed
- the MRI technician before the procedure.

Your child will hear a rhythmic knocking sound like a drumbeat when

the MRI machine is on. If your child is awake during the MRI you will have the option to stay in the room with them, if it's safe to do so. If you cannot be cleared for MRI safety, you will need to stay in the waiting room. The MRI radiographer will always be able to hear, see and communicate with your child during the scan. The MRI can last from 30 minutes to two hours and your child will be able to watch a movie while they are in the scanner.

An MRI does not hurt but some children do not like the loud knocking sound and/or may become uncomfortable from lying still. Where appropriate, children over four years of age will be considered for a 'mock MRI'. This will involve practising lying still and listening to the sounds of the MRI machine with one of our occupational therapists to determine if your child will be able to complete their test without a general anaesthetic.

Routine test results will usually be available in one week.

Nerve conduction studies

Nerve conduction studies (NCS) and electromyography (EMG) assess how the nerves and muscles are working. They also help diagnose some neuromuscular disorders and conditions that affect the peripheral nerves. Your peripheral nerves are located outside your brain and along your spinal cord. These help you control your muscles and experience the senses. Healthy nerves send electrical signals more quickly and with greater strength than damaged nerves. These procedures measure how quickly electrical signals move through your peripheral nerves and muscles.

The procedures will be performed by a consultant neurologist and may take up to one hour. If your child requires light sedation for this procedure, they will need to remain in hospital for observation for at least one hour afterwards.

Results will usually be available in one week.

Neuropsychology

Neuropsychology provides a detailed profile of your child's cognitive strengths and weaknesses. It is used to help understand your child's thinking skills, particularly in cases where changes are subtle and not evident through other assessments or neuroimaging. It helps with diagnosis and treatment planning for children experiencing difficulties with memory, attention, language or other aspects of cognition or behaviour.

Neuropsychological conditions can worsen or improve with time and treatment. An initial neuropsychological evaluation provides the information we need to monitor these changes and can be used to predict and enhance social, educational and vocational outcomes. Evaluations can range from brief to detailed sessions involving several hours of face-to-face contact. These will usually involve discussions with the neuropsychologist as well as question/answer, and puzzle-like activities. The results assist with developing individual treatment recommendations or plans. Neuropsychology testing is completed in Allied Health (6a) or Rehabilitation Outpatients (6g), and occasionally during inpatient admissions.

Please discuss result timeframes with the neuropsychologist who is performing the evaluation.

Positron emission tomography

A positron emission tomography (PET) scan is an imaging technique used to observe metabolic processes in the body. A small amount of a radioactive glucose-like substance will be injected into your child's vein and scans will be taken to determine how the glucose is used in the brain or body at a cellular lever. This scan may be used as part of the preparation for epilepsy surgery and completed during an inpatient admission or an outpatient visit. A general anaesthetic is often required as the patient needs to remain still for up to 30 minutes. The study is performed at the Royal Brisbane and Women's Hospital or Princess Alexandra Hospital.

Please discuss result timeframes with your consultant neurologist.

Respiratory function tests

Respiratory function tests (RFT) measure how effectively the lungs are working. The respiratory function test that is usually performed is spirometry. In this test, your child will be asked to blow into a plastic mouthpiece connected to a machine. The machine will measure how much air the lungs can hold and the force of the air breathed out. Your child will probably be asked to repeat the test a few times to obtain an accurate reading.

Results will usually be provided on the day of your child's appointment.

Single photon emission computed tomography

A single photon emission computed tomography (SPECT) scan uses a combination of a CT scan and a radioactive substance (injected into a vein) to detect changes in the blood flow in the brain. The scan provides 3D images and may be used as part of the preparation for epilepsy surgery. It may be performed during an inpatient admission or an outpatient visit. A general anaesthetic is often required as your child needs to lie still for up to one hour.

Please discuss result timeframes with your consultant neurologist.

Somatosensory evoked potentials

Somatosensory evoked potentials (SSEP) test sensory nerve pathway functions. This studies how body sensations are relayed to your child's brain and how the brain receives that information. A stimulating electrode will be placed on your child's arm or leg and this will generate an electrical signal. Recording electrodes will also be placed on the head or spine to provide information about the health of your child's peripheral nerves and spinal cord. This test is conducted in 6c Neurosciences and Metabolic Outpatients or under a general anaesthetic during an inpatient stay.

Results will usually be available in one week.

Spirometry

See respiratory function tests.

Ultrasound

An ultrasound works by bouncing sound waves off parts of the body. Gel is placed over the part of the body that is being studied. A camera (or transducer) will then be placed on the gel and moved around to obtain a clear picture of the tissue or organ.

An ultrasound does not hurt, but sometimes the sonographer may have to push the camera quite firmly. Some preparation may also be needed such as fasting or drinking water. Staff from Medical Imaging and Nuclear Medicine will provide you with preparation information when the test is booked. Please refer to your booking letter for further instructions.

Results will usually be available in one week.

Urine tests

Urine tests are often used to help diagnose and monitor children with neurological conditions. For example, these common tests may be used to monitor your child's ketones (if they are on a ketogenic diet) or as part of a metabolic study.

Results will usually be available within two to four weeks.

Visual evoked potential

A visual evoked potential (VEP) tests the function of the optic nerve pathways. This test is conducted in 6c Neurosciences and Metabolic Outpatients or under a general anaesthetic during an inpatient stay.

Results will usually be available in two weeks.

X-ray

An X-ray is a picture of the inside of the body. For example, X-rays can show if a bone is broken, if there is an infection or fluid in the lungs. X-rays do not hurt but your child will need to stay still for a short period of time.

Results will usually be available in one week.

Treatments

The following treatments are commonly used to help treat and manage children with neurological conditions at the hospital. Your consultant neurologist will advise if these are needed for your child.

Anticonvulsive medications

Anticonvulsive medications are used to help manage epileptic seizures. The choice of anticonvulsant will be depend on your child's epilepsy syndrome and this will be determined by your clinician.

Monitoring the effects of this medication for effectiveness and side effects throughout treatment is needed. For example, your child's bone health and organ function will be monitored by your consultant neurologist using blood tests and/or DXA scans (see p. 98). Please ensure you advise your consultant neurologist of any side effects your child experiences.

In general, we start anticonvulsants at the lowest possible dose and increase this slowly until seizure control is obtained. Several other anticonvulsants are available if the initial selection is ineffective or inappropriate for your child. Please note, there is a seizure diary in this handbook (see p. 45) to help you monitor your child.

Intravenous Immunoglobulin

Immunoglobulins, also known as antibodies, are proteins found in the blood. They are made by a type of white blood cell (called B-lymphocytes) as part of the body's immune (defence) system. Immunoglobulins can help the body to fight infections caused by bacteria, viruses and some autoimmune disorders.

Within neurology, intravenous immunoglobulin (IVIG) is most commonly used to treat autoimmune disorders where the immune system mistakenly attacks and damages cells or tissues in the brain, spinal cord or peripheral nervous system. When IVIG is used in these instances, it is referred to as immunomodulatory therapy. Sometimes it can be used at a high dose for one to two treatments or as a long-term treatment given every four to six weeks. Regular IVIG infusions are performed in the Medical Day Unit.

If IVIG is recommended for your child, your consultant neurologist will provide you with more detailed information about the treatment.

Rituximab

Rituximab is a medicine that works on the immune system to remove some of the white blood cells in the body, called B cells. In neurology, this is used to treat autoimmune disorders where the immune system attacks the nervous system. By removing the B cells, the medication helps stop the body making the antibodies that may play a role in your child's illness. Rituximab is injected into a vein by a slow infusion (through a needle in the back of the hand) once a week for four weeks, then as required as the B cells start to repopulate. You child will have regular blood tests to monitor B cell suppression.

If Rituximab is recommended for your child, your consultant neurologist will provide you with more detailed information about the medication.

Steroids

Corticosteroids, commonly known as steroids, are often used to treat neurological disorders and include medications such as Prednisolone, Dexamethasone and Deflazacort. This medication suppresses the immune system and may be used for short or prolonged courses of treatment depending on the needs of your child.

Steroid therapy is closely monitored for effectiveness and side effects. For example, your child's bone health and organ function will be monitored by your consultant neurologist using blood tests and/or DXA scans (see p. 96) if the steroid course is prolonged. Additional medications may also be required to counteract steroid side effects, e.g. reflux. Your consultant neurologist will provide you with a steroid emergency management plan to help ensure your child's treatment is managed safely.

Please see *Missed medications* (see p. 117) for further information about taking steroids. If steroid treatment is recommended for your child, your consultant neurologist will provide you with more detailed information about the medication.

Therapies

Orthotics

Orthoses are externally fitted splints or braces that are usually custom-made. They are used to improve the range of motion across a joint and reduce contractures (permanent restriction of joint movement), help improve functions such as walking, or prevent or correct a deformity. In most cases, orthotics are used for the ankle and foot however, they may also be used for the spine or arms. Commonly used orthotics include ankle foot orthoses (AFOs), supramalleolar orthoses (SMOs) or in-shoe orthoses. Orthotics can be solid (to maintain joint range) and worn when in a wheelchair or at night, or designed to move flexibly with a joint (to help improve walking).

If needed, orthotics will be prescribed by your neurologist with physiotherapy advice. An orthotist will make the orthotics to fit your child comfortably. Currently, these are available under the Medical Aids Subsidy Scheme (MASS)(health care card required) or through the hospital. If your child qualifies for the National Disability Insurance Scheme (NDIS), you will be able to list the orthotics as part of their package. They are also available through private orthotists via private health insurance or self-funded payments.

Your child should be encouraged to wear their orthotics as prescribed. If the orthotics no longer fit comfortably or rub the foot, please discuss this urgently with your child's orthotist, physiotherapist or neurologist.

Physiotherapy

Physiotherapy exercises may be prescribed for your child to help improve their walking or joint movement. The physiotherapist will go through these with you and your child during the appointment and, if needed, will provide a handout which outlines the exercises.

Exercises such as stretches are only beneficial if they are performed daily and it's important to encourage your child to do these regularly. Many families find it easier to remember the exercises by making them part of their child's daily routine, e.g. doing them just before brushing their teeth or straight after dinner.

Clinical trials

A clinical trial is a research study which aims to improve treatments and patient outcomes. The goal is to establish if a treatment is safe and how well it works in treating a specific disease or condition. In a trial, children are followed closely over time to see which treatments improve their condition with the fewest side effects. New trials are planned based on the results of past trials, what we know about the condition and effective treatments.

Importance of clinical trials

Findings from clinical trials add to our knowledge and progress in the treatment of some neurological conditions. As many neurological conditions are rare, trying different treatments and looking at the results can help us establish which treatments are effective.

Types of clinical trials

The different types of clinical trials are called phases. Each phase of a clinical trial helps answer a different question about the disease or treatment.

Benefits and risks of clinical trials

When treated on a clinical trial, your child receives access to a new therapy for their condition. Just as your child benefits from what was learned through previous trials, other children in the future will be helped by what we learn from current clinical trials.

Some trial medications may have side effects and your child may need to spend more time at a clinic or the hospital to receive the treatment or have tests done. It's also possible that the treatment may not work for your child's disease or condition.

Does my child have to be on a clinical trial?

Participation in a clinical trial is always optional. Please read the *Participant Information Sheet* (provided by your consultant neurologist) carefully before deciding whether you would like your child to take part. Ask questions about anything that you don't understand or want to know more about. Before deciding if you would like your child to take part, you may want to talk about it with a relative or friend, or your child's GP, paediatrician or LCCH health care team.

You may choose not to enter your child on a clinical trial. You may also choose to remove your child from a trial at any time. Your choice will not affect how the health care team feels about you or your child. Your child will still receive the best possible care.

If you decide not to enrol in a clinical trial, your child will receive standard treatment. This is the best known therapy at the time.

How are trials planned?

The proposed aims, eligibility criteria and procedures (called protocol) for the trial is sent to the Children's Health Queensland Hospital Human Research Ethics Committee. The committee will review the clinical trial to make sure that the rights of people participating are protected.

Each trial is reviewed many times by experts before a treatment centre can start a trial.

Information and consent

If you are interested in participating, your consultant neurologist will review the *Participant Information Sheet* with you. This will include a schedule for every treatment, test and procedure that will be required during the trial.

Keep in mind that each child is different and the treatment schedules may change. These changes will depend on how your child responds and a delay in treatment is common if your child gets a fever or has low blood counts.

After your consultant neurologist reviews the treatment plan with you, you will be asked to give permission for your child to start treatment. This is called giving parental permission or informed consent.

You will also be asked to sign a form that describes the plan. This form lists the risks and benefits of the treatment and the other treatments that may be available. When you sign the form, you are saying that you understand what the consultant neurologist has explained to you and you agree to start the treatment.

If appropriate, your child will be asked to agree to the treatment plan. When a minor (a child under 18-years-old) agrees to the plan, the child is giving consent.

Members of your health care team will help explain the treatment plan to your child in words that he/she can understand.

Informed consent is a process that does not stop after you sign the form or start treatment. Every day in the hospital or at each clinic visit, your consultant neurologist will talk with you about the plan of care. This is your chance to ask questions and decide whether or not you agree with the plan.

Special access schemes

Special access schemes enable patients to legally access unregistered medications. These schemes include compassionate access schemes and expanded access programs. The medications may be:

- free, subsidised or available for a fee from the manufacturer
- available to patients who cannot access a clinical trial
- available to patients who have been on a trial that has ended.

These schemes aim to provide treatment for a patient's disease or condition, rather than collect data about the medication.

Current trials and schemes

The Department of Neurosciences is active in clinical research. For information about current trials available for your child's condition, please visit **www.anzctr.org.au**. Children's Health Queensland also participates in schemes from time to time, including the Compassionate Access Scheme testing Epidiolex, which is a medicinal cannabis product. Read more here: **http://conditions.health.qld.gov.au/HealthCondition/condition/8/60/810/medicinal-cannabis-queensland-clinical-trial**

If you are interested in a particular trial or scheme, please speak directly to your consultant neurologist about your child's eligibility.

Surgery

Some children with complex neurological diseases or conditions will require surgery as part of their care and treatment. If your child requires surgery, a period of fasting will be needed before they are given an anaesthetic. Your health care team will provide you with instructions about when your child should commence the fast and which foods and fluids are acceptable. Please follow these instructions to avoid a delay in your child's surgery. Fact sheets about fasting for morning and afternoon surgery are available on the Children's Health Queensland website **www.childrens.health.qld.gov.au/fact-sheets**

If surgery is planned for your child, please notify your consultant neurologist and neurological nursing staff as specific precautions may be required depending on your child's condition and treatment.

Infection management

An illness or infection in a child with a neurological condition may have a mild or severe impact on their overall condition.

All children will become unwell at some time in their childhood. However, there are steps you can take to prevent the spread of disease and reduce the chances that your child and/or family become unwell.

Immunisation

Immunisation is a simple, safe and effective way to protect your child from certain diseases. The risks of these diseases are far greater than the very small risks of immunisation.

It is recommended that your child is vaccinated on time according to the National Immunisation Program Schedule which you will find in your child's Personal Health Record or online at **www.immunise.health.gov.au**

If your child has a medical condition they may be eligible for extra, free vaccinations in addition to the annual influenza vaccination. Your treating doctor or health care team will discuss this with you. Within LCCH, your child may be vaccinated as an inpatient in the ward, as an outpatient through the Queensland Specialist Immunisation Service or at the Immunisation Centre (2g) on the second floor of LCCH.

It's also important that all family and friends in contact with your child are up-to-date with their vaccinations (including annual influenza) as this will offer your child extra protection.

If you have any concerns or questions regarding immunisation, please speak to your consultant neurologist or GP, or call 13 HEALTH (13 432584) or the LCCH Immunisation Centre on 07 3068 5600.

Preventing infections

To prevent the spread of infections, our nurses, doctors and other staff will always wash their hands or use hand sanitiser before and after contact with your child. We ask that families and visitors also do the same.

Hand sanitiser stations can be found in several locations in ward areas and around the hospital. This makes it easier for everyone to remember to keep their hands clean at all times.

It is perfectly okay to remind your child’s health care worker to wash their hands. They are highly aware of the need for hand hygiene, but if you have concerns, it is okay to ask!

Please help protect our families and staff by not visiting the hospital if you are unwell. Cover coughs and sneezes using a tissue or your sleeve.

If you have any concerns or would like some advice, please speak to the person caring for your child or the treating team.

HOSPITAL HYGIENE

All visitors please:

Wash or clean your hands on arrival and before leaving

Cover coughs and sneezes using a tissue or your sleeve

Wash or clean your hands after coughing or sneezing

Do not visit if you feel unwell

If you are ill and MUST visit...

ASK FOR A MASK

Infections and your child

Please see your GP immediately if:

- your child is taking steroids and they, or a family member, has an infectious disease
- you suspect your child has been in close contact with someone who has an infectious disease.

Your GP will be able to advise if your child needs additional medication during this time.

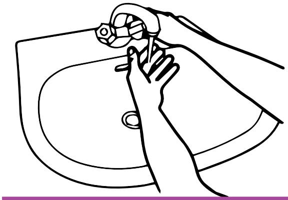
Children's Health Queensland Hospital and Health Service

Lady Cilento Children's Hospital

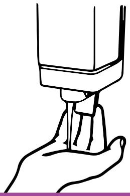
Infection Management and Prevention Service

How to handwash

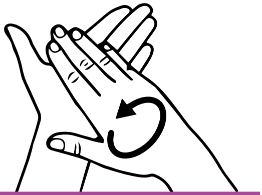
Handwashing technique with soap or antiseptic and water.
Procedure should take 40-60 seconds.



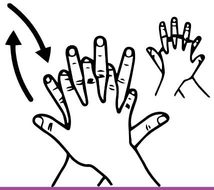
Wet hands with water



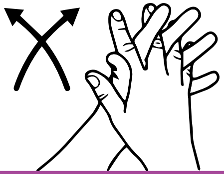
Apply soap or antiseptic to wet hands



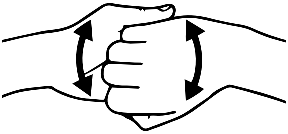
Rub hands palm to palm



Right palm over left back of hand and left palm over right back of hand

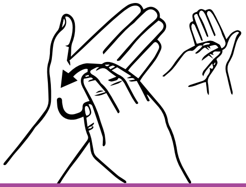


Palm to palm with fingers interlaced

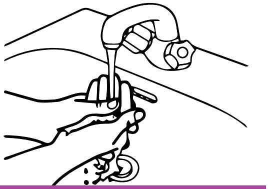


Backs of fingers to opposing palms with fingers interlocked

Rotational rubbing of right thumb clasped in left palm and vice versa



Rotational rubbing, backwards and forwards with clasped fingers of right hand in left palm and vice versa



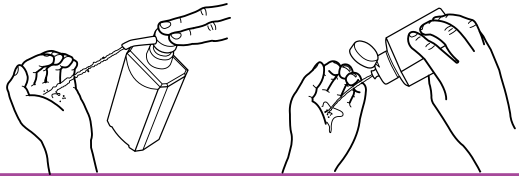
Rinse hands thoroughly and gently pat dry

Based on World Health Organisation *How to Hand Wash* www.who.int/gpsc/5may/How_To_HandWash_Poster.pdf

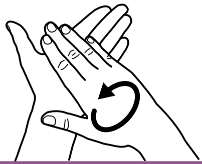
Infection Management and Prevention Service

How to handrub

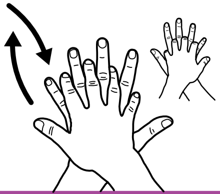
Rub hands for hand hygiene. Wash with soap/antiseptic and water when visibly soiled! Procedure should take 20-30 seconds.



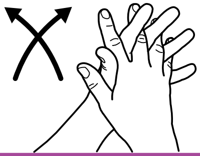
Apply a palmful of the alcohol based hand rub in a cupped hand.



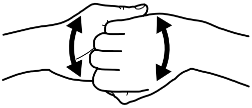
Rub hands palm to palm



Right palm over left back of hand with interlaced fingers and vice versa

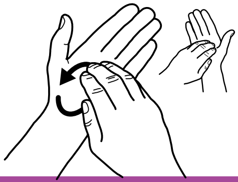


Palm to palm with fingers interlaced

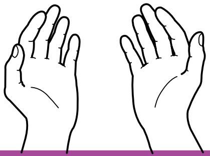


Backs of fingers to opposing palms with fingers interlocked

Rotational rubbing of left thumb clasped in right palm and vice versa



Rotational rubbing, backwards and forwards with clasped fingers of right hand in left palm and vice versa



Once dry your hands are safe

Based on World Health Organisation *How to HandRub* www.who.int/gpsc/5may/How_To_HandRub_Poster.pdf

Nutrition and diet

Monitoring nutrition, growth and development, and dietary therapies are important for some neurological conditions. For some children, specialised diets (e.g. Ketogenic) may also be used to manage conditions such as epilepsy.

You will be linked with a dietician if regular nutritional support is part of your child's management plan. You may also be referred to a dietician at your local hospital if your child requires monitoring closer to home.

Medications and supplements

Your child may be prescribed medications and/or supplements as part of their overall treatment and management. This may occur when your child is an inpatient or outpatient, and will follow an assessment by your health care team.

Your child's medications and doses may be changed over time and your consultant neurologist will provide you with information including:

- the reason for taking the medication or supplement
- what dose to take and when
- common side effects and when/who to contact if your child experiences these effects
- any special precautions associated with the medication or supplement
- the duration of the treatment
- the expected outcomes.

Please talk to your consultant neurologist about your expectations for each medication or supplement and what to do if you have any concerns.

Prescriptions

Your GP and paediatrician can write prescriptions (including repeats) for most, if not all, of your child's medications. Please speak to your GP in the first instance regarding repeats and let them know when you have only one repeat left. This will allow time for a new prescription to be written.

Most of your child's medications (including repeats) can be obtained from your local pharmacy. Please ask your consultant neurologist or local pharmacy if this is possible for your child's medications.

Please note, medication costs may vary between pharmacies. Medications can also be dispensed by the LCCH Pharmacy (only LCCH prescriptions will be accepted).

Complex and restricted medications

Your child may require complex and restricted medications which can only be dispensed by Queensland Health hospital pharmacies. In these cases, it may be more appropriate for your child's medications to be managed and dispensed by the LCCH Pharmacy (where your prescription repeats can be kept on file). Please contact the Pharmacy via email or phone at least five working days before the repeat medications are required.

Send your repeats request email to LCCHPrescriptionRepeat@health.qld.gov.au or call 07 3068 1900 (option 1).

Restricted medications are often only available through the Special Access Scheme (SAS) and require an Individual Patient Authority (IPA). Your consultant neurologist will complete the application paperwork each year to allow you continued access to the medication for your child. Your consultant neurologist will receive a notification when these need to be renewed. Where possible, the LCCH will work with other QH hospital pharmacies so you can collect the medication from your local hospital pharmacy.

Please ask your consultant neurologist or LCCH pharmacy if it's possible to collect restricted medications from your local public hospital.

Taking medicines

Medications can be administered in different ways including:

- by mouth
- via an assisted feeding device e.g. nasogastric tube, jejunostomy or percutaneous endoscopic gastronomy (PEG), gastrostomy
- directly into your child's veins e.g. intravenous (IV), peripherally inserted central catheter (PICC) line or infusaport
- by injection into the skin.

Your consultant neurologist, pharmacist and nursing team can provide you with advice about the medications and how they should be administered.

Always make sure your child is taking the right medicine in the right amount at the right time via the right route. Your consultant neurologist will provide written information if the doses need to change. Your pharmacist can also provide you with written information about any medication/s your child is taking, including possible side effects.

Each medication will have one generic name and may have several trade names. Medications in tablet forms will have a number of milligrams per tablet and liquid

Lady Cilento Children's Hospital Pharmacy

Lady Cilento Children's Hospital, Level 2 (near B lifts)
Monday to Friday, 8am-6pm; weekends and public holidays 9am-5pm
t 07 3068 1900 **e** LCCH.Pharmacy@health.qld.gov.au

medications will have a number of milligrams per measure of liquid. Your consultant neurologist will advise the dose for your child and, if you are unsure of any aspect relating to medications, please ask a member of your health care team for assistance.

Liquid medications

Liquid medications are primarily used:
- for younger children
- for children who have difficulty swallowing tablets
- to avoid blockages for children with assisted feeding devices.

Reusable 'oral dispenser' syringes are available to ensure liquid medications are accurately measured. It's important to use only recommended dosing dispensers. Please discuss this with your pharmacist.

Speak to your consultant neurologist about changing over to tablets (if an equivalent is available) when your child shows signs that they may be ready to start taking them or if they are spitting out more than half their dose.

Tablets

Tablets come in varying sizes, shapes and strength. Most are intended to be swallowed whole and some may be crushed or dissolved in a liquid. Check with your consultant neurologist or pharmacist about whether you can crush or dissolve your child's tablets.

Here is how you can help your child take oral medicine:
- if the tablet can be crushed, put it in a small amount of food (apple sauce, yoghurt, juice or flavoured syrup). Use a small amount of food so your child can swallow all of it.
- if giving medications in food or drinks, offer the food or drink first in a small quantity.
- avoid putting medication in full bottles of drink or mixing it into an entire bowl of food as your child may not eat it all and may miss some of their medication.
- some medicines can be crushed and/or put in a gel cap for older children.

Ask your doctor or pharmacist about the best time to take each medicine.

Feeding devices

Your child may need an assisted feeding device such as a nasogastric tube, percutaneous endoscopic gastrostomy (PEG), button or a jejunostomy during their treatment. If this is required, your child's medication regime may need to be reviewed by your health care team and additional precautions will need to be taken.

Please check with your health care team about:
- when the medications should be given in relation to the enteral feed
- what is the best preparation to give via the tube, e.g. liquid or tablet medication
- which combinations of medications are safe to be given at the same time.

Remember to always flush the feeding tube with at least 10ml of water after giving medications. This will ensure your child receives the full dose.

Medication reminders

Every family will find different ways to remember when to take medication. Some ideas are:

- associate medications with activities such as breakfast and dinner for twice-daily medications or brushing your teeth for nightly medications
- use a tablet container with the days of the week on it
- write a chart for the refrigerator
- set alarms on your phone
- find an app for your phone that works for you.

Gaining independence

Many children will be able to take some or all of the responsibility for their medication management as they move into their teenage years. Every young person will develop at their own pace and parents will probably need to keep providing support for a period of time to ensure the medications are still being taken.

Teenagers, where able, are encouraged to learn the names of their medications and the doses. During consultations with staff at the hospital, where appropriate, please support your teenager to state their medication name/s and dose/s to further assist with their independence.

Missed medications

Generally, if medications are missed or forgotten, give the next dose as soon as possible (within two hours). If greater than two hours, please discuss this with your doctor or pharmacist. Never give a double dose to catch up on a missed dose.

Steroids

Regardless of how long your child has been on corticosteroids, it is important that people taking corticiosteroids **do not miss their dose for more than 24 hours**. When taking corticosteroids your body's production of natural cortisol is reduced which can cause serious illness and be life-threatening if you miss a dose of corticosteroid. Please refer to your child's Emergency Management Plan if you are concerned and/or contact the Department of Neurosciences during business hours. If urgent or after hours, please call the hospital switchboard on 07 3068 1111 and you will be transferred to the appropriate medical officer. **In emergencies call for an ambulance on 000.**

Vomiting or spitting out medication

If your child spits out their dose of medication, repeat the dose. If your child vomits within 15 minutes of taking the medication, repeat the dose after the child has settled i.e. within 30-60 minutes. If your child is consistently spitting out their medication, please contact the Department of Neurosciences during business hours for advice from the nursing staff. If urgent or after hours, please call the hospital switchboard on 07 3068 1111 and and you will be transferred to the appropriate medical officer. **In emergencies call for an ambulance on 000.**

Non-prescription medications and supplements

As part of your child's treatment or by family choice, you may be giving your child over-the-counter medications, vitamins, herbal/natural medicines, or other supplements.

You may be considering giving your child nutritional and/or herbal supplements (also known as complementary or alternative medicines, homeopathic remedies, or vitamins). While some of these products may be safe, some natural products may adversely interact with your child's medications.

To avoid unwanted interactions, please tell your health care team about all non-prescription medicines/supplements during each hospital visit.

Many types of vitamin and herbal supplements are available through pharmacies, health food stores, online and from naturopathic physicians. These supplements, unlike pharmaceutical medications, are not subject to the rigorous approval process of the Therapeutic Goods Administration which ensures safety, effectiveness, labelling, purity, sterility and other standard measures are applied. Therefore, caution is advised when purchasing these items. Talk with your child's consultant neurologist,

! General supplement guidelines

1. Please inform your health care team about any supplements your child is taking. This is important because things that may seem safe, such as certain foods or medications, may interfere with your child's treatment.
2. Pharmacy staff can provide information about the use of supplements and any possible interactions with the medications and treatment being given to your child.
3. If you are still interested in using herbal supplements after considering these guidelines and discussions with your consultant neurologist, you are advised to purchase products from named brand manufacturers who have established procedures to ensure quality and potency. Look for products showing the scientific name and quantity of any botanical, the name and address of the manufacturer, a batch or lot number, and the date of manufacturing and expiration date. This information is critical to identifying the supplement and dealing with any problems related to their use.

pharmacist or nurse for advice and support regarding over-the-counter medications, vitamins, supplements, herbal or natural products.

Medication safety

Wash your hands before and after giving medications. It is also important to store all medication, including over-the-counter products and alternative medicines in a secure place, out of reach of children.

Tips for storing medication safely:

- Store medication out of reach and out of sight of children (at least 1.5m high) in a lockable cupboard
- Ask your pharmacist to supply your medication in a child-proof bottle or container
- Never leave medications on the bedside table
- Take out-of-date medications to your local pharmacist to dispose of safely or place in an outside bin so it cannot be retrieved and swallowed by children
- If you keep medication in your handbag be sure to keep it out of reach of children – don't leave it in the back seat of your car with your child. Store medication in a child-proof container
- Put medication away as soon as it has been taken or purchased. Many poisonings occur when medication has been left out on the benchtop or while travelling from the shop to home
- Make sure your child is well supervised when visiting other people's houses or other unfamiliar locations where medication might not be stored safely
- Keep medication that requires refrigeration in a tightly sealed or lockable container at the back of the fridge where it can't be reached or seen by children.

Overdoses and poisoning

If you give your child too much of their medication or supplement, please call the Queensland Poisons Information Centre on 13 11 26. They can provide first aid instructions, information on possible symptoms and advice on the need for assessment by a doctor or referral to hospital.

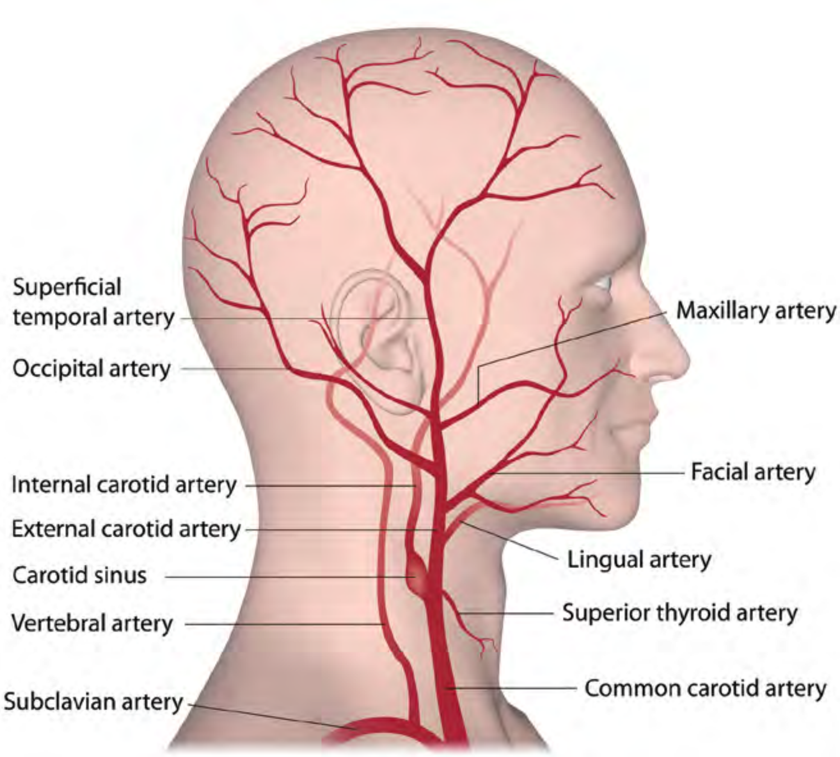
Call 000 immediately if your child is less responsive than usual or having breathing difficulties.

For more non-urgent information visit www.childrens.health.qld.gov.au/poisons-information

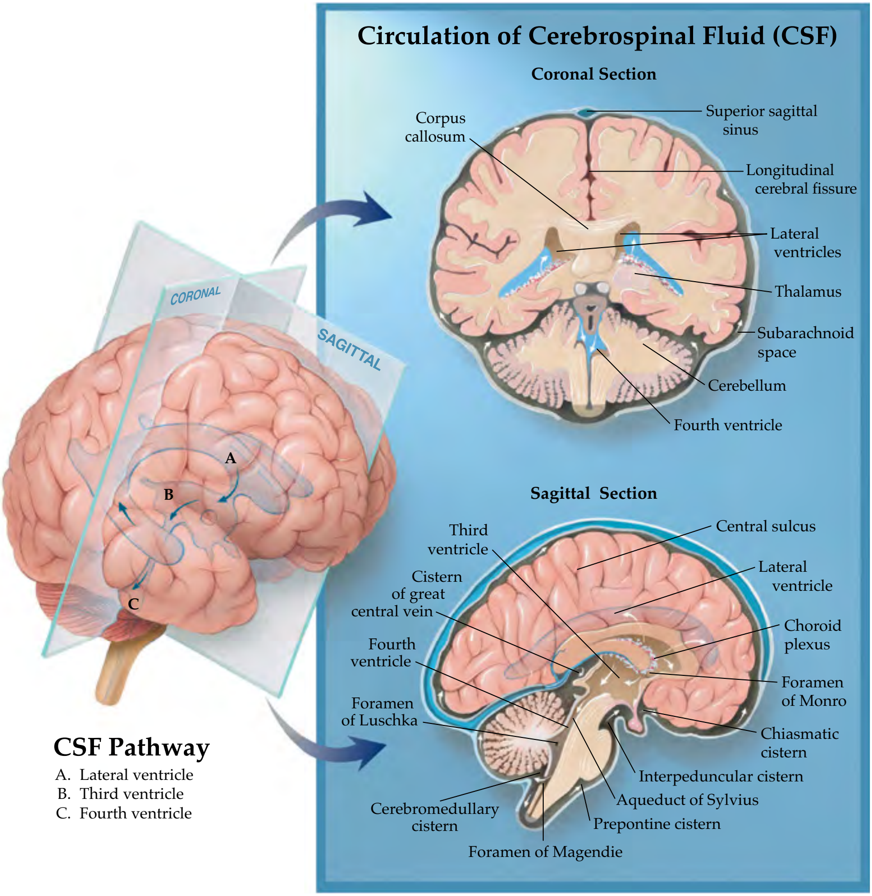
Medical illustrations

Use the illustrations on the following pages to discuss your child's condition and treatment with clinicians.

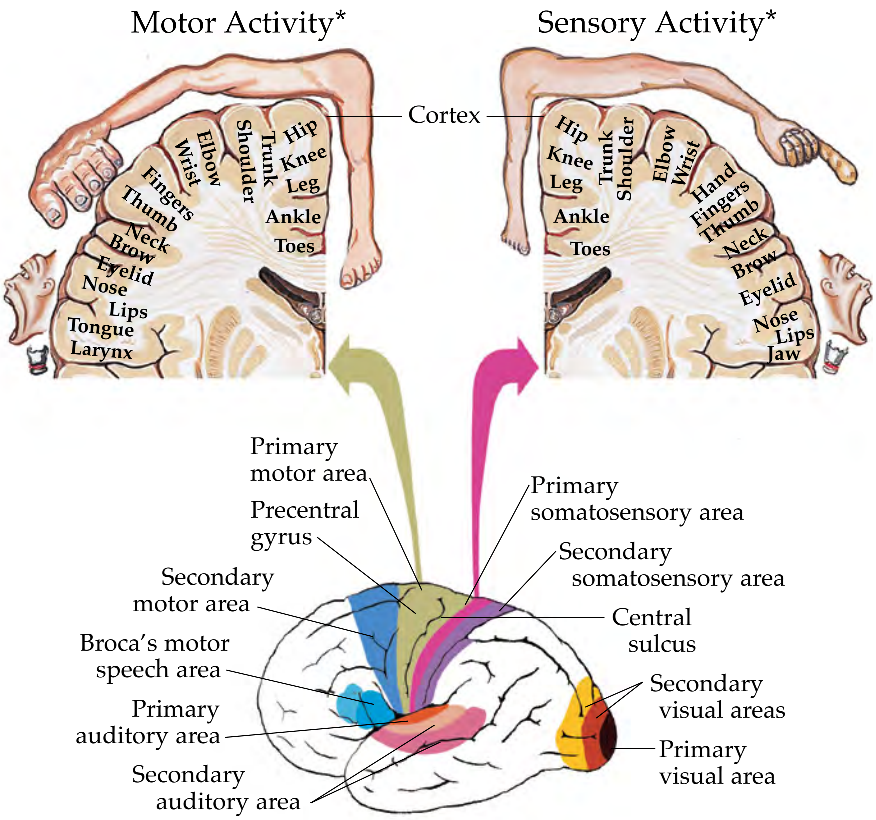
Blood supply of the head and neck



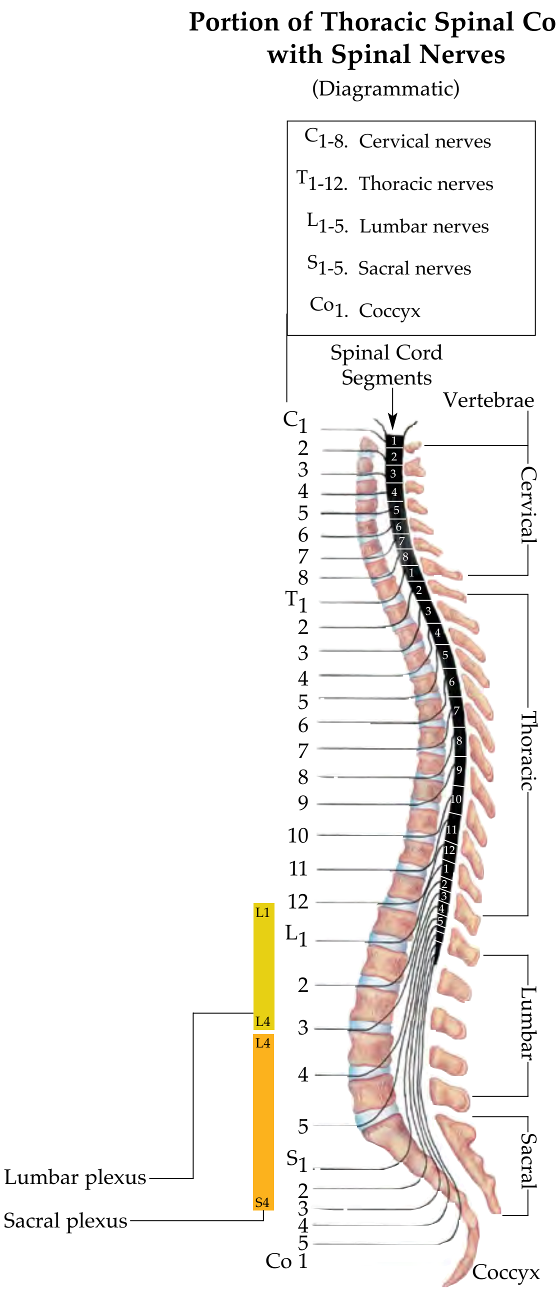
Circulation of cerebrospinal fluid



Somatotopic organisation of the cerebrum

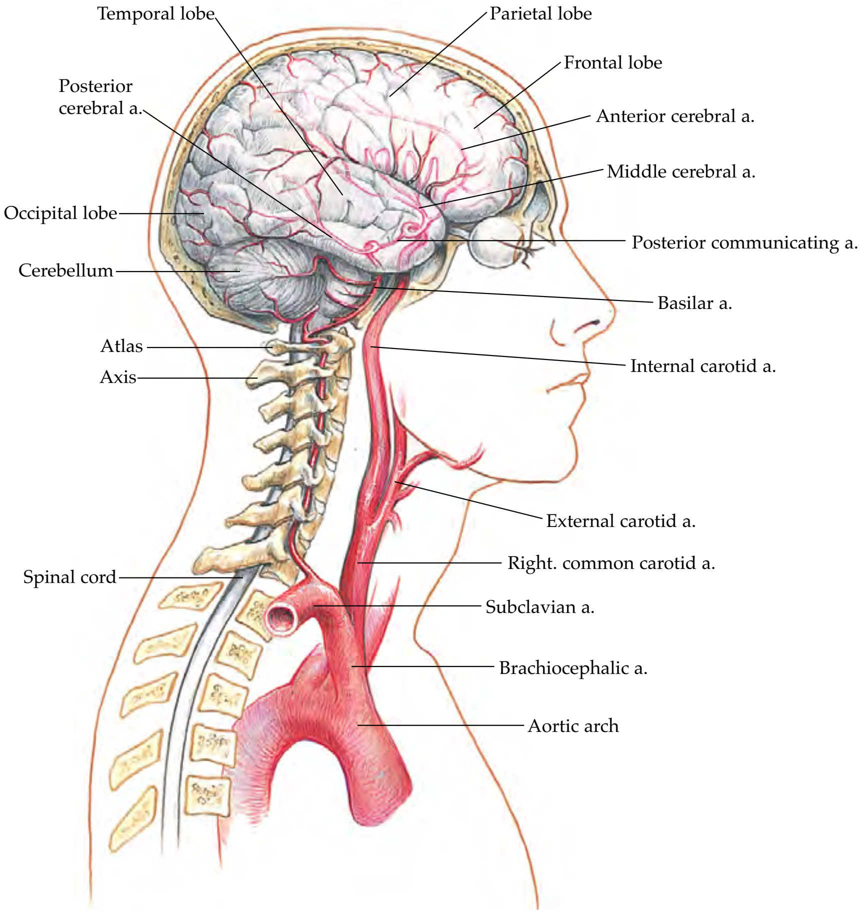


Portion of thoracic spinal cord with spinal nerves

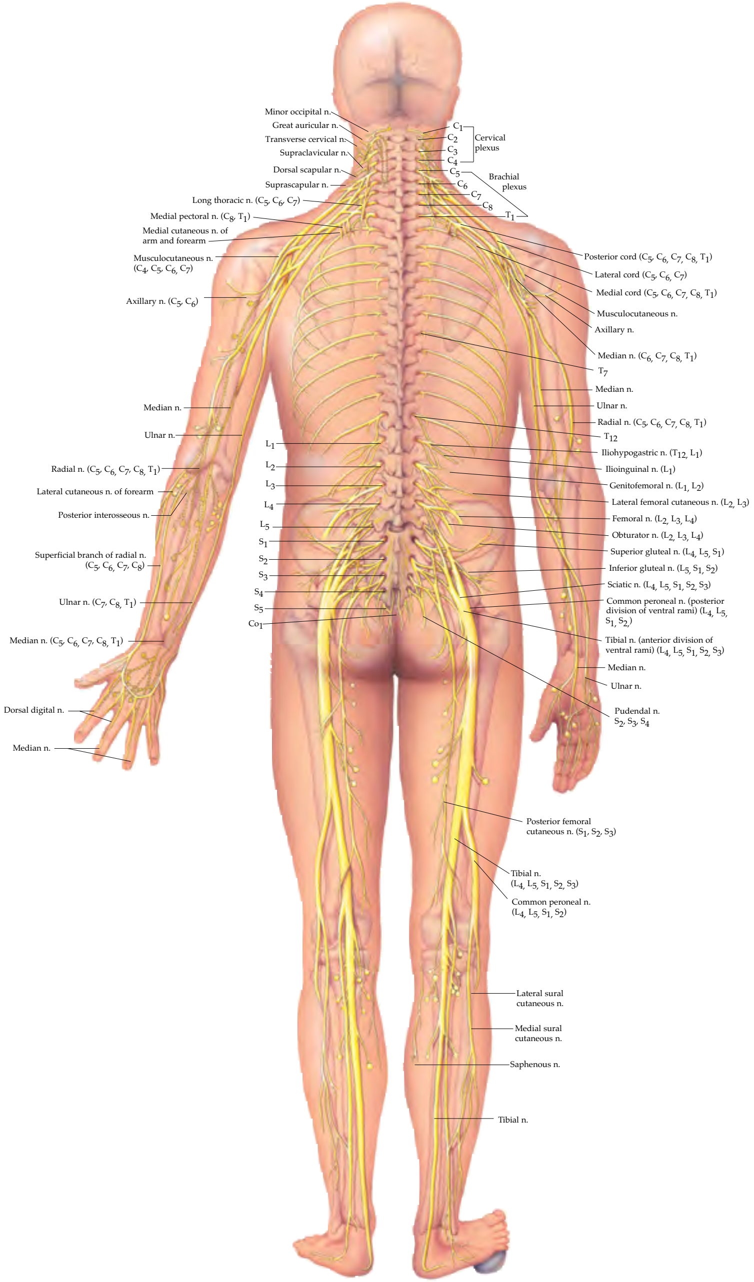


Internal carotid and vertebral arteries

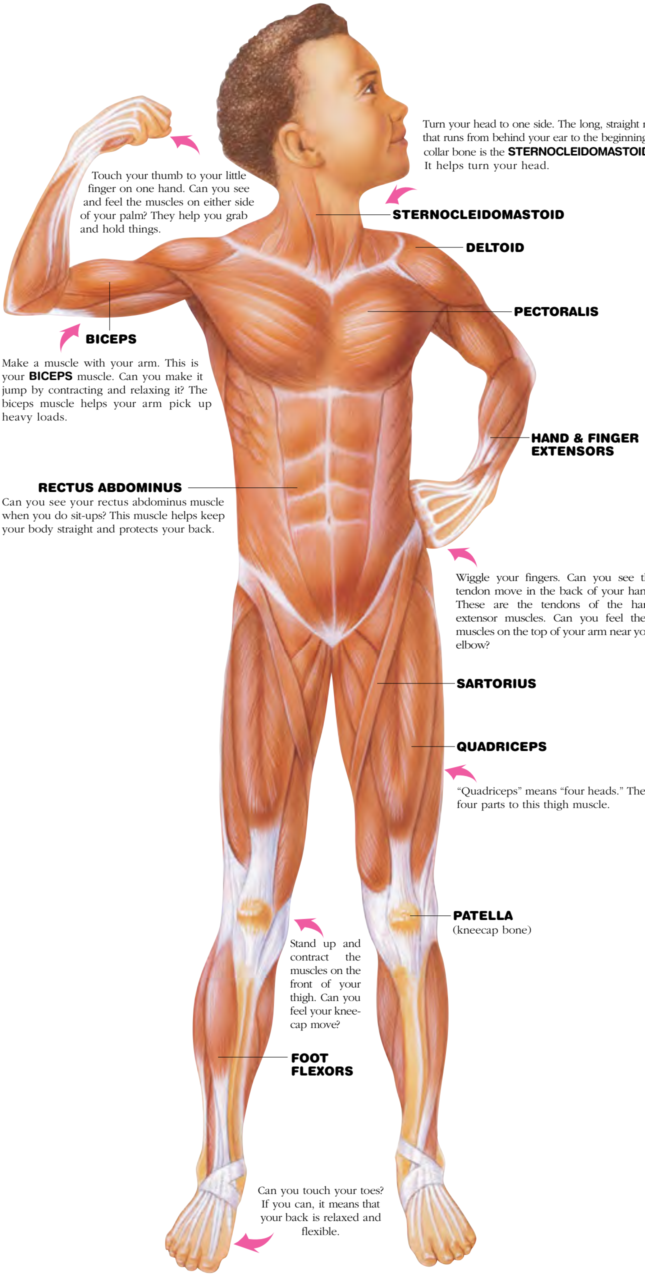
Internal Carotid and Vertebral Arteries



The peripheral nervous system



Muscular system



Turn your head to one side. The long, straight muscle that runs from behind your ear to the beginning of your collar bone is the **STERNOCLEIDOMASTOID.** It helps turn your head.

Touch your thumb to your little finger on one hand. Can you see and feel the muscles on either side of your palm? They help you grab and hold things.

Make a muscle with your arm. This is your **BICEPS** muscle. Can you make it jump by contracting and relaxing it? The biceps muscle helps your arm pick up heavy loads.

RECTUS ABDOMINUS

Can you see your rectus abdominus muscle when you do sit-ups? This muscle helps keep your body straight and protects your back.

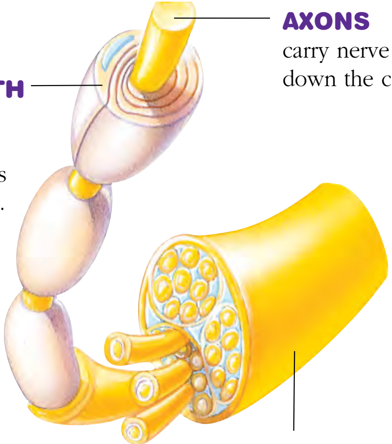
Wiggle your fingers. Can you see the tendon move in the back of your hand? These are the tendons of the hand extensor muscles. Can you feel these muscles on the top of your arm near your elbow?

“Quadriceps” means “four heads.” There are four parts to this thigh muscle.

Stand up and contract the muscles on the front of your thigh. Can you feel your knee-cap move?

Can you touch your toes? If you can, it means that your back is relaxed and flexible.

Nerve

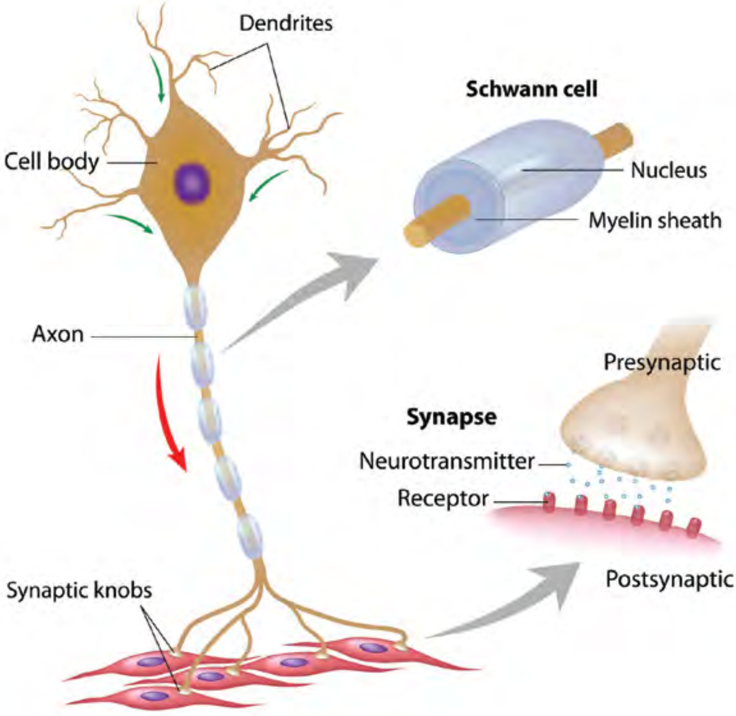


A **MYELIN SHEATH** wraps around the nerve axon. This insulation speeds up the nerve impulse.

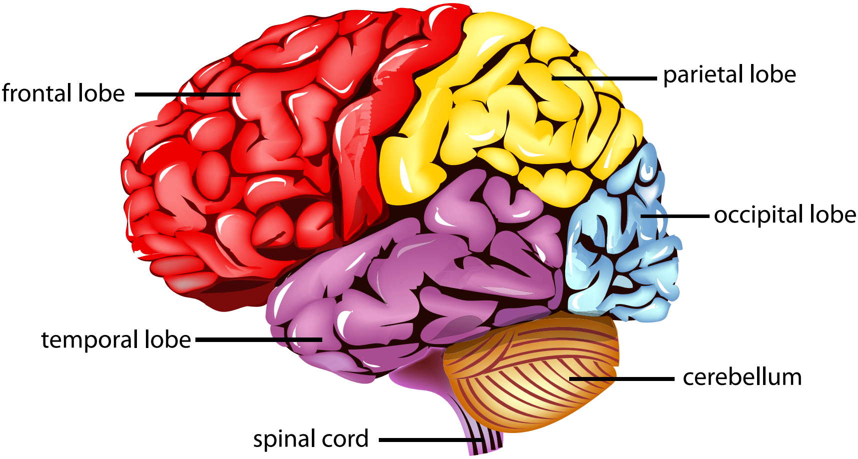
AXONS carry nerve impulses down the cell.

NERVES are made of bundles of nerve cell axons.

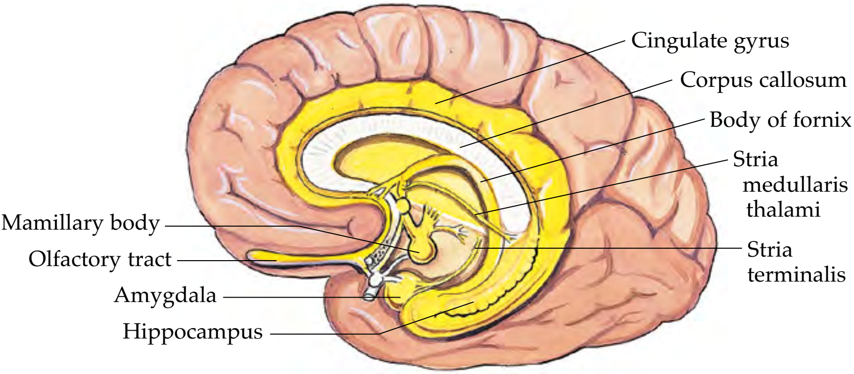
The motor unit



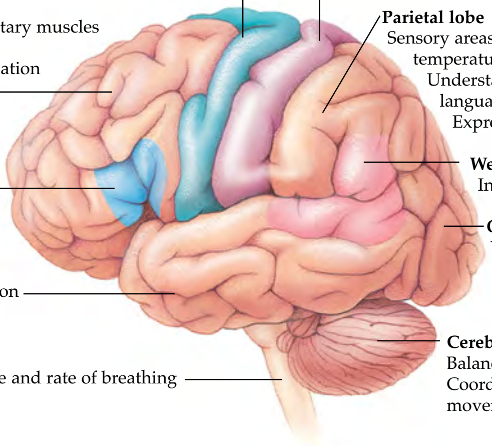
Parts of the human brain



Limbic system



Functions of the brain



Motor strip

Sensory strip

Frontal lobe
Motor control of voluntary muscles
Personality
Concentration, organization
Problem-solving

Parietal lobe
Sensory areas of touch, pain, temperature
Understanding speech, language
Express thoughts

Broca's center
Motor control of speech

Wernicke's center
Interpreting speech

Temporal lobe
Hearing
Memory of hearing and vision

Occipital lobe
Visual recognition
Focus the eye

Cerebellum
Balance
Coordinating muscle movement

Brain stem
Controls heart rate and rate of breathing

Section 5
Caring for the family

Your child's diagnosis, treatment and management of their condition can cause many changes and challenges for your family as you learn how to integrate their needs into daily life. Your health care team, including Social Work and Welfare, can provide support to help your child and family navigate this process.

Helping your child cope

As a parent or caregiver you may be asking:

- What does my child know about their condition?
- How will my child feel about the treatment or management of their condition?
- How can I support my child?

Children of different ages understand and react differently to their condition, its treatment and management. Your child's personality, normal coping style, support system and treatment plan as well as age or developmental level will affect how they cope. When children are faced with stress their normal behaviours may change. They often become more dependent on adults or may act younger than their age (e.g. baby talk, wetting pants after being toilet-trained, etc.). Your child may not know how to handle the many feelings that have been caused by their diagnosis and may not have developed the language skills to tell you how they are feeling.

You're a very important part of your child's life for many different reasons. You know what your child has experienced in the past and how your child usually handles stress. You can help the health care team to understand your child and work with them to find new ways to help your child cope with their condition and treatment.

Talking to your child about their condition

Parents often find it difficult to speak to their child about their condition when it's first diagnosed. We know speaking honestly and using language children can easily understand is best. Children quickly sense when something is wrong and can react by feeling lonely and separated from family and friends. Children often imagine things are worse than they are and that's why explaining things is helpful.

You may ask yourself, 'Why should I tell my child about their neurological condition?' Many parents want to protect their child by not telling them information they think might scare them. But a child's world is scarier when they don't know what is happening to them and around them.

The benefits of talking with your child about their condition and its management are:

- Your child can build trust in both you and their health care team which encourages them to ask questions about their diagnosis and the management of their condition
- Your child will know what to expect
- Children fill in information gaps with their imagination. Honest information helps correct wrong ideas about their condition
- If your child understands the importance of doing some things (e.g. taking medicines, coming to the hospital, etc.) they may be more cooperative and less resistant to these activities
- Knowing and understanding their condition allows children to have a sense of control during times when they feel out of control
- You can help your child learn how to get through difficult situations
- Your child will develop skills that will be useful later in life.

Consider your child's age and intellectual capacity when choosing the words to talk about the condition and how it's managed. Keep in mind that children learn from doing, seeing and hearing things over and over. You may need to tell your child about their condition more than once. As children grow older they may also need and want to know more about their condition and its management.

Tips on talking with your child

Here are some tips on how to talk to your child about their condition. Remember, you will need to share more or less information depending on your child's age and developmental level. The hospital also has trained staff who can help you find ways to explain things to your child. Please talk to your child's consultant neurologist, specialist neurology nurse or social worker if you need help with explaining the condition to your child.

What is the condition?

Help your child understand about their condition by firstly talking about how the nervous system works.

For example:

> *"Our nervous system is like a computer for our body. It's made up of different parts and controls everything we do. It controls our muscles so that we can walk and talk; it controls our hearing, our sight and our touch; and it also controls our breathing and our heart."*

After explaining how the nervous system works, talk to your child about their neurological condition and how it affects them. It's important to use the correct name for their diagnosis initially so they become familiar with it. However, as some conditions have long medical names, you may want to abbreviate it or use less medical terms to communicate with your child more easily. It's also helpful to use photographs and diagrams showing how the nervous system works as you explain things to your child (see Section 4 Disease and treatment information).

For example:

> *"Sometimes our brain sends mixed up or slow messages to our body which may stop us from walking, talking or remembering things. In seizures, it might make you fall down and shake all over or stop what you are doing and stare."*

OR

> *"Sometimes, our body is unable to make specific things we need to be healthy, called proteins. This affects our body's ability to protect and repair our muscles or cells in the spinal cord. This causes muscles to become weaker over time and makes physical activities such as walking difficult. When this happens you may need a wheelchair or scooter to help you get around."*

OR

> *"Sometimes our body's immune system gets confused and attacks healthy cells and tissues in the brain, spinal cord or peripheral nerves. When this happens your body's nervous system doesn't process or communicate messages as well and you may have problems walking, swallowing, speaking, remembering things or sometimes even breathing."*

You will need to talk to your child about how their condition specifically affects them. Your consultant neurologist and neurology nurse may be able to provide you with some useful resources, storybooks or websites to help you explain the condition.

Feelings

After talking to your child about their condition and treatment, it may be helpful to talk about feelings.

Reassure your child that any feeling they have is normal. Many times children will feel angry, guilty, sad, lonely, scared and sometimes even happy. Any feeling is okay.

Be honest with your child about how you feel as they will sense when something is bothering you. If you don't share your feelings, your child may become scared. Sharing your feelings sends the message that it is okay to feel upset or angry.

Play, sports and exercise

It's important your child continues to play and exercise even though they have a neurological condition. Play is an important part of learning and socialising for children while exercise and sporting activities provide many overall health benefits.

However, some activities can be dangerous because your child's condition or treatment puts them at greater risk, e.g. seizures and climbing high trees or excessive physical activity with certain neuromuscular conditions.

Please check with your consultant neurologist about the types of play, exercise and sports that are suitable for your child and if any precautions are needed. All children are advised to wear the recommended protective equipment when playing sport.

Your child may need a medical check-up if they sustain injuries during sporting activities. Please ensure you tell the medical staff about your child's neurological condition and any medications they are taking during any medical check-up or assessment.

Positive behaviour management

The normal family routine is disrupted from the moment a child is diagnosed with a neurological condition. The child becomes the centre of attention for family members and friends and may receive extra gifts. The gifts and attention are fun and children can get used to being ‘special’ and want the special treatment to continue. Behaviour management issues are most common when the special attention stops and normal activities resume.

Children are likely to be less confident and more dependent when they feel sick or uncertain about their future. Pain and/or the side effects of treatment and medications such as steriods can also make them irritable. These behaviour changes can make it difficult to know what is reasonable to expect of your child.

Many parents feel helpless and guilty when they see their child suffer and you may feel the need to make up for the suffering by giving special privileges or reducing expectations. These feelings are normal. However, children expect and need adults to give them structure. Rules and limits also provide security. If you don’t expect your child to behave or follow the same rules that were in place before the illness or diagnosis, or you treat them differently to their siblings, they may think their condition is worse than he/she has been told. Keep in mind the following guidelines when deciding on how you can provide limits for your child:

- Set clear, consistent and age-appropriate limits.
- Adjust your expectations to your child’s current condition, e.g. expecting your child to say ‘please’ and ‘thank you’ may not always be reasonable if they are unwell for a period of time.
- Use praise and attention to reward good behaviour.
- Try using the ‘time out’ approach or taking away privileges if there are problems with behaviour.

School

Going to school is an important part of your child's routine as they need to continue to learn, grow and interact with their peers and friends. School also helps children feel good about themselves and hopeful for the future. Your consultant neurologist will talk to you about when your child can go back to school.

Please advise your school to:

- **notify you immediately when cases of infectious diseases occur within the school community** (e.g. chicken pox). Also ensure your child's vaccinations are up-to-date and, if needed, visit your GP or the Specialist Vaccination Centre on Level 2 of the Lady Cilento Children's Hospital to discuss your child's specific needs.
- **not administer any medications to your child without discussing these with you first** (except in emergency situations). Make sure you give the school a copy of your child's emergency plans (as provided by your consultant neurologist or paediatrician).

If teaching staff need information to help them look after your child, please talk to your neurology nurse. Many children find it hard to go to school for different reasons, e.g. if their medical symptoms are noticed by their peers, if they have changes in their body or they are having difficulties keeping up with their schoolwork. Tell your consultant neurologist or neurology nurse if your child is worried about going to school. Your social worker may also be able to help.

Ask for extra help at school if your child is having problems doing school work and talk to your child's teacher if your child is not able to go to school for a period of time. Your paediatrician or consultant neurologist can write a letter to the school explaining your child's diagnosis and treatment if additional formal education support is being requested for your child. Your child's teacher can also send schoolwork home and find ways to keep your child in touch with other children in the class.

If your child has an extended stay, the Lady Cilento Children's Hospital School has teachers available to help your child keep up with their schoolwork. These teachers can also link in with your child's usual school.

Caring for the whole family

Coping with your feelings

You child's condition may create significant changes for you and your family. Every family has different ways to cope with stressful experiences. Many families speak of feeling fear, anger, sadness and guilt. All these feelings are common human emotions. You are not alone. Talking with family and friends, a member of the health care team or another parent who has a child with the same or a similar condition may be helpful. By sharing your feelings you may find it easier to cope with the changes and challenges you are experiencing.

Fear

The diagnosis is often the most difficult time and the fear of the unknown may be overwhelming. This experience may be your child's first visit to the hospital. Dealing with the stress of your child adapting to a new and sometimes frightening environment may be difficult. You may also have fears about treatment, expenses or how you will help your child to cope. Talking about these concerns openly can be helpful. The health care team is here to listen to your concerns and help you.

Anger

At times you may feel very angry at what is happening. Some families say they are angry with God or a cruel fate for singling them out. Some are angry with the health care team for not finding an answer to what is happening with their child. You may even feel angry with your child for getting sick and turning your life upside down. Feeling angry is a normal reaction and finding a safe outlet to let off steam may be helpful. Take a walk or talk to someone to let the tension out.

Guilt

Parents often feel guilty about their child's condition. Many parents wonder if they did something to cause their child to develop their condition and siblings may feel guilty that they are healthy. Young children may even experience 'magical thinking' and worry that they caused the illness or condition e.g. 'We had a fight and I wished he would die'. Open discussions about your child's condition, treatment options and expected outcomes can help manage these feelings.

Grief

Grief is a normal response to loss and is often experienced when your child is diagnosed with a neurological condition. Grief is an emotional and often physical reaction accompanied by strong and painful feelings that may change frequently including disbelief, sadness, anger, denial, confusion and guilt.

The way we grieve can be shaped by our past experiences, culture, family background and gender. We all have individual grieving styles and can often be experienced very differently between men and women. It's important to be aware of these differences in order to prevent misunderstandings and conflict.

To generalise, men's grief may be more practical or functional. Men may be less comfortable to talk about their feelings, or even find it difficult to find the words. Stereotypically men may use work as a distraction and limit displays of emotion in order to be 'strong' for their partner. For some men the strong feeling of grief may be very new and frightening. Women tend to express their feelings more readily. Women are often more comfortable with crying and sharing their feelings and seek out family and close friends to talk about their emotions. There are also men who cry and women who are silent in their grief.

Everybody responds differently to loss – there is no right or wrong way. It is also important to remember that at times of grief people are still who they always are. So if you are normally quiet and shy, or outgoing and talkative, then you are also likely to react in these ways in grief.

Crowe, E. 2004. *When children have a life-limiting illness: questions and answers around loss and grief.*

Read more: **www.health.qld.gov.au/cpcre/publicns.asp**

Chronic sorrow

Chronic sorrow is a form of grief common in parents of children with chronic medical conditions and disabilities. Chronic sorrow is best described as the grief that is ongoing and ever changing when you have a child with chronic needs. It describes the long-term periodic sadness for caregivers in reaction to the continual losses when children have ongoing issues. Chronic sorrow is different than other types of grief or bereavement. Chronic sorrow is a normal grief response to an ongoing loss.

Parents and carers, despite their chronic sorrow are usually able to manage their child's increased needs and juggle the demands of family life. However, sometimes an event or situation will trigger intense feelings of profound sadness, this is chronic sorrow.

Common triggers may be a deterioration or change in your child's health, delays in your child's development or seeing another child growing and developing the way you had dreamt for your child. You may exhibit symptoms similar to depression like sadness, anger, frustration and guilt. However, chronic sorrow is different to clinical depression as it generally requires a trigger and doesn't usually interfere with daily functioning.

Strategies to help manage your

feelings include:

- having honest, accurate and easy to understand information about your child's condition
- accessing information and support available at the hospital
- accessing support groups and family networks in the community for parents and carers of children with similar medical conditions
- developing positive coping strategies
- being able to recognise triggers.
- Not making judgements of yourself and your sadness
- Recognising that you and members of your family may experience chronic sorrow at different times with different triggers

Not everyone with a child with a neurological condition will experience grief or chronic sorrow. Chronic sorrow and grief does not mean that you do not love your child or that you want to change the situation. It is just recognising that sadness is completely normal.

Joy and hope can sit alongside grief and sorrow and can assist to help your feelings of sadness. Some parents have observed feeling a sense of peace and calmness with their unwell child while others feel their child's medical condition has led them to grow as a person and realise great personal strength. Parents often feel a renewed sense of needing to live life to the fullest and appreciate the simple things in life.

As individuals we all experience life and loss differently. Try to be gentle with yourself whatever your reaction.

There are many materials available online about grief, loss and chronic sorrow. Your social worker can also provide brief counselling and community referrals.

Maclean, Mary. 2017. *Living with chronic sorrow.*

Read more: **www.chronicsorrow.org**

Depression

Many parents and carers feel sad when their child has been diagnosed with a serious medical condition. This is a normal response to any serious illness and it may take time to work through and accept all the changes that are taking place.

When you're sad, you may have very little energy, feel tired or not feel like eating. For some, these feelings go away or lessen over time. But for others, these emotions can become stronger. The painful feelings don't get any better and they get in the way of daily life. This may lead to depression.

Depression can be treated. Medications and therapies have helped many parent. These can also help you to manage and cope with the acute and chronic stress, and the trauma resulting from your child's diagnosis and treatment.

It should also be noted that some adolescents living with a chronic illness can also develop depression.

When to seek help

Speak to your GP, social worker, psychologist or psychiatrist if you have any of the following signs that persist over a number of weeks.

Physical changes

- Unintended weight gain or loss not due to illness or treatment
- Sleep problems (not being able to sleep, having nightmares, sleeping too much, etc.)
- Feeling agitated/stressed
- Difficulty breathing
- Racing heart, dry mouth, increased perspiration, upset stomach, diarrhoea
- Excessive eating or inability to eat
- Sweating, flushing
- Nausea or vomiting not associated with an illness
- Going to the toilet frequently
- Changes in energy levels
- Fatigue that doesn't go away
- Headaches, other aches and pains.

Emotional signs

- Endless feelings of sadness
- Feeling emotionally numb or withdrawn
- Feeling nervous or shaky
- Repetitive thoughts
- Having a sense of guilt or feeling unworthy
- Feeling helpless or hopeless, as if life has no meaning
- Feeling fearful a lot of the time
- Feeling short-tempered, moody
- Feeling startled easily, jumpy
- Difficulty concentrating
- Crying for long periods of time or many times each day
- No interest in the hobbies and activities you used to enjoy
- Panic attacks – dizziness, trembling/shaking, fast or irregular heart-rate, tightness in the chest, numbness, bad feelings, spinning or vertigo, feeling 'out of control'
- Feeling that you may be sick with an illness that doctors cannot detect
- Doing things that are out of character
- Abusing drugs such as sedatives or alcohol 'to calm your nerves'
- Thoughts of harming yourself and/or others.

Please refer to *Resources* on page 64 of Section 3 Lady Cilento Children's Hospital for additional support.

Coping with your child's illness

Some suggestions to help you cope with your child's illness include:

- Find time to talk to your spouse or a close friend. Try to talk about things other than your sick child
- Try not to talk about your child in his/her presence unless he/she is included in the conversation
- Find ways to reduce stress – whatever works best for you e.g. exercise, reading or shopping
- If appropriate, take turns with your spouse or another support person when staying with your child in the hospital or coming to clinic. Check with your health care team if this is the best option for your child
- Both carers can be involved with your child's treatment. Sharing responsibilities also helps reduce the gap that may grow between parents when one is more involved in your child's care than the other
- Ask a member of the health care team for help and support
- Talk to other parents who have children with the same condition or attend a support group.

Impact on grandparents

Grandparents have a variety of responses when they hear their grandchild has a serious condition. Like you, they may feel shock and disbelief. Grandparents may feel guilty for living a long life. They may also feel they are responsible and think they in some way passed the condition through the family. Grandparents may also feel sadness, not just for their grandchild, but for you, their own child, as well.

Grandparents can be a great help to you and your family. If they are still in good health and can be with you, they can relieve you in the hospital ward or help at home. A grandparent may also give your other children additional attention, comfort and love. Grandparents can also serve as contact people. They can give information to other family members so you don't have to spend as much time on the phone or emailing. Including grandparents in meetings with the health care team can also help them understand the plan of care for their grandchild.

Impact on siblings

Brothers and sisters of a child with a serious neurological condition may have many different feelings and responses. Often they will have needs similar to the sibling who has the condition. They may feel upset, scared and unsure of what the future holds or fear the condition and worry about death. Regardless of age, they will sense a change in their family life. While siblings may feel sad and worried about their brother or sister, they may also feel some resentment or anger. Mum and Dad are spending all of their time with, or talking about one child. Friends and family may send gifts and this may cause other children, especially young ones, to feel jealous. Often siblings have problems of their own such as depression, trouble sleeping, physical complaints or problems at school.

How to help siblings

The following suggestions may help your other children to cope with their brother's or sister's neurological condition:

- Try to spend time alone with your other children and do things that interest them
- Let your other children know they are loved and important too
- Talk to your other children about the condition and its treatment and how their brother or sister is affected. What you tell them will depend on their ages and ability to understand. Reassure them that the condition is not contagious and they are not responsible for their brother or sister's condition.
- Take your other children with you to the hospital to help them feel involved in the care and treatment if your child is in hospital for a prolonged period of time. Taking them to the hospital or clinic may help to decrease their fears and help to keep a feeling of closeness with their brother or sister
- Ask a loving friend or relative to stay in your home rather than sending your children elsewhere.
- Allow your children to help with chores at home. This will help them to feel needed and help you too.
- Talk to your children's teachers. Teachers can provide support for your children and let you know about any school-related problems.
- Ask for help from a member of the health care team – nurse, social worker, psychologist or psychiatrist.

Impact on a marriage or relationship

A chronic condition can quickly turn a family's life upside down. Parents often become exhausted as they try to cope with the needs of the child and the rest of the family. Many parents try to continue to work at their jobs and keep the home routine as normal as possible. But many couples feel a strain on their relationship and couples often say they do not have time for each other. They may feel angry and frustrated about what has happened to their child.

As both parents are often experiencing grief and loss at the same time, it is important to remember it can be difficult for either parent to support the other as they usually would. Respecting coping styles, maintaining communication and accepting changing roles may help your relationship.

Respecting coping styles

Each person responds differently to stress. Some people withdraw, cry or get angry while others may cope by gathering information. Parents need to learn and respect the different ways each cope with their child's illness. Try to understand where your partner is in accepting what is happening.

Maintaining communication

The key to any successful relationship is communication, and the need to talk about feelings, fears, appreciation and information is even greater during times of stress. Silence can make you feel separated from your partner. By sharing feelings and information you can stay connected and be more able to make decisions. Try to maintain communication with supportive friends as well.

Accepting changing roles

The demands of chronic neurological conditions and associated management can change the roles of family members. For example, the father may have been the decision-maker in the family but now the mother is making the decisions with the health care team because her partner is at work. Or the mother is used to taking care of the home but doesn't have time now because she's caring for the child in the hospital. An older sibling, other family member or friend may have to help out more in the home. The change in roles can cause stress within a marriage or relationship. Some temporary role changes may be necessary depending on your child's diagnosis and how it impacts your family. Some of these changes may become permanent if they help improve how parents or family members work together.

In some cases, parents may also choose to give up or reduce their paid work to care for their child. This may cause financial stress for the family as their income is reduced. Please refer to page 67 for more information regarding allowances, subsidies and financial assistance.

Parents working together

The following suggestions may help parents to adapt to the changes resulting from their child's condition:

- Give your partner sympathy and understanding instead of blame and criticism
- Make the child with a neurological condition a priority. Both parents can come together to learn about the diagnosis and treatment
- Recognise that you must continue to share in caring for and loving your other children
- Share your own feelings of anger, sadness, sorrow and hope with each other
- Accept the help of family, friends and neighbours
- Be loyal to your partner in the face of criticism or blame from others.

Suggestions for divorced or separated parents

While divorce and separation is very difficult for all families, problems may get worse when a child is diagnosed with a serious neurological condition. In families where parenting issues are unresolved, children may use the diagnosis and treatment to ‘bring together’ divorced or separated parents.

Work together and don’t allow divorce stress to affect your child’s care. Communication helps both parents get the best care for their child.

Some suggestions to help avoid problems include:

- Talk with a member of the health care team if your child is having behavioral problems
- Place a copy of the divorce decree, custody and visitation rights in your child’s medical record and advise your treating team about any orders that are in place
- Meet together with the care team to avoid confusion about the plan
- Share notes or information if one parent is not present for a meeting
- Ask for two copies of all teaching materials, information sheets and outpatient letters so both parents can have the same information.

Going on a holiday or a trip

A diagnosis of a neurological condition shouldn't prevent your family from taking a holiday or trip if this is affordable and practical.

If you and your family wish to take a holiday, especially if it is interstate or overseas, advise your consultant neurologist and neurology nurse as soon as possible. Your consultant neurologist will let you know if it's safe to take a holiday, when is the best time and if any specific precautions will be needed.

You may need to adjust medication times if travelling overseas. Please advise your consultant neurologist or neurology nurse during your clinic appointment if you are planning an overseas holiday.

When you travel:
- Take copies of clinic letters with you
- Take copies of your child's Emergency Management Plan and make sure this is up to date before you leave. Some parents also take a photo of the plan on their smart phone in case they lose the original copy
- Ensure you have a sufficient supply of medications, particularly if you will be travelling overseas.

Before you leave, find out if you need a medical letter to authorise travelling and carrying a supply of medications and check the specific requirements for other countries you are visiting.

Health insurance can be difficult to obtain for pre-existing conditions, so allow yourself time to research and contact a number of providers. They may also ask for medical reports to be completed for your child.

Looking to the future

Children with serious neurological conditions will usually require long-term medical assistance and appointments into adulthood.

These patients must be transferred to adult services by the age of 18 or before. The period leading up to transfer is called transition. Your consultant neurologist and neurology nurse will work with your teenager and you to determine the best adult service for your child and prepare you both for the change. Moving to adult services is considered an important and normal part of growing up.

It's normal to feel a range of mixed emotions during this time as you'll be moving from the security of a familiar environment to a different hospital and new clinicians. Your neurology nurse and social worker can provide support and information to help you manage the transition.