



COLORECTAL AND PELVIC
RECONSTRUCTION SERVICE

Neonatal Care

Information for families

Neonatal Care

Colorectal and Pelvic Reconstruction Service (CPRS)
Information for families

Design, photography and medical illustrations by
The Royal Children's Hospital Melbourne

© The Royal Children's Hospital Melbourne 2020

Authors

Associate Professor Sebastian King, Director CPRS,
The Royal Children's Hospital Melbourne

Mrs Suzie Jackson-Fleurus, Clinical Nurse Consultant CPRS,
The Royal Children's Hospital Melbourne

Ms Jessica Taranto, Clinical Nurse Consultant CPRS,
The Royal Children's Hospital Melbourne

Dr Kim-Michelle Gilson, Psychologist CPRS,
The Royal Children's Hospital Melbourne

Acknowledgements

The CPRS team would like to thank Mrs Melissa Stewart
and Mrs Jessica Dennett.

We are indebted to the contributions of the many families
that are cared for by the CPRS team. This resource is for
all families affected by colorectal and pelvic conditions.

About this booklet

The Colorectal and Pelvic Reconstruction Service (CPRS) at The Royal Children's Hospital Melbourne (RCH) is leading the way in colorectal and pelvic care in Australia.

We aim to deliver the highest quality clinical care to children and families with colorectal and pelvic conditions. We play a vital role in increasing the awareness, understanding and knowledge of these conditions in the community, and work collaboratively to educate health care professionals.

This booklet has been developed to support parents, carers and children who have colorectal and pelvic conditions. The CPRS seeks to establish a healthy relationship with all families, as we believe this enables the best care possible. The content of this booklet has been developed based on the extensive clinical experience of the authors and the most recently published evidence for this clinical condition.

This CPRS booklet has been categorised into different stages of your child's journey, which allows you to read the information that is important to you at the time. Some parts may appear repetitive. This is because some of the information is relevant throughout different periods of your child's care.

Everyone learns differently. Some people like to read instructions, some like to learn by having information explained to them, and many like to do both. Make sure you tell the members of the CPRS team if you are finding any information in this booklet difficult to understand.

Neonatal care

Your first interaction at the RCH is in the Butterfly ward.

The Butterfly ward is the Newborn Intensive Care Unit (NICU), which provides neonatal care for children from Victoria, interstate and overseas.

The care of Butterfly patients involves extensive co-operation with many other teams and departments within the RCH.

Surgical teams:

- Paediatric Surgery
- Neurosurgery
- Urology
- Plastic Surgery
- Gynaecology
- Cardiac Surgery

Medical teams:

- Cardiology
- Nephrology
- Clinical Nutrition
- Endocrinology
- Gastroenterology
- Neurology
- Genetic Medicine

Nursing teams:

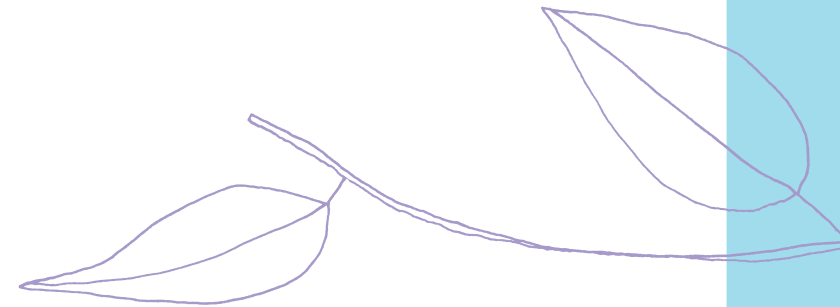
- Clinical Nurse Consultants
- Stomal Therapists
- Butterfly ward Nurses

Allied Health teams:

- Infant Mental Health
- Music Therapy
- Social Work
- Educational Play Therapy
- Psychology
- Audiology
- Speech Pathology
- Occupational Therapy
- Physiotherapy

Administrative team:

- Coordinators



Butterfly

Entering the Butterfly ward for the first time may be overwhelming. Nursing staff, and the CPRS team, will be there to support you and your family throughout your child's admission.

A maximum of three people are permitted at the bedside in Butterfly at any one time, one of whom must be a parent (unless parents nominate family members who may visit in their absence). Children under 12 years may only visit if they are siblings of the patient.

It is very important to wash your hands and apply antibacterial hand gel prior to entering Butterfly. Any visitors who are unwell with an infection, cold or flu, or who have recently come into contact with an infectious disease, should check with the bedside nurse or nurse in charge by phone before visiting.

General hospital visiting hours are 8.00am to 12.30pm and 2.30pm to 8.00pm. Doors into the hospital are locked at 8.30pm. Entry and exit after this time is via the Emergency Department only.

If you are staying with your child overnight and need to leave the ward, please speak to the nursing staff.



Butterfly — environment

Children in Butterfly will rest in an open cot, a heated cot or a covered incubator, depending on their size and condition, to help maintain their temperature.

Your child may also have:

- A ventilator to help with their breathing
- Machines and pumps to deliver fluids and medicines
- Monitors to measure their heart rate, breathing and the amount of oxygen in their blood

Parents are always encouraged to spend time in Butterfly, although it may be very hard to see your child needing this level of medical care and support.

What is important is that you continue to bond with your child, talking to them and touching them as much as possible, so they know you are there. This will help your child develop a sense of security.

Butterfly — supports

Infant Mental Health — this service is available in Butterfly if you feel that you are struggling to attach and adjust to your child's medical situation. Please alert the bedside nurse or the CPRS Clinical Nurse Consultant if you would like to see the Infant Mental Health team.

Breast feeding support — this service is provided at the RCH by the International Board-Certified Lactation Consultants (IBCLCs). Breast pumps are also available for use on each ward. Families are welcome to bring in their own pump device, if desired.

Parent meals — this service is provided by the RCH kitchen for breast feeding mothers. Meals must be collected from the central formula room (Level B2 via the Green Lifts) between 11.45am-12.30pm for lunch, and 5.30pm-6.15pm for dinner. Family members are permitted to collect meals on behalf of the breastfeeding mother; the UR number of the child must be provided. Allergies and intolerances are also catered for.

Butterfly — discharge planning

While you are staying on Butterfly, the CPRS team will organise a family meeting. This will be an opportunity for you to meet with the CPRS surgeon, Clinical Nurse Consultant, Stomal Therapist, Social Worker and Psychologist to discuss the plan of care for your child.

You will have the opportunity to ask questions about your child's condition and the treatment plan going forward. You will be given a binder and booklets that will help you navigate your child's condition, with lots of helpful information and resources. You will also be provided with the CPRS team contact details so that you may contact us anytime via email.

Prior to discharge from Butterfly you will also be shown the surgical ward by the CPRS Clinical Nurse Consultant. Platypus is the main surgical ward and is where you will likely stay in future visits to the RCH.

Once you are discharged from Butterfly the CPRS team will ensure that you have your first outpatient clinic appointment booked with the team. You may also expect a phone call from the CPRS team shortly after discharge.

Remember, you may contact us anytime via email at colorectal.coordinator@rch.org.au







The Royal Children's Hospital Melbourne

Department of Paediatric Surgery
Colorectal and Pelvic Reconstruction Service (CPRS)

Clinical Offices
Level 3, West Building
50 Flemington Road Parkville
Victoria 3052 Australia

Telephone + 61 3 9345 6979
Facsimile + 61 3 9345 6668
Email colorectal.coordinator@rch.org.au
www.rch.org.au/paed-surgery

www.rch.org.au/cprs