

More detailed information about Monash Children's Hospital Cancer Services

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1 Monash Children's Hospital Cancer Centre

1.1 Partners

Monash Children's Hospital Cancer Centre is a formal partner of the <u>Paediatric Integrated</u> <u>Cancer Service (PICS)</u>. The PICS works with health services to improve patient experiences and outcomes by connecting cancer care and driving best practice. For more information about the PICS and to access information for families visit <u>www.pics.org.au</u>.

Through the PICS, our Monash Children's Hospital has essential external partnerships with the Royal Children's Hospital http://www.petermac.org

The Monash Children's Hospital Cancer Centre also has a strong focus on clinical and translational research. We are members of the Children's Oncology Group and participate in international clinical trials, as well as other clinical research.

We also have a Children's Cancer research program focusing on brain tumours and solid tumours in children and adolescents. This is in the Hudson Institute of Medical Research http://hudson.org.au/paediatric-cancer-research-program/ through the Monash Health Translational Precinct http://www.mhtp.org.au, which is part of the Monash Health Clayton campus.

1.2 Our team

At the Monash Children's Hospital Cancer Centre, an integrated multidisciplinary team of specialist medical, nursing, psychosocial and allied health professionals provide care and services to meet the clinical, physical, social and psychological needs of patients and parents.

This multidisciplinary approach is directed towards maximising quality of life outcomes associated with cancer treatments and long-term survivorship. A range of sub-speciality paediatric and administrative services supports the clinical service.

Consultant Medical Staff:

Our senior medical staff has a wide range of expertise in all aspects of childhood and adolescent blood diseases and cancer. They include:

- Dr Peter Downie MBBS FRACP Director, and Head of Unit. Consultant Oncologist and Consultant Paediatric Haematologist.
- Dr Paul Wood BPharm MS MBBS FRACP PhD Consultant Oncologist
- Dr Leanne Super MBBS FRACP Consultant Oncologist
- Dr Katie Moore MBChB MRCP FRACP Consultant Oncologist
- Dr Anisha Pillay MBBS FRACP Consultant general paediatrician
- Dr Kottayam Radhakrishnan MBBS FRACPath FRACP Consultant haematologist and haematopathologist

Haematology/Oncology Medical Fellows:

- Oncology Fellow supported by the Bailey's Day Clinical Fellowship
- Oncology Fellow in Research Dr. Sara Khan, the Australian Lions Childhood Cancer Research Foundation Fellow.

Nursing Team:



- Nurse Unit Managers Day Oncology Unit
 - Natalie Radin
- Sharon De Graves
- Nurse Practitioners
 - Kate McLachlan Paediatric Oncology Nurse Practitioner
 - Katy Walshe Paediatric Oncology Palliative and Supportive Care Nurse Practitioner Candidate
- Clinical Nurse Coordinators
 - o Karen Egan
 - Sarah Huggins
- Nursing education team
 - o Clinical Nurse Educators Chantelle Cabral and Carly Fletcher
 - Clinical Support Nurses Temora Senior and Jane Templeton
- Associate Nurse Unit Managers
 - Jennifer Grant
 - o Lauren Haddad
 - o Elizabeth Andrews
- Registered Nurses
 - Casey Alveyn: Clinical Nurse Specialist
 - Erin Bentley

Clinical Trials Team:

- Maree Williams
- Wilson Low

Psychosocial Team:

- Social workers
 - Lynette Ozols
 - Stephanie Arrott-Watt
- Psychologist Kate Holt
- Neuropsychologist Sarah Knight

Allied Health Team:

- Procedural Pain and Play Therapists
 - Karen Jolly
 - Emily Young
- Music Therapy
 - o Priscilla Pek
- Dietitians
 - Natalie Koopmans
 - o Caitlin Watson
 - Kristin Mellett

Oncology Pharmacists:

- Tanya Selth
- Lisa Janson
- Brodie Smith

Support Services:

- Education advisors (teachers)
 - o Heidi Gilmour
 - Kristy Taylor
- Family and Community Liaison Coordinator Rebecca Pahl

Administration Team:



- Lisa Richards
- Najia Zekaria

1.3 Our services

A wide range of services within the Monash Children's Cancer Centre support children, adolescents and their families through their treatment and care. These include:

NURSING SUPPORT

Our Children's Cancer Centre (CCC) nursing team is a team of dedicated nurses who have chosen to specialise in the care of children with cancer and serious haematological conditions.

NURSE UNIT MANAGER

There are two part-time Nurse Unit Managers in the Children's Cancer Centre. The Nurse Unit Manager has overall responsibility for the running of the unit. There is always a Nurse Unit Manager on duty in the CCC should you wish to speak to her. Currently, our NUM's are:

- Natalie Radin
- Sharon De Graves

NURSE PRACTITIONER

A Nurse Practitioner (NP) is a senior clinical nurse, with a Master's of Nurse Practitioner qualification and advanced clinical knowledge and competence in their clinical specialty. Through a two year training process an NP develops extensive skills in the assessment, diagnosis, interpretation of results and knowledge of medications. Nurse Practitioners are recognised as possessing expert clinical skills and can practise at a different level from other nurses. They must undergo a process of endorsement through the Nursing and Midwifery Board of Australia to be authorised to practise.

Within the Children's Cancer Centre (CCC), there is both a fully endorsed and practising Nurse Practitioner and a Nurse Practitioner Candidate.

What does this mean for the Children's Cancer Centre?

Nurse Practitioners work as part of the team in the CCC. They may see and assess your child during a normal clinic visit or when your child comes into the unit when they are unwell.

The NP may prescribe the treatment, medication and specific tests that your child may need.

In conjunction with the senior medical staff in the unit, the NP may recommend that your child is admitted to the ward for a period of observation.

As part of their role, NPs also teach other professionals, are actively involved in research and provide clinical leadership within the CCC.

The Nurse Practitioner team

Kate Vandenberg is the Nurse Practitioner for Paediatric Oncology. She has full endorsement and sees children at all stages of treatment for cancer.

Katy Walshe is the Nurse Practitioner candidate and is undergoing a scholarship for two years to be a fully qualified NP. She may see children at all stages of treatment but will focus on supportive and palliative care.

ASSOCIATE NURSE UNIT MANAGERS

Associate Nurse Unit Managers are experienced nurses responsible for the day to day running of clinical nursing care within the unit. They make sure that your child is seen promptly and has the right treatment at the right time.

They support nurses in the unit who are learning and have overall responsibility for the clinical care of your child.

There is always an Associate Nurse Unit Manager on duty in the CCC, should you wish to discuss any aspect of your child's clinical care or management.

The Team

Jennifer Grant Liz Scanlon Lauren Haddad

Clinical Nurse Coordinators

A Clinical Nurse Coordinator (CNC) helps manage all aspects of a child's treatment both in hospital and at home. This means that you will see the CNC when your child is first diagnosed, whenever your child is in hospital as an in-patient on the ward, or when your child comes in to the CCC for day chemotherapy.

The CNC books scans for your child whenever they are needed, helps organise blood tests, ensures that your child has the necessary referrals in place for other things like radiation therapy, stem cell harvesting and nursing care in the community or palliative care.

The CNC works closely with the medical, allied health staff and other nurses to ensure that your child receives a seamless service in the delivery of their cancer treatment.

The Team

Karen Egan Sarah Huggins

Clinical Support Nurses

Our Clinical Support Nurses (CSN) work both on the wards and within the CCC. They primarily support nurses to safely deliver chemotherapy and other supportive care that children with cancer require.

Sometimes you will see the Clinical Support Nurses in the CCC helping your child.

The CSN has a wide-range of responsibilities such as teaching and support in other areas where children with cancer might be cared for. You may see them in the Intensive care Unit, Emergency Department or Diagnostic Imaging.

You may see the CSN teaching other nurses at Monash Health, both at the bedside or holding formal teaching sessions about children's cancer care.

The Team

Jane Templeton Temora Senior

Clinical Nurse Educator



The Children's Cancer Centre has a nurse educator whose primary responsibility is to provide more formal education and support for a variety of nurses who are working within both the CCC and as part of the ward nursing team.

At Monash CCC, we run formal education days for nurses who wish to learn about paediatric cancer care. It is the responsibility of the Nurse Educator to organise and run these education days.

You may also see the Nurse Educator within the CCC supporting nurses who are learners in our environment or on the wards with the ward nursing team.

The Nurse Education team is highly trained and have expertise in the care of children with cancer.

The Team Chantelle Cabral

Carly Fletcher

Nursing Rotation Position

Monash Medical Centre is a teaching hospital and as such we have learners in a variety of areas including paediatric oncology. Nurses will rotate from the wards into the CCC for three months before returning to the ward.

CLINICAL RESEARCH TEAM

The Monash Children's Hospital Cancer Centre is a member of the Australian and New Zealand Children's Haematology/Oncology Group (ANZCHOG) and the International Children's Oncology Group (COG), which is the world's largest organisation devoted exclusively to paediatric cancer research. These groups develop treatment protocols and clinical trials for children diagnosed with cancer.

These protocols have been developed over years of extensive clinical research and are considered the most up to date treatment schedules available. The Clinical Research Team (CRT) at Monash Children's Cancer Centre support the Medical staff to ensure that the correct treatment and tests are performed.

The CRT, nursing staff and medical staff aim to ensure that the rights, safety and well-being of children and adolescents participating in clinical trials are protected.

A summary of CRT work includes the following:

- Perform clinical research studies and clinical trials according to the international ethical and scientific quality standard for designing, conducting, recording and reporting of clinical trials and research that involve the participation of humans.
- Feasibility review and application of new national and international clinical research studies and clinical trials relevant to our patient population.
- Collect, verify and report data collected for clinical research and trial purposes
- Shipping and storage of biological specimens for analysis and bio-banking
- Liaise and work with human research ethics committee, external institutional review boards and research sponsors

The Team

Maree Williams - Lead Clinical Research Associate



Wilson Low - Clinical Research Associate

Resources

Victorian Cancer Clinical Trials - https://www.cancervic.org.au/trials/

Australian and New Zealand Children's Haematology/Oncology Group - http://www.anzchog.org/

Children's Oncology Group - https://childrensoncologygroup.org/

PSYCHOSOCIAL SERVICES

Psychology:

A diagnosis of cancer can have a profound impact on paediatric patients and their families' ability to psychologically process, manage and cope with the many changes to their lives. These include dealing with painful or uncomfortable medical procedures, being socially isolated from family members and education, and adjusting back to "normal" life following treatment.

Our psychology service is part of the broad multidisciplinary team, contributing an essential component of the treatment protocol within the Monash Children's Hospital Cancer Centre to enhance patient (inpatient and outpatient) outcomes.

A referral to the Clinical Psychologist for specialised mental health assessment and intervention for patients and families with complex psycho-emotional needs can be discussed with senior medical staff, senior nursing staff and social workers of the Monash Children's Hospital Cancer Centre team.

The team:

Dr Kate Holt PhD is a Senior Clinical and Health Psychologist with extensive experience in working with children, adolescents and their families to promote their psychological wellbeing. Kate has worked at Monash Children's Hospital Cancer Centre since 2010.

Neuropsychology

Children who are diagnosed with a brain tumour or whose medical treatment may affect brain development will be referred to see a neuropsychologist. Neuropsychology assessment looks at different aspects of thinking and behaviour. This helps to understand a child's cognitive strengths and weaknesses and allows their developmental progress to be monitored, so that we can recommend suitable ways to best support them at school and at home.

The neuropsychologist provides a service for children who are an inpatient, outpatient or who attend the dedicated long term follow up clinic. Your doctor, nurse or other allied health professionals can refer your child to the neuropsychologist.

The team

Dr Sarah Knight, PhD is a senior clinical neuropsychologist and researcher. Sarah has been with the Monash CCC since 2014.

Resources

A number of related written resources are available on the PICS website, see link below.

Monash Children's Hospital

http://www.pics.org.au/WrittenResources

Social Work

Social workers are part of the multidisciplinary health care team, and are trained to provide a range of psychosocial services to enhance the quality of care for children and their families in both the inpatient and outpatient setting. Each newly diagnosed paediatric oncology or haematology family will be assigned to one of the two social workers who work full time in the Monash Children's Hospital Cancer Centre. The social worker will meet with the patient and family regularly to assist with issues such as:

- Coping with diagnosis, illness and hospitalisation
- Impact of illness on patient and families
- Parenting and care giving concerns
- Cultural differences
- Navigating and understanding the healthcare system
- Financial difficulties
- Access to community resources and supports
- Family issues and conflicts
- Grief, loss or end of life issues

The social worker will ask parents to complete a Psychosocial Assessment Tool which asks questions about your family, any support/s you have available and how your child and your family are coping during this difficult time.

The Team

Lynette Ozols MSW Stephanie Arrott-Watt BSW

ALLIED HEALTH SERVICES:

Procedural Pain and Play Therapy

Procedural Pain and Play Therapists (also called Child Life Therapists) support children during their hospital experiences. Play Therapists work with children of all ages, from infants to adolescents.

The procedural pain and play therapy team work closely with individual children and families to:

- Provide opportunities for age appropriate play and diversion activities
- Provide play and activities to facilitate emotional expression and ongoing development
- Encourage a sense of playfulness and fun in the hospital environment
- Familiarise children with medical procedures and equipment through medical play, discussion or written materials
- Facilitate coping with medical procedures using strategies such as comfort positioning, deep breathing, distraction and individualised support plans
- Offer participation in The Beaded Journey program, where children collect colourful beads to represent their individual treatment path

The Team

Karen Jolly Emily Young

Resources



https://www.campquality.org.au/how-we-help/find-a-program/child-life-therapy

http://childlife.org.au/

http://www.pics.org.au/Proceduralpainmanagement

Music Therapy:

The Music Therapy service provides music therapy sessions to infants, children and adolescents who attend the Monash Children's Hospital Cancer Centre Clinics and who are inpatients on the paediatric wards. Siblings, parents and family members are also encouraged to participate in sessions when appropriate.

Music Therapy provides a unique avenue for expressing feelings and emotions through the medium of music. It can also address acute, chronic and procedural pain and may provide opportunities for relaxation and learning new strategies to cope with treatment and hospitalisation.

The premise of music therapy is based on providing the patient with opportunities for choice and control in order to experience autonomy and empowerment in an environment where there are very limited opportunities for choice.

Some of the music therapy techniques you may experience in a music therapy sessions include:

- Singing familiar songs
- Song writing
- Recording your own songs
- Music assisted counselling
- Composition on computer based music software programs
- Playing instruments and improvisation
- Music relaxation and guided imagery
- Listening to live or recorded music
- Music library: borrowing instruments or recorded music
- Therapeutic music lessons

The Team

Pricilla Pek

Resources:

Australian Music Therapy Association Website www.austmta.org

Nutrition and Dietetics

The nutrition team at Monash Children's Hospital is dedicated to providing nutrition assessment, education and intervention for children who are being treated for cancer or blood disorders.

Our dietitians are specialised and experienced in paediatric oncology and haematology and provide advice based on the most up to date nutrition research.

Children who attend the Children's Cancer Service at Monash Children's Hospital may need to see a dietitian for a number of reasons. These may include:

- Assessment and education following a new diagnosis

- Management of malnutrition, which may result from poor appetite, nausea or vomiting, diarrhoea or increased nutritional needs. These symptoms may be caused by the effects of cancer or side-effects of the treatment (chemotherapy, radiotherapy or surgery)
- Management of tube feeding

The dietitians provide a service for children who are an inpatient, outpatient or who attend a long term follow-up clinic. Your doctor, nurse or other allied health professionals can refer your child to the dietitian.

The Team

Natalie Koopmans, APD Caitlin Watson, APD Kristin Mellett, APD

Resources

A number of nutrition related written resources are available on the PICS website, see link below.

http://www.pics.org.au/WrittenResources

ONCOLOGY PHARMACY

We have a dedicated oncology pharmacy service based within the Monash CCC. Our pharmacy staff are very experienced in paediatric oncology and haematology. They can give advice on drug side-effects, management of administering oral medications at home, as well as helping to keep an accurate record in partnership with parents, of dispensed and administered medications. We have a dedicated oncology clinical trials pharmacist, and all our pharmacy staff are members of the Children's Oncology Group.

The Team

Lisa Jansen – lead pharmacist BPharm

Tanya Selth - BPharm

Brodie Smith BPharm, TNP

SUPPORT SERVICES:

Education advisors

For children and young people who are diagnosed with cancer, school work might be the last thing they want to worry about but maintaining a strong link between a seriously ill child and their school community has positive impacts for a child, both while they are undergoing treatment and once they return to school.

These benefits cover all areas of a child's wellbeing, including mental health, emotional wellbeing, social connectedness and academic performance. This link is also vital for families and carers of the child, and particularly for siblings, who may require additional support from their school communities.

The teachers at Monash Children's Cancer Centre will help support education by:

- Liaising with the schools to provide useful resources and maintain the link with their education
- Providing useful resources for both the school and family



- Linking the child with additional support services (The Visiting Teacher Service and Ronald McDonald Learning Program)
- Offering advice on alternate educational pathways
- Supporting the student while completing work

The Team

Heidi Gilmore - Teacher Kristy Taylor – Teacher

Resources

What about school' – by Ronald McDonald Learning Program - https://learningprogram.rmhc.org.au/parents/useful-resources.php
When a Student Has Cancer – by The Cancer Council - http://ww2.rch.org.au/emplibrary/edinst/AW580 Student cancer pages.pdf 'Learning curve': education and socialisation after childhood cancer http://www.pics.org.au/Assets/886/1/LCurvePrimary_FINAL.pdf

Family and Community Liaison

The Family and Community Resource Liaison provides non-clinical support for patients and families during their visit to the Monash Children's Cancer Centre or stay in hospital.

They facilitate fun and engaging games and activities for patients and allow parents to have a break without having to leave a child alone; they can play with siblings to allow the parents 'one on one' time with the unwell child, or to have a private discussion with the medical staff.

They also coordinate activities with philanthropic organisations that support programs such as visiting art therapy sessions, book club and school holiday activities.

The team

Rebecca Pahl

Reception

The Children's Cancer Centre at Monash Children's Hospital is dedicated to providing a place that is friendly, safe and comfortable for children undergoing treatment and their families.

When you enter the unit parents should let the receptionist know you are here before going through to the waiting room.

Patients coming for the first time will need a referral letter from a Consultant (valid for three months) or their General Practitioner (valid for 12 months) and on expiry of the letter you will be asked to bring a new letter.

The clinic is bulk billed so please make sure you bring your Medicare card. On leaving the unit please make sure you have arranged for another appointment at the reception desk.

The Team

Lisa Richards Najia Zekaria

1.4 Referral process



Appointments to the Monash Children's Hospital Cancer Centre can be made directly via telephone, email or fax. You will need a referral letter from your doctor. Depending on the urgency of referral an appointment will be made for you to see one of our specialist doctors any time between 24 hours and 2 weeks.

Monash Children's Hospital Cancer Centre is part of the larger teaching hospital of Monash University. The director of the Monash CCC Dr Peter Downie is also a faculty member of the Monash University Department of Paediatrics. Medical students and junior doctors in training will from time to time be part of the consultation process.

2 Paediatric Integrated Cancer Service

The <u>Paediatric Integrated Cancer Service (PICS)</u> was established as part of the Victorian Government's cancer reform strategy. Partnering with Monash Children's Cancer Centre at Monash Medical Centre Clayton, The Royal Children's Hospital, Peter MacCallum Cancer Centre and regional health services, the PICS aims to improve Victorian paediatric cancer care, working with the paediatric cancer community to establish co-ordinated services that are consistent, evidence based and family-centred.

The PICS supports <u>health professionals</u>, develops <u>information for families</u>, and runs two statewide clinical programs, the <u>Regional Outreach and Shared Care Program (ROSCP)</u> and the Long Term Follow-up Program (LTFP).

Information for health professionals

The PICS works in partnership with the health services to maximise opportunities for education and professional development for nursing, medical and allied health staff. The information for health professionals included on the PICS website is designed to provide paediatric oncology clinicians with a user friendly and up to date portal containing paediatric oncology information and learning opportunities.

Click here for further information >>> Information for health professionals

Information for families

The PICS has an ongoing commitment to developing information resources for families. These are developed in partnership with the health services and consumers. The PICS has developed many resources including <u>written information</u>, <u>videos and podcasts</u>. Some of these resources have also been <u>translated</u> into other languages. As well as being relevant for families, these resources are also relevant for health professionals.

Click here for further information >>> Information for families

Regional Outreach and Shared Care Program (ROSCP)

The ROSCP is a program which facilitates the transition between the primary treating hospital and the regional centre that cares for children and adolescents with cancer. The program provides opportunities for shared care and ensures there are agreed levels of training and standards of care of medical, nursing, allied health and supportive services. Click here for further information>>> Regional Outreach and Shared Care Program (ROSCP)

Long Term Follow-up Program (LTFP)

The LTFP facilitates the transition from completion of curative treatment to the 'survivorship' phase of the cancer journey. The aim of the program is to provide a clear and consistent



standard of long term follow-up care across Victoria, which is responsive to the needs of all childhood cancer survivors and their families.

The program is accessible to all paediatric, adolescent and young adult survivors of childhood cancer living in Victoria. It provides each individual with a tailored approach to meet their ongoing needs and an appropriate transition plan to adult-based, community or hospital services.

LTFP clinics are held at The Royal Children's Hospital, Monash Children's at Monash Health, Peter MacCallum Cancer Centre, Alfred Health and at designated regional centres.

Click here for further information>>> Long Term Follow-up Program (LTFP)

3 Childhood cancers

Having a child/teenager diagnosed with a serious illness such as cancer can impact the entire family and also extended family/friends/school. Families describe feelings like shock, disbelief, anger, fear and sadness. These feelings are all normal.

It is often very overwhelming in the initial diagnosis phase. The Children's Cancer Centre team will help provide support, information and education to help you and your family at all stages of care and treatment. Sometimes the information provided can be hard to take in all at once. The team will help by providing important information in different formats. This includes The Information Book – Life After Diagnosis. The Information Book is also available on line: http://www.pics.org.au/Assets/446/1/TheInfoBookFORWEB.pdf

The following links provide helpful information about various aspects of childhood cancer. The Children's Cancer Centre team is always happy to talk to you if you are unclear or have questions about your child's diagnosis, care and treatment.

3.1 Diagnosis

http://www.cancervic.org.au/about-cancer/cancer-and-children/diagnosing-childrens-cancer

3.2 Types of childhood cancers

http://www.cancervic.org.au/about-cancer/cancer-and-children/children-cancer-types

3.3 Treating childhood cancers

http://www.cancervic.org.au/about-cancer/cancer-and-children/treating-childrens-cancers

3.4 Living with childhood cancer

http://www.cancervic.org.au/about-cancer/cancer-and-children/life-childhood-cancer



4 Non-malignant haematological blood conditions

Monash Children's Cancer Centre provides care and treatment for children and teenagers with a range of non-malignant haematological paediatric blood conditions. These can include:

- Newborn consultation service to the neonatal intensive care unit, and newborn nursery
- Consultation and management of thrombosis
- All other congenital blood diseases (including hereditary spherocytosis, Blackfan-Diamond syndrome, Schwachman-Diamond syndrome, and congenital neutropaenias)

THALASSAEMIA

Monash Health is also the Victorian state-based thalassaemia service providing diagnosis, treatment and genetic counselling for these patients. <u>Click here</u> for more information about the thalassaemia service.

5 Contacts

Monash Children's Cancer Centre – key contacts	Contact no.
CCC Administration and Management	9594 7653
CCC Day Oncology Unit	9594 7660
CCC Inpatient 41N Ward Nurses Station	9594 4160
CCC Inpatient 42N Ward Nurses Station	9594 4260
CCC Outpatient Appointment Bookings	9594 7660
CCC Outpatient Desk and Outpatient Reception	9594 7661
CCC Outpatient Pathology Blood Tests	9594 7660
CCC Patient Accounts	9594 7653
CCC Pharmacy (phone switchboard and Page Paediatric Oncology Pharmacist)	Pager# 4223
MMC Emergency Desk	9594 2149
MMC Hospital Switchboard	9594 6666