

NSW Paediatric Palliative Care Programme

A local initiative of the Sydney Children's Hospitals Network and Hunter New England Local Health District

May 2023

END OF LIFE AND PALLIATIVE CARE NETWORK

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Specialist paediatric palliative care services

Overview

There are three specialist paediatric palliative care (PPC) hospital-based services in NSW and one hospice. The Children's Hospital at Westmead (CHW); Sydney Children's Hospital (SCH), Randwick; John Hunter Children's Hospital (JHCH), Newcastle; and Bear Cottage Children's Hospice, Manly. Together these services are known as the NSW Paediatric Palliative Care Programme (NSW PPC Programme) and aim to provide a statewide approach to supporting the delivery of care to children with a life-limiting illness and their families.

The NSW PPC Programme provides care to patients aged 0-18 years in addition to antenatal referrals. There are four main referral methods:

1. Internal inpatient referrals across the Sydney Children's Hospitals Network (SCHN) are an electronic palliative care consult order
2. Internal inpatient referrals at JHCH are facilitated via a discussion between the referring specialists and the specialist palliative care team
3. Referrals external to NSW Health or from community services can use a referral form on the [NSW PPC Programme website](#), and are also asked to contact the relevant NSW PPC service
4. Some parents self-refer, which is welcomed, but a referral still needs to be completed by the child's primary medical consultant or GP.

The NSW PPC Programme supports approximately 125 new referrals each year (60 at CHW, 45 at SCH and 20 at JHCH) new referrals each year, as well as providing ongoing support to patients year-on-year. Linkage with each specific service often depends on the location of the child's primary medical team and the tertiary paediatric hospital this service is provided from. For example, if a child is under an oncology team at CHW, the referral will be made to the CHW NSW PPC team.

Each NSW PPC Programme team is a multidisciplinary consultancy service which encompasses inpatient, outpatient and home visiting models, with inpatient hospice care at Bear Cottage. The NSW PPC service provides:

- guidance, support and education to local hospital and community health staff who are involved in patient and family care across NSW
- outreach support for patients and families across the hospital and community setting, in all metropolitan, regional and rural NSW locations
- family consultations via virtual care, which may include other healthcare professionals involved in the care
- referral coordination with the local hospital and community health services, when needed, to support the patient and their family at home or in a location as close to home as possible
- home visits where possible and/or virtual care to connect the patient and their family with the local clinicians
- medical after-hours advice to NSW healthcare professionals
- inpatient care at Bear Cottage for respite, symptom management or end of life care.

Medical after hours service

The NSW PPC Programme Medical After Hours Service provides a statewide specialist paediatric palliative care model to ensure consistency in the provision of palliative care for children and families. The NSW PPC services hold weekly medical after hours handover meetings, where children and families with complex care needs are identified and discussions held to ensure that their wishes are identified and/or processes are in place to escalate care in the after hours period. NSW PPC Programme Medical After Hours telephone advice is available to all NSW healthcare professionals who are providing care to a child who requires paediatric palliative care advice (whether the child is known/unknown to a NSW PPC service). It is a rotating roster shared across the staff specialist and medical fellows at CHW, SCH, JHCH and Bear Cottage. Calls received are maintained on a spreadsheet to capture service activity data.

Nursing after hours service

If patients are at home, parents/carers can seek after hours nursing advice through the NSW PPC Programme Nursing After Hours Support Service, which is facilitated through Bear Cottage. Families are given a brochure to ensure they have the contact details if needed. The nursing service will escalate to the NSW PPC Programme Medical After Hours Service if advice is needed.

Multidisciplinary support

The child will remain under the care of their primary medical team throughout their illness, with the NSW PPC service offering specialist support as required.

There is multidisciplinary support available (during business hours) to meet the holistic care needs of children and their families. The multidisciplinary team may consist of doctors, nurses, physiotherapists, occupational therapist, child life therapy, music therapy, social work, bereavement counsellors and an Aboriginal health worker. Medical staff support patient care by assessing and managing their symptoms; developing comprehensive management plans to guide healthcare professionals in both hospital and community settings; and facilitating advanced care planning as a child's illness progresses. Specialist nursing staff are central to providing outreach support to patients and families. This includes the coordination of equipment and medication, referrals to community nursing and community palliative care; which also involves the provision of education and training to support the care and management of the child and family at home.

The NSW PPC Programme allied health team supports child development through:

- promoting play and participation
- supporting families to identify and work towards a broad range of functional goals
- assessing and facilitating the provision of equipment to support movement, patient comfort, safety and any other developmental needs.

The NSW PPC Programme allied health team also provides education to local community allied health teams and NDIS providers, and supports families to access these community services. While its services are primarily a consultative model, if there is no local team the NSW PPC Programme allied health staff may take on some direct roles in providing inpatient support and visiting the home or community setting. Support can also be provided via telehealth or virtual care.

Social work and bereavement support

Families receive social work support from the NSW PPC Programme throughout their child's illness. This may include counselling and/or other therapeutic interventions to assist with family adjustment, including sibling support; facilitating memory making; or coordinating practical supports that can reduce the burden of care experienced by families.

The NSW PPC Programme also provides bereavement follow-up to families after their child has died. Support may include grief and loss counselling to parents/carers and siblings, and sending a card to acknowledge important dates (birthday and anniversary of their child's death) in the initial 12 months following their death. All three hospitals and Bear Cottage also invite bereaved families to attend one of their regular Remembrance Services.

Benefits of the NSW PPC Programme

Through integration, collaboration, access to interventions and support, the NSW PPC Programme is able to support and improve the statewide delivery of care to children with a life-limiting illness and their families.

- **Integration and collaboration across services:** The NSW PPC Programme works collaboratively to help streamline patient and family care across NSW to support improved service planning and delivery. It aims to raise awareness of paediatric palliative care; increase education and knowledge for clinicians and the community; and streamline the PPC model of care for children and families who are supported across the hospital and community setting.
- **Pop-up interventions:** The NSW PPC Programme teams provide timely and responsive interventions to support patients and families in the hospital and community as a child's condition changes during their illness trajectory. This may include updating their symptom management plan, providing equipment, psychosocial assessment and interventions, or navigating complexities related to the geographical location of the child. Pop-up interventions involve providing individualised education and training to the identified local healthcare providers to improve their knowledge and ensure that they feel confident in supporting the care of the child and their family, especially in rural and remote locations.
- **Access to a multidisciplinary team:** The NSW PPC Programme's multidisciplinary approach is fundamental to delivering holistic care to meet the physical, psychosocial and developmental needs of the child and support for families.
- **Access to bereavement support:** The NSW PPC Programme ensures families have access to appropriate bereavement care when needed before or following the death of their child.
- **Enhanced service delivery model:** Through statewide collaboration, the NSW PPC Programme facilitates new projects/programs with improved efficiency and provides resourcing to support these.
- **Data and quality improvement:** A quarterly meeting is held to discuss statewide initiatives and review service activity across each of the NSW PPC services.
- **Statewide working groups:** The NSW PPC Programme has established several clinical working groups across sites, including for website development; consumer engagement; allied health, bereavement and other initiatives such as the [Last Days of Life Toolkit: Paediatric and Neonatal](#).

Paediatric palliative care support and advice

- Support and advice from the multidisciplinary team is available to all members of the local team when needed. Medical advice is available after hours (see below). There is substantial collaboration between the local team and NSW PPC Programme staff, including outreach support to community nurses and community palliative care services across the state.
- A partnership model of care is established with local community and hospital-based health providers who are involved in the care of a patient and family throughout the terminal illness of the child.
- Staff wellbeing is recognised as important in the provision of paediatric palliative care. Support is offered in the form of pre-briefing and debriefing opportunities, or through participation in the NSW PPC Programme 'Death Review' after a child has died. Community and hospital clinicians involved in the child's care are invited to attend the Death Review as an opportunity to jointly reflect on the care that was provided to the child and their family, including what was done well, the challenges experienced and what could have been done better or differently.
- Education and training is often provided at the time a family is referred to a local community team. It is part of the pop-up model of care where the NSW PPC Programme services ensure that they are available to provide the specialist support related to the management plan and other identified care needs. Given that the NSW PPC Programme teams are closely involved with the primary treating team and the child's family, there is regular, ongoing contact and communication to assess the need for additional support. This increases at end of life and after the time the child has died, at which point local teams are invited to participate in the NSW PPC Programme Death Review.

Patient, carer and family experience

- The NSW PPC Programme contributes to improved quality of life during the illness of the child, which is enhanced by early assessment and the creation of a multidisciplinary management plan.
- The NSW PPC Programme improves support at home to reduce the stress experienced by families, especially during the end of life period. This is established by linking families with community health services in their local area.
- CHW, SCH and Bear Cottage offer a home support volunteer program where the NSW PPC Programme Service Volunteer Coordinator places a carefully matched volunteer with a family to assist with practical supports based on their individual needs (e.g. time spent with siblings, outings to medical appointments). The Home Support Volunteer Program is complementary to the care provided by the NSW PPC Programme multidisciplinary team and both work together to support families in the home setting.
- Patients, carers and families benefit from access to NSW PPC Programme service advice during business hours and after hours through the Nursing After Hours Advice Service (facilitated through Bear Cottage)
- Improved holistic care that is available from the NSW PPC multidisciplinary service.

Feedback from families

What have you found most valuable about being supported by the specialist paediatric palliative care service?

“We have found all the support provided by palliative care very valuable – counselling, nursing, doctors, physiotherapy, music, child play therapy, the Home Support Volunteer Program and respite care. Also, the Palliative Care Nursing After Hours Support Service, A Little Piece of Me portrait, U-Play and Starlight Moments are wonderful programs. The care was not just to our daughter but to our son who was facing a difficult time. The Bereavement Coordinator helped us to support our son with the school counsellor to understand more about our daughter’s condition.”

“The Paediatric Palliative Care service focuses on providing integrated care to enhance the quality of life of my child, and supporting our family in all the ways, including the siblings. They work with us to ensure the best interest of my child are best addressed.”

Why is it important?

“Paediatric palliative care for children is very important because it aims to provide the best quality of life and care possible and to support the family. It begins when the illness is diagnosed and continues while still pursuing the curative measures.”

“Our daughter’s condition is the hardest struggle as a family we have ever been through. However, tremendous support and check-ins when we were home shined light on our family. We always enjoyed seeing the NSW PPC Programme multidisciplinary team. It’s been more than half a year since we left hospital, and we would not have got this far without their help.”

Supporting resources

The [NSW PPC Programme website](#) has a broad range of information for healthcare professionals and families, including:

- fact sheets for families about paediatric palliative care and the NSW PPC Programme services
- information on [how to refer a patient](#).
- feedback from families who have been supported by the NSW PPC Programme service and opted to provide ‘Website Stories’ about their child’s care
- bereavement education and information for families, siblings, grandparents, friends and community members
- helpful resources for healthcare professionals and families, including links to books and websites to guide conversations with dying or bereaved children
- a list of upcoming education events, including virtual education seminars and the annual SCHN Paediatric Palliative Care Symposium.

Appendix

Alignment of the NSW PPC Programme with the Clinical Principles for End of Life and Palliative Care Guideline

Key action area		Evidence of alignment
1. Screening and identification	✓	Screening and identification occurs before referral, by local health teams or GP who recognise the need for PPC and complete a referral form. The NSW PPC Programme website includes a 'Triggers for referral to palliative care: Diagnosis of a life limiting illness' infographic for referrers
2. Triage	✓	Children are triaged on intake to the service, based on their palliative care needs. The NSW PPC team screens patients to identify the need for a comprehensive palliative care assessment
3. Comprehensive Assessment	✓	A holistic palliative care assessment is completed on intake and reviewed as required, which identifies the need for allied health input or on-referral to external services
4. Care Planning	✓	A comprehensive care plan is developed and documented on the patient's health record, which can include advance care planning and provides for timely and responsive interventions
5. Open and Respectful Communication	✓	NSW PPC is a consult service which works in partnership with the child's primary treating team and local health service Provides a consistent, centralised contact point for family and carers to seek information and support
6. Symptom Management	✓	As a consult service, the NSW PPC team provides specialist advice to local teams on appropriate pharmacological symptom management for their patients
7. 24/7 Access to Support	✓	Provides medical support and advice to healthcare professionals after hours, through the NSW PPC Medical Telephone Advice Service. On intake to the service, families are provided with a brochure about how to access nursing support after hours facilitated through Bear Cottage.
8. Place of Death	✓	The NSW PPC team assists parents/carers to identify the preferred end of life location of care for their child. This includes hospital, home or Bear Cottage
9. Grief and Bereavement Support	✓	Families are offered bereavement counselling following their child's death. The SPPC will provide bereavement follow up for approximately 12 months after death to stay linked with the family. This will occur via phone calls, virtual care or home visits. Cards will also be sent to acknowledge a child's birthday and anniversary over this time.

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