

Impact Report



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The Sydney
children's
Hospitals Network
care, advocacy, research, education

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Healing, Caring, Curing





Progress Report from 2016 to 2017

This document outlines the Mark Taylor Outreach Program 2016/2017. This document outlines the scope, breadth and virtues of the program from the perspective and experiences of the Clinical Nurse Consultant, Bridget McGinley.


The Mark Taylor Outreach Program

The Mark Taylor Outreach Program commenced in August 2005 at the Children's Hospital at Westmead (CHW). Sporting Chance Foundation provided funding to CHW to sponsor a Clinical Nurse Consultant (CNC) to support children and young people with cancer in rural and regional New South Wales (approx. 400,000 square KMS). In addition the program supports oncology children and young people from Darwin, Perth, Adelaide and Melbourne. Further funding was provided in 2009 by Sporting Chance Foundation to employ a Registered Nurse (RN) to work alongside the CNC supporting children, young people and their families in rural NSW diagnosed with cancer with support, education and medical care as close to their home, as safely possible.

The principle aim of The Mark Taylor Outreach Program is to facilitate the transition of the child/young person and family between the primary treating hospital (Westmead) and regional hospitals. Subsequently, further development of the "shared care" model has enabled children and young people with cancer to be cared for safely and effectively in a familiar environment at local hospitals. Through the shared care model medical and nursing staff at local hospitals have increased knowledge and skills, to support the patients whilst in local hospitals while communicating with CHW.

Dealing with a diagnosis of cancer presents a range of challenges not only for the patients themselves, but also for their families and / or primary carers. It is well documented that children, young people, and their families who are affected by childhood cancer face significant emotional, practical and financial difficulties. These difficulties are more pronounced when family and social networks are disrupted by both the diagnosis and associated treatment regime.

Through the Mark Taylor Outreach Program, we invest in supporting rural families and local and regional services to further enhance their knowledge and skills, enabling more children and young people with cancer the opportunity to have safe care closer to home. Ensuring that there are agreed levels of training and standards of care put into place in these shared care facilities provides insurance that those children and young people, no matter where they live in NSW, will receive high quality, safe, effective and efficient care and support closer to home. There has been a steady increase in the occasions of service being delivered by shared care over the last few years which has resulted in a reduction in the number of visits some families need to make to The Children's Hospital at Westmead.



The vision for The Sydney Children's Hospital Network (SCHN) strategic plan 2017-2023 is "Working together.....for the children". This ties in very well with The Mark Taylor Outreach Program philosophy aiming to provide a family centered approach to rural children and young people and their family/carers. Our belief is that care fits around the child and family hence the foundation that supports the development of our Shared Care model.

This report provides a summary of services, achievements and family experiences during 2016/17; we would also like to take this opportunity to highlighting our vision for the future of The Mark Taylor Outreach Program.

The mission of The Cancer Centre for Children is to continue to be a leader in the field of childhood cancer, in designing and implementing new and more effective treatment protocols and modalities; to increasing cure.

Program Snapshot 2016-2017

There are approximately 140 newly diagnosed patient referrals per year. Of these referrals, approximately 36-39% of these children and young people live in rural and regional areas.

Presently 60 children are on The Mark Taylor Outreach Program.

New patients	29 on active therapy late 2015- August 2017
Interstate patients	3
Maintenance Therapy	8 patients on 2 weekly blood monitoring with Chemotherapy monitoring
Surveillance	6 patients on monthly blood monitoring 12 patients requiring monthly monitoring for bloods +/- 3/12 EUA MRI's PETs & CT Scans (some organized locally)
Transition of care	2 young people transferred into adult services
Palliative	2
Deaths	1
Local referrals	822 referrals updates and on-going care requirements.
Little Wings	23 families' assisted approximately 481 passengers

170 Flights + 30 van transfers (patients outside of NSW coordinating their own flights)

All of above patients currently receiving shared care/and or follow up with local services



Level One

- No planned inpatient paediatric medical service or designated beds.
- Primary and emergency care including stabilisation for children and young people prior to transferring to an appropriate higher level of service.

Level Two

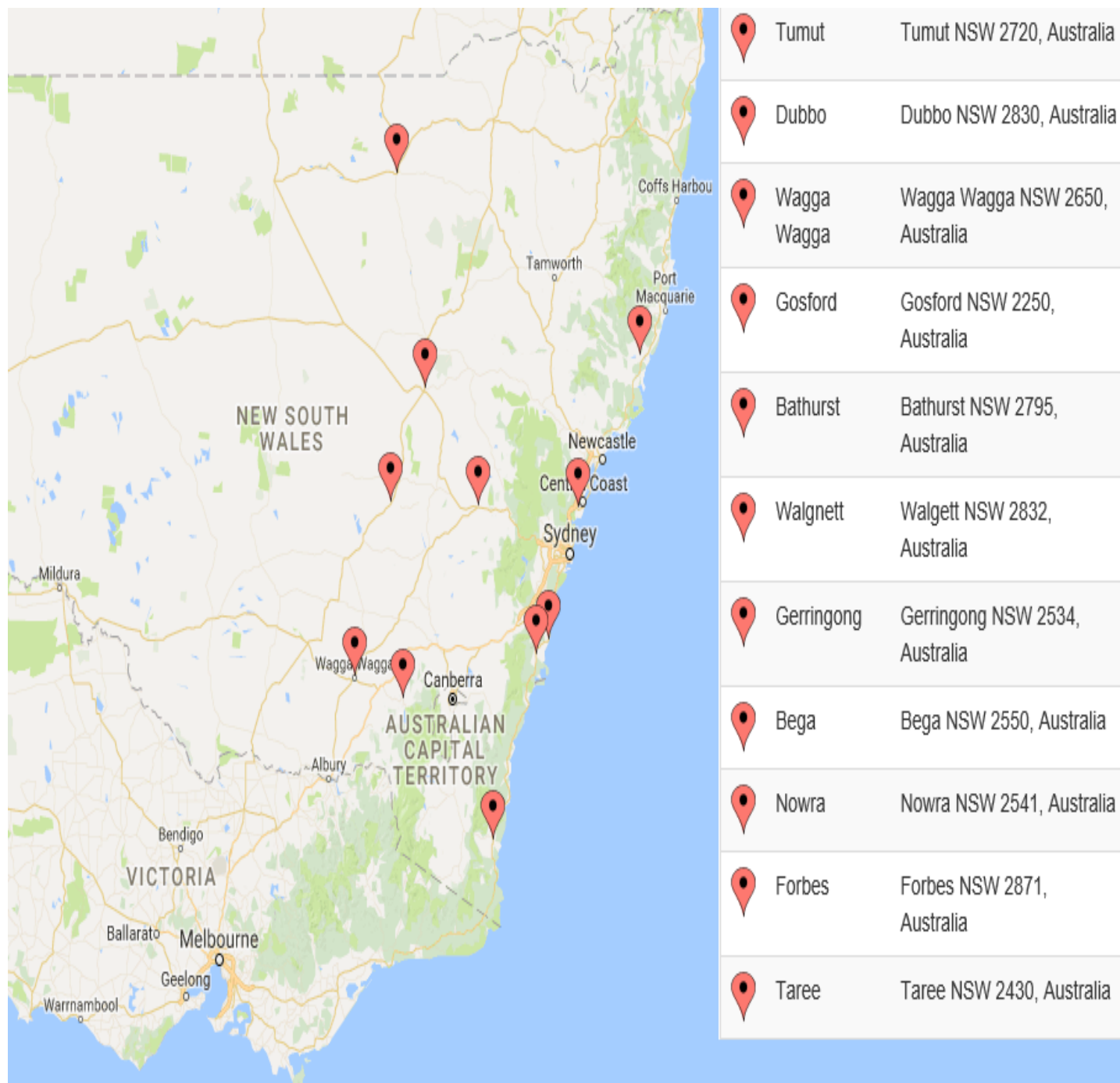
- Designated paediatric inpatient in a general hospital in an outlying and geographically isolated area.
- Formal consultative links with paediatrician.
- Registered Nurses with skills consistent with a Paediatric Nurse.

Level Three

- As per level two, plus designated paediatric ward/area with patient amenities. Has isolation capacity in separate rooms.
- Access to Clinical Nurse Consultant within the area and Registered Nurses with skills consistent with a Paediatric Nurse.
- Has 24 hour access to Medical Officer on-site or available within 10 minutes.
- Access to allied health professionals. Formal link to community child and family health service.

The table in Appendix 1 – Shared Care Services represents the significant increase in the shared care services and initiatives aligned with The Children’s Hospital Westmead. The Oncology Services Outreach Team Clinical Nurse Consultant and Registered Nurse are responsible for providing supportive care through education, visits and via phone and teleconference.

Initial outreach visits for newly diagnosed patients July 2016 – August 2017



2016-2017 Update on Shared Care Facilities

Initial Outreach Visits for new patients	19
Educational visits	14
Educational presentations	7
Conference calls	6
Resources provided	as new information and protocol changes arise.
School visits	21
Home visit/ongoing support	18
Chemotherapy accreditation hospitals	9
Chemo Study day	8
Chemo study day 13/12/17	9 (booked to attend at present)

Mark Taylor Outreach Program: 2017 Strategic Inclusions

New establishment of Shared Care Services with Blue Mountain Katoomba Hospital.

- Commenced in April 2017 **Level 1**
- Collaborative service development plan implemented highlighting the needs of the patients in the Blue Mountains district (awaiting approval from SCHN Executive)
- Formal training and education provided to medical/nursing staff within the Blue Mountains Katoomba Hospital to care for our oncology children in an acute emergency, prior to transfer CHW as per Level 1 agreements.
- Intensive education program provided to staff on the paediatric ward.
- Presentation and educational resources provided.
- 5 registered nurses and NUM accredited to care for Central Venous Access Devices as per SCHN Practice Guideline
- 3 patients are able to have bloods collected locally, CVC dressing changed and IV push chemotherapy administered by the paediatric registrar.

Newly established July/ August 2017

- Advertisement of Nursing Management of Children with Cancer Study Days to Shared care hospitals November 2017
- Zoom used to provide 1st session of education across multiple sites via internet. Provided by medical + outreach staff
- Project within the executive level is being undertaken to establish a collaborative service development document between SCHN Westmead campus and shared care hospitals in New South Wales

The Mark Taylor Outreach Team at The Children's Hospital Westmead

The Mark Taylor Outreach Program funded by the Sporting Chance Cancer Foundation supports a full time Registered Nurse – Clinical Nurse Consultant – Bridget McGinley.


Parents' Perspective – Patient Story Ava Garland

We are the Garland family, parents Andrew and Kathy and our five lovely daughters, Scarlett (14), Olivia (12), Polly (9), Willa (7) and Ava (4). We live 50 kilometres out of Forbes on a farm in the central west of NSW, more than 400 kilometres from Sydney.

In May 2016, Kathy took Ava to the GP after she had been unwell for a few days and looked a bit yellow. The appointment was at 1.30 pm which was perfect as they could pick up the older girls after school, saving them from the one and half hour bus trip home and might even be able to get a milkshake in town.

Little did we suspect, we would be sent straight to Westmead Hospital for Ava to commence treatment for Acute Lymphoblastic Leukaemia. No waiting for Andrew to come to town, no time to pack a bag, straight in the car for the five and half hour trip to Sydney.





Following a bone marrow biopsy, which determined 98% of Ava's bone marrow was leukaemia cells, she commenced an intensive chemotherapy protocol which resulted in us having to stay in Sydney for nine months.

Our family was reeling with the diagnosis and the separation, for the rest of the year our eldest daughter, moved in to live at her high school and the three younger girls moved to Orange (200 kilometres away from home) to live with their aunt and uncle and attend a new school, living in a new house.

Our time together as a family suddenly became precious and much needed. Regardless of how unwell Ava was through the intensive chemo, a visit from her sisters gave her an emotional boost, much needed for a three year old. We were even lucky enough to go home twice in that time and just get some air away from the hospital, which was very necessary for us both to survive the rest of the treatment in Sydney. It has generally been agreed by our family and our medical team these breaks proved significant in Ava's recovery.


In the early days of diagnosis we were introduced to our Oncology team and the Rural Oncology Nurses who coordinated and made it possible for those very important trips home and our eventual return home with more than a year of daily maintenance chemotherapy still required. Without the Rural Oncology Nurses, our family would still be living under four different roofs. A situation that makes me teary just thinking about it as I'm pretty sure we only just made it for the nine months we were all apart.

Since our return home, at the end of February 2017, it has still taken a solid six months to readjust and that is just our regular family life. This did not include any the liaison and coordination, discharge procedures and all the pre and post medical advice that was required for our local hospital, our GP and our regional hospital, where we are required to attend if Ava is admitted and which was undertaken wholly by our Rural Oncology Nurses.

Unfortunately Ava wasn't terribly well in the first few months at home and she was admitted to hospital in the first ten days, (un)fortunately Paediatric Oncology patients aren't common and we encountered difficulties and challenges during this first admission. Thankfully I had the Rural Oncology Nurses who stepped immediately in as my Patient Advocates and were able to quell an upsetting experience. Furthermore, our Rural Oncology Nurses followed up with significant protocols and procedures to ensure if Ava was admitted again the same situation would not arise.

I am very pleased to report after a recent admission it was a completely different and pleasant experience, which makes a stay of several days, hundreds of kilometres from home much easier to cope with.

Another vitally important step in Ava's recovery has been her commencing preschool. Since leaving Westmead, Ava has turned four and was very keen to start a day a week at her local preschool. The Rural Oncology Nurses worked with Forbes Preschool to educate and prepare them for Ava's transition considering all aspects of her immunity and other post-chemo issues. That single preschool day quickly became the highlight of Ava's week and since her enrolment she has progressed significantly in speech and development, she has regained full bladder control and is no longer wearing nappies, as well as her massive improvements in her general confidence and bubbly nature. We have been hugely impressed with the meticulous anti-contamination procedures undertaken by the preschool after working with the Rural Oncology Nurses, a staff member sterilises the toilet before Ava uses it. It is such a massive relief to know she is in a clean, fun and safe environment. Particularly through what has been a pretty bug-ridden winter, Ava has remained very well thanks to these procedures.



Finally our Rural Oncology Nurses have been my first go-to with any questions since I have returned home. When we first arrived home Ava began maintenance chemotherapy which involves taking a varied program of chemotherapy medications, as well as regular blood tests and medical checks. It is a massive learning curve when you are trying to adapt to readjusting to returning home after a significant time away. As well as getting used to having four other children again. The Rural Oncology Nurses were and are my first phone call to check prescriptions, dosages and any medical or other concerns I have. They have consistently proved to be my experienced go-to person through this phase of returning home. I do not hesitate to ring or text as I know I will always get a response and I trust the information given due to the rapport developed while based at Westmead.

Now after more than six months at home, I am more confident with Ava's maintenance protocol but I still speak with the nurses very regularly to talk about any signs or symptoms or issues we may have. It is a great relief and when problems do arise I find the team are also a great liaison between us and the doctors and can break down or explain in other ways what is happening and going on.

Through diagnosis and those intensive chemo protocols, it is very scary and often a very isolating time for a parent, especially when you are solely on hand 24/7 to comfort and tend to a very sick and sometimes quite demanding child, who doesn't understand or often care why they are so ill. They just want comfort and for someone to make them feel better, NOW. After more hours than I could ever count spent in the oncology unit and oncology clinic, parents often talk to each other to give support and a few tips or shortcuts to getting through. The cancers may differ and the children's ages and coping strategies are different but it was surprising how often there are similarities or things cross over. As well as helping each other, we also just got it and sometimes you just needed someone to understand and to empathise with your situation, rather than having to explain every detail. Many metropolitan parents were envious of that extra support, help and assistance the rural based patients received through the Rural Oncology Nurses. We, the parents, have established a social network to keep in touch and support each other emotionally but it would be a vital cog in the oncology treatment program for specific support and to provide medical mentoring through the many phases of your child's chemo treatment.

If you need a village to raise a well child, you need entire informed communities to help you to get through childhood cancer.

Yours sincerely

Kathy and Andrew Garland.

Reflective Patient Story: 'Jacob'

'Jacob', aged 15, was diagnosed with an Osteosarcoma of his right tibia in October 2013.

'Jacob' lives with his family in Coffs Harbour which is 526 kilometres from The Children's Hospital at Westmead and approximately six hours drive by car. He commenced an intense chemotherapy regime which required him to have surgery. He completed treatment in July 2014.



Jacob Today

'Jacob' has now completed his last term at school and is very excited about going to college. As Jacob has turned 18 his last visit to the Oncology clinic in August was very sad, although 'Jacob' claims "he will still come to visit us when he comes back to the adult services in 6 months.





Future Vision for The Mark Taylor Outreach Program

The vision of The Mark Taylor Outreach Program is to provide high-quality safe and effective clinical and supportive care in appropriate environment as close to the child's/ young person's home as possible.

The Mark Taylor Outreach Program is currently undergoing review through multiple perspectives:

- the Mark Taylor Outreach team
- oncology multidisciplinary team
- shared care hospitals
- patients and their families

Strategic Plans

- Formalise relationship with each local hospital which meets the agreed criteria for “shared care services” which is agreed between treating hospital and local hospitals
- Development of agreed levels of shared care hospitals working within The Mark Taylor Program and SCHN Westmead campus.
- Development of The Mark Taylor Outreach supportive care document
- Development of The Mark Taylor “Outreach” Link Nurse Program”
- Commence work on E learning packages for Shared care hospitals.

Nursing Roles

- CNC role to support development, implementation and evaluation of the strategic plan items
- Continue to build good relationships with our shared care hospitals.
- Continue to act as resource for medical/nursing staff in regional NSW.
- Supporting our children and young people and families through transition from Cancer Centre to local shared care services.
- Continue to deliver a dedicated program including excellence in patient care and communication throughout The Mark Taylor Outreach program and shared care hospitals.

Future Workforce

Since 2005 The Mark Taylor Outreach Program has strived to deliver high quality care, support and communication to our shared care hospitals. Looking to the future the service requires the following workforce additions to ensure we are a world class outreach service delivering a consolidated comprehensive service:

- A dedicated outreach physician is required
- A dedicated education position is required to develop, implement and maintain e-learning.
- Additional nursing positions to enhance the service through case management due to the increased work load , expectations of shared care hospitals and family support.

Partners in Care



Through your continued partnership, we have achieved so much and been able to significantly improve the already great cancer care services we provide at The Children's Hospital at Westmead.

We are grateful to the Sporting Chance Cancer Foundation for enabling us to provide the best possible health care outcomes for regionally based children with cancer, so that they may live their healthiest lives to their full potential.

We can't thank Sporting Chance Cancer Foundation enough for the support you have given to us to develop The Mark Taylor Outreach Program during 2005 to 2017.

With your ongoing help, our team will continue to strengthen their skill to heal, devotion to care, and vision to cure.

For further information please contact
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