



# Impact Report

Written and Reported by

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Mark Taylor Outreach Program

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## Progress Report from 2017-2018

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This progress report for the Mark Taylor Outreach Program 2017/2018 outlines the scope, breadth and achievements of the program at the Cancer Centre for Children (The Children's Hospital at Westmead). It has been prepared by Clinical Nurse Consultant Ms Bridget McGinley and reviewed by Ms Rachel Graham (Nurse Manager Oncology) and Dr Luciano Dalla-Pozza (Director, Cancer Centre for Children).

### The Mark Taylor Outreach Shared Care Program

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The Mark Taylor Outreach Program was established 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 and their families in rural and regional New South Wales (approx. 800,000 square kms). In addition, the program supports children and adolescents with cancer from interstate centres in Darwin, Perth and Adelaide. Further funding was provided in 2009 by the Sporting Chance Foundation for a part time Registered Nurse (RN) to work alongside the CNC to expand the capacity to deliver education and safe medical care for regional families as close to the patient's home environment as possible.

Since the commencement of The Mark Taylor Outreach Program demand for services has exceeded expectations. This has resulted in part from an increase in population. Additionally the introduction of new therapies and protocols requires ongoing education and support for medical and nursing staff to enable best practices to be available and delivered to regional patients in NSW.

A review of how the service could better meet the needs of regional patients would help inform the direction and priorities of the Outreach Program to enable it to continue its role as a critical provider of tertiary paediatric oncology services in regional NSW.

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 (SCHN-The Children's Hospital at Westmead-CHW) and regional hospitals. This "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 and through general pediatricians and family doctors. With the expansion of the shared care model, medical and nursing staff have increased their knowledge and skills to more effectively support oncology patients during their stay in local hospitals maintaining close communication with CHW. There has been a sustained increase in the occasions of service being delivered through this shared care arrangement over the last few years which has resulted in a reduction in the number of visits families are required to make to CHW. The shared care model has allowed children to remain at home for longer periods and to receive supportive care (antibiotics, blood transfusions, nutritional support, pain relief) as required in the local hospital. This has decreased the bed stay nights at CHW as well as the oncology clinic visits.

Dealing with a diagnosis of cancer presents a range of challenges not only for the patients themselves, but also for their families and primary carers. Children, young people, and their



families affected by childhood cancer face significant emotional, practical and financial difficulties; social networks are disrupted by both the diagnosis and associated treatment regimes. These difficulties are more pronounced when therapy has to be delivered across different centres (radiotherapy, surgery and chemotherapy). A young patient with bone cancer may require chemotherapy initially at our Cancer Centre, followed by limb salvage surgery at another centre in Sydney and finally radiotherapy at Westmead Hospital (adult institution). Children and young adult cancer services often involve close interaction between surgical services as well as radiation oncology services. Surgical oncology services for children involve the initial biopsy of the tumour, tumour resection, as well as insertion of central venous access devices. Surgical procedures for children and young adults are provided by paediatric surgeons, orthopaedic surgeons, as well as neurosurgeons. Radiation services are provided within the Westmead adult campus with paediatric radiologists.

Through the Mark Taylor Outreach Program, we invest in supporting rural families 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. High levels of training and education are needed to maintain excellent standards of care are necessary in these shared care facilities provides to ensure that our patients, no matter where they live in NSW, receive high quality, safe, effective and efficient care and support close to home.

Since the introduction of the CHW Clinical Service Plan 2018-2032 one of the key principles of clinical care moving forward is ensuring that “every child and young person receives the best care wherever possible – ensuring that the patient journey and hospital experience is more centered around bringing services to the patient and family”, CHW has a goal to increase delivery of care closer to the child and young person’s home.

The central philosophy of the Mark Taylor Program is to provide a family centered approach to regional children and young people and their family/carers. The program’s central belief is that care must fit around the child and family, which forms the foundation that supports the development of our Shared Care model. The Mark Taylor Program aligns with both the SCHN Strategic Plan 2017-2023 as well as the CHW Clinical Service Plan 2018-2032

This report provides a summary of services, achievements and family experiences during 2017-2018. We would also like to take this opportunity to highlighting our vision and strategic plan 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 further increase cure rates among children and young people.



## Program Snapshot 2017-2018

There are approximately 160 newly diagnosed patient referrals to our Centre each year. There has been a significant increase in the numbers of children and young people from rural and regional areas.

**Presently 88 children and families participate in The Mark Taylor Outreach Program.**

**Children and young people referrals to outreach service 2017 – 2018 (regional NSW) data collated by CHW CRA manager.**

	Number of Patients	
	2017/2018	Q1 2019
New Diagnosis	106	10
Relapse	13	1

The figure above represents the number of patients from our Cancer Centre accessing Oncology Services within the 2017 to 2019 period. As of Quarter 1 2019, there are already 10 newly diagnosed patients, as well as 1 patient who has had a relapse of the cancer. 18 children with brain cancer from regional NSW also receive support and treatment through the Mark Taylor Program.

Across the oncology service, 30 children in the past year received chemotherapy in regional centers

<b>New patients</b>	40 on active therapy 2018-2019 21 children completed therapy end of 2018 1 patient moved to Ireland 1 patient moved to Melbourne
<b>Interstate patients</b>	3
<b>Maintenance Therapy</b>	8 patients on 2 weekly blood monitoring with Chemotherapy monitoring
<b>Surveillance tests for</b>	6 patients on monthly blood monitoring 12 patients requiring monthly /bimonthly monitoring for bloods +/- 3/12 EUA MRI's PETs & CT Scans (some organized locally)
<b>Transition of care</b>	1 young person transferred into adult services
<b>Palliative Care</b>	0
<b>Deaths</b>	3
<b>Local referrals</b> Clarify referrals. What do you mean by this?	979 referrals updates and on-going care requirements. eg: Patient with bone tumour will have 25/30 referrals per 6 months treatment protocol
<b>Little Wings : 2017 2018</b>	48 families assisted approximately 69 families assisted equates to 612 flights
<b>Transport</b> - <b>Flights</b> - <b>Van Transfers</b>	267 flights increased from 170 in 2017 30 (all patients coordinate their own flights outside of Little Wings)

**\*\*All of above patients currently receiving shared care/and or follow up with local services, coordinated through the Rural Outreach CNC to facilitate continuity of care across all hospital campuses\*\***

The figures above not only demonstrate the commitment to allow our oncology children and young people to have care closer to home, they also highlight the amazing commitment Little Wings has shown by their continuous support to the regional families enabling them to fly home as often as possible.

Little Wings has also assisted some of our families whose children have required intensive therapy, by flying additional family members to CHW at very short notice.



# The Mark Taylor Outreach Shared Care Model

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All of our shared care centres are aligned to CHW; we have three levels of shared care:

## Level One

- No planned inpatient paediatric medical service or designated beds.
- Primary and emergency care including stabilization for children and young people prior to
- Transferring to an appropriate higher level of service.
- Blood test and review can be carried out.

## 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.
- CVAD Care, Bloods, Blood & Platelet Transfusion, Antibiotics, Immunoglobulin Therapy, & Anti-Fungal therapy

## 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.
- Chemotherapy can be given a day care patient – No overnight chemotherapy- or hydration fluids
- 30 patients received chemotherapy in local level three shared care hospitals in 2018
- Has 24 hour access to Medical Officer on-site or available within 10 minutes.
- Access to allied health professionals.

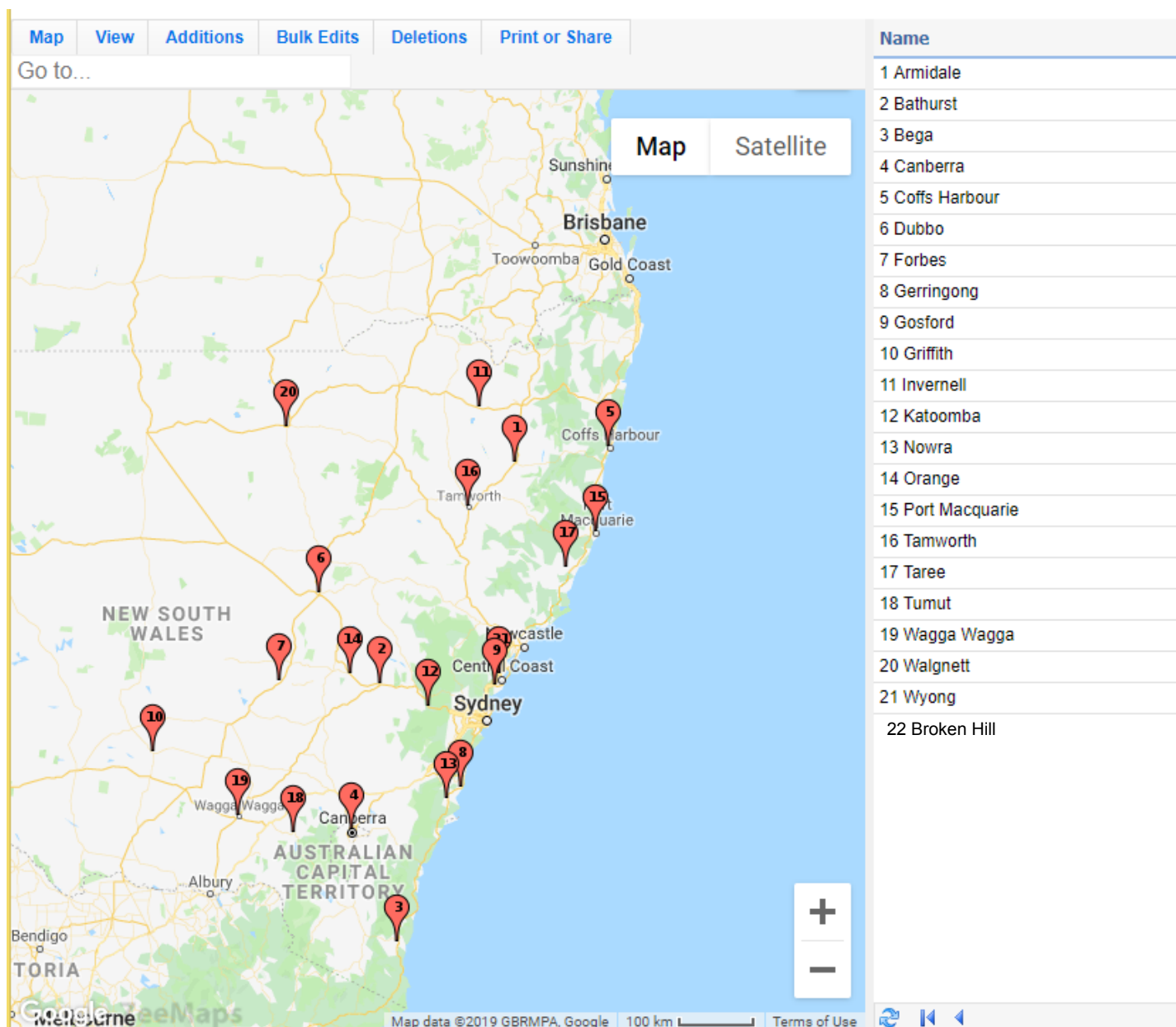
As part of the shared care program, formal links to community child and family health service's continues to develop. For a complete pictograph for the levels of shared care within paediatric health care centers, please refer to the below.





## Initial outreach visits for newly diagnosed patients 2017 – 2019

The map below indicates the locations where the Outreach CNC has visited and made formal referrals via phone, email and teleconference calls for home care, intra-hospital hospital care and support.



**NOTE:** Base hospital for Outreach CNC is approximately within Sydney location.



## 2017-2018 Update on Shared Care Facilities

<b>Initial Outreach Visits for new patients</b>	11
<b>Educational visits</b>	8
<b>Educational presentations</b>	7 (Katoomba, Bathurst, Bowral and Orange)
<b>Conference calls includes school conference</b>	39
<b>Resources provided</b>	Subject to change as new information and protocol changes arise.
<b>School visits</b>	8
<b>Home visit/ongoing support</b>	6
<b>Chemotherapy accreditation hospitals</b>	7 (on-going)
<b>Chemo Study day 2017-2018</b>	9
<b>Chemo study day 2019</b>	6 (attended to present date 4/4/2019)

### Current Outreach Program

- 1 Full time CNC
- 1 P/T Registered nurse (5days a fortnight)
- The Registered Nurse (RN) position has remained vacant since August 2017.

The care provided in regional centres as well as visits/treatments to the local paediatric ambulatory care services (PACS) has had a significant impact on CHW bed utilization. Statistics collated from the previous 2 years 2017-2018 and 2018-2019 demonstrate the increase supportive care that has been provided by our shared care hospitals in the regional area.

The below is a table of overnight stays, PACS visits and further stays for children within the service.

	<b>2017</b>	<b>2018</b>	<b>2017</b>	<b>2018</b>
	<b>LDH Bed stays</b>		<b>LDH PACS visits</b>	
<b>Total</b>	<b>220</b>	<b>244</b>	<b>476</b>	<b>598</b>

### PACS visits:

**Children / young person reviewed on paediatric ward in local hospital or on the day care unit**

### Supportive care provided

Medical review, Bloods, Central line care, antibiotics, blood and platelet support, chemotherapy if required, social work support.



## Mark Taylor Outreach Program: 2017-2018 Strategic Inclusions Update

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New establishment of Shared Care Services with Blue Mountains Katoomba Hospital in 2017 has continued to thrive despite significant changes to staff. This required considerable investment of time to sustain the required skill base and education. In March 2019 a high risk oncology patient received supportive care on the paediatric ward with guidance from the outreach CNC and medical team –this was really important to the family as they were able to remain closer to home.

- Commenced in April 2017 Level 1 - **progressed to Level 2 (with ongoing support)**
- 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.
- Intensive education program provided to staff on the paediatric ward.
- Presentation and educational resources provided.
- ALL registered nurses and NUM accredited to care for Central Venous Access Devices as per SCHN Practice Guideline and local guidelines
- Three patients are able to have bloods collected locally, CVC dressing changed and IV push chemotherapy administered by the paediatric registrar.

## The Mark Taylor Outreach Team at The Children's Hospital at 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 – The Hammond Family

The Hammond Family – Josh, now 6, has Pre-B Cell Acute Lymphoblastic Leukaemia

There is a lyric in Baz Luhrmann's Sunscreen song about the real troubles in your life blindsiding you on 'some idle Tuesday'. Baz was right. Although not about the idle bit, because getting three small boys out of the door to school isn't exactly relaxing, but it was a Tuesday.

Josh had had a fever, no other symptoms, for a week. We were keeping it at bay with the usual paracetamol and ibuprofen, and as soon as they kicked in he was a normal 5 year old for a couple of hours, before getting shiny-eyed and rosy-cheeked and creeping up to 40 degrees. On the third day I took him to the GP who prescribed antibiotics for a suspected sinus infection. Everything else was clear: chest, throat, no infected cuts or grazes... 48 hours later I lay in bed with him at midnight holding a damp flannel on his forehead willing the paracetamol to kick in more quickly. My hand rested on his little chest and I could feel his heart absolutely hammering.

Fast forward five days and two different antibiotics have failed to do anything so the GP suggests a blood test "just to rule out something more serious like Glandular Fever." Oh Glandular Fever, could it not have been you?

8.50am Tuesday morning. Baby Albie is strapped into his removable car seat by the front door; I am filling water bottles and shouting all those morning mum commands in various tones of stress which make me feel like I have become someone I am not.

My phone rings. I glance at it in exasperation: 'No Caller ID'. The only time my phone has said 'No Caller ID' has been when I was pregnant and midwives would ring me to make exciting, happy appointments. I consider ignoring it and then something in me says, 'medical'. So I answer it.

And then in one peculiar, inconclusive phone call everything changes. The school run is diverted to the local Emergency Department. Friends are called on in a blur, to this day I have no idea how I reached them. My still-breastfeeding baby is further away from me than he ever has been. Josh and I are in an ambulance on our way to The Children's Hospital at Westmead. We have entered a parallel universe. Josh has leukaemia. *Leukaemia*.



Late that night, curled in a hospital armchair-bed I roll onto my side, my face an inch from the blue fake-leather side of the armchair. My stomach is caving in. I make a fist and jam my knuckles into my mouth and screw my eyes tight shut and cry absolutely terrified, silent tears. We are in a twin room; the mum sharing our room lying on her identical armchair bed next to the girl with the brain tumour must be able to hear me gasping for air, stifling it like mad. I also know, already, that she has been here too and knows not to offer any comfort yet. I consider going out into the corridor and finding a nurse to have a breakdown on. Then I realize I am so exhausted I am probably better off lying down.

The next day dawns, somehow, and the information begins. Time and again we are warned about the impact this diagnosis will have on our family life – we have 3 small boys, one is still a baby, my husband works away four nights a week, we live a long way from the hospital. It is a 2 year minimum treatment plan 'if all goes well'. I wonder why on earth they keep talking about the impact on family life when surely all they should be talking about is how to stop my son from dying. Now, just over a year in, I begin to understand. The ripple effect is huge. Problems you didn't think were problems, cracks, tiny fissures, become gaping crevasses. Family relationships shift; some uproot their whole lives to help (I am English, my mum has moved across the planet to keep our other



boys' lives as normal as possible), some who you thought were distant turn out to be steadfast rocks, some go silent; life is clarified, you become tough as nails, hardened to the essentials. Survival of my son, my little unit, my other sons, my husband, and, somehow, god knows how, my sanity, these are the only things.

It's terrifying, and in the darkness of night it feels truly hellish, but seeing the treatment protocol unfurl is also like watching a well-oiled machine clicking into action. I begin to exist in a permanent state of knee-buckling gratitude; while I have been going about my life other people have discovered things, scientists in white coats in laboratories have made breakthroughs, *they know what to do*. I can almost feel the gratitude enveloping me. I give it a name: my Gratitude Cloak. On a good day it swirls about me and my head is high. On a bad day my shoulders slump inside its folds and it cocoons me from this hideous world we have been thrust into.

There is a constant presence through this journey, as your child morphs physically and psychologically from the child you knew into a bald, puffy, then skinny, moody little stranger, and then back again: the Outreach Nurse. I had no understanding or appreciation for what this role really meant in the first few weeks, sometimes she would be on the sidelines, sometimes she would be focussed on us, always she was being called on by multiple families and colleagues, always absolutely run off her feet.

From visiting our home to give Josh chemo 'pushes' through his central line, then explaining the overall treatment protocols in a way that we parents can understand, to giving the desperately-needed practical advice in moments of exasperated panic (such as how to get a physically strong 5 year old with steroid-induced 'road rage' to swallow a genuinely disgusting crushed tablet several



times a day without deliberately vomiting – and the vomit is cytotoxic), the Outreach Nurse is fundamental to the family's experience of paediatric cancer. And going back, briefly, to my earlier point about the ripple effect on the family, I would say there are times when they become almost a counsellor, an experienced, calm person walking alongside us who has seen it before and has an idea of what is ahead.

Always available on the phone, night or day, always ready with the right words, this is a role of vital importance. Without it we would be floundering, and when parents flounder, month after month as time grinds along and exhaustion sets in, families fall apart. To have the support is a wonderful thing, and there are not enough words to explain the gratitude we feel. And yet we are just one family! The idea that this one role is so valued and needed by so many families simultaneously is hard to comprehend. I imagine there must be huge job satisfaction, but my goodness this is taxing, exhausting job. To be constantly faced with the raw emotion and 'crisis' mental state of family after family, and to be able to pitch the response each of them needs correctly, is an amazing skill. Many times after a phone call or a hospital stay I found myself hoping our Outreach Nurse was going home to a hot bath and a long sleep, but I think the reality is probably more like a constantly beeping phone, as other families navigate the peaks and troughs of the cancer journey. Many, many times our phone calls have ended with the words, "I need to divide myself into four clones!" We would laugh, but it wasn't really funny; many a true word is spoken in jest.

As Josh's treatment continued we saw the true meaning of resilience and stoicism. This lion cub is an absolute warrior; do not mess with a 5 year old boy. Dose after dose after dose of chemo dripped in at the hospital, given at home as tablets, the other meds to combat the side effects, the frequent general anaesthetics for lumbar punctures to measure how it's all going, the shots of chemo straight into the spine, the fingerprick tests...and yet he takes it in his stride and gets back to lift-the-flap books or Lego or David Attenborough or brothers or whatever else is happening, and gets on with the day. Again the Outreach Nurse is there, ever-present, checking in and providing a constant at a time when nothing is normal, nothing is predictable.


Amazing and wonderful opportunities have also come from this tough experience: Josh was given the incredible opportunity to be a Researcher for a new 'lift the flap' book for Usborne Children's Books, 'Look Inside a Hospital'. He took this responsibility very seriously and is very clear that he wants the book to stop children being scared of going to hospital, because 'everyone in a hospital actually wants to help you mummy'. He says this as though it is new news, in an amazed tone of voice. The book was published globally in February 2019, and Josh has presented it with his older brother Ollie in his school assembly, and been featured in the local newspaper.



And so at the time of writing we still have any months of treatment to go, but Josh is doing as well as he can be. No-one tells us the longed-for 'everything will be fine', but they say he is doing really well.

If you are reading this, and you are a parent, I hope you never have to go through this. Having a child with cancer is, for me, purely terrifying. I am lucky to have found people who help me find ways to walk alongside the ever-present fear; with two other small children either side of Josh, I somehow have to find the strength to continue to be their mum, I can't let my fear of Josh dying destroy their childhood, or of course Josh's. And the Outreach Nurse is

absolutely key to this. She knows the fear, she can see it even on the days when I am hiding it, she has watched enough parents to understand. This is a multifaceted role: practical nurse, phone counsellor, multi-tasker in the extreme, long-distance-traveller who doesn't get to fly Business Class (!) but still has to be ready for anything when she (or he) lands.



To finish, in this situation you experience trauma, but you also get to see the special stuff, the 24 carat gold kindness of humans, the conga line of goodwill that exists in this world. Before this began I often found myself almost panicked about how bleak and horrible today's world can seem, how on earth were we meant to raise three boys into this mess that humans have created. Well only 2 days after that horrible Tuesday we had already felt a deluge of warmth and love on a personal level from friends, family and total strangers. Good comes from bad. And that is what is going to get us through this. And if God forbid it happens to you, or someone you know, then that is what will get you through it too.

Just make sure you have an Outreach Nurse walking next to you all the way.

## Summary of Conclusions and Recommendations for The Mark Taylor Outreach Program

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The Mark Taylor Outreach Program delivers a high-quality safe and effective clinical and supportive care in appropriate environments as close to the child's/young person's home as possible.

1. With the advent of increasingly complex regimes of care and improved survival rates, and the increasing number of children and young people with cancer has meant that the activity of the Mark Taylor Outreach Program has increased significantly since 2005.
2. Also with the complex and often intensive treatment has led to generating significant resource demands from increased admissions and sicker children who require more supportive care.
3. There are excellent communication links between the tertiary center (Westmead) and our regional center which has allowed us to build the Mark Taylor Outreach Program. However for the Mark Taylor Program to develop into a formal agreement between centers further support would be required from the network.
4. There are unmet needs within the service and ample scope to grow the service to achieve maximum benefits for regional patients and their families. Looking to the future priorities identified that would substantially enhance the service with additional staff are outlined below.

## Strategic Plans for 2019-2020

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*Appointment of a CNC would allow us to undertake the following:*

- 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 The Children's Hospital at Westmead
- Development of The Mark Taylor Outreach supportive care document
- Development of PONF (Paediatric Outreach Nursing Forum )
- Develop E learning packages for Shared care hospitals.





## Nursing Roles

- CNC to undertake joint home visit with each new family at home with regional team which includes school, GP, paediatrician, and hospital staff who would support the child and young person locally.
- CNC role to support development, implementation and evaluation of the strategic plan items
- Continue to build and foster 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

## Succession planning and service development

- Explore innovative ways to encourage oncology staff to consider career opportunities within the outreach service.
- Consider ways to enhance existing service through review of CNC and RN scopes of practice
- Participate in regular service review and feedback from patients and families and LDH's utilizing the service



## Partners in Care

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