Raylene Boyle Outreach Program

Sporting Chance Cancer Foundation

IMPACT REPORT

Missy, then 10, Leukaemia (ALL)

www.childrens.org.au

We are pleased to provide an impact report on the Raelene Boyle Outreach Program for 2018. The considerable impact that the Children's Hospital Foundation has on the lives of patients and their families wouldn't be possible without the generous support of the Sporting Chance Cancer Foundation.

Background – Raylene Boyle Outreach Program

Childhood cancer is the leading cause of death in Australian children under 14 years, apart from accidents. Nearly 200 Queensland families are affected by childhood cancer each year. When a child is diagnosed with cancer it affects the whole family and requires a family centred philosophy of care that supports everybody impacted. For families living in regional and remote locations, it is critical that they receive the same standard of care that city-based families can access and that their health, emotional and social needs are understood and met during this highly stressful time.

The Raelene Boyle Outreach Program supports children diagnosed with cancer and their families from Queensland's regional and remote areas who are receiving treatment at the Queensland Children's Hospital in Brisbane. The program works with families to help them make informed decisions about the services they need and ensure the strengths and needs of all family members are acknowledged. The program first started in 2009 as a telehealth service with clinicians at the former Royal Children's Hospital and has evolved into an outreach program that connects specialists and support workers across services to better serve the needs of children with cancer. Since 2009, the Program has supported more than 600 families from regional Queensland and approximately 650 families from Metro Brisbane.

The Queensland Children's Hospital is the tertiary referral hospital for all children diagnosed with cancer in Queensland, northern New South Wales and surrounding Pacific islands. The hospital accepts state-wide and interstate referrals for children from birth to eighteen years of age to its oncology service. For patients from regional and remote areas, the hospital's oncology service works with the relevant regional centre with paediatric services, known as an 'away centre', to develop shared-care plans that facilitates treatment, care and support for each child. Where appropriate, the goal is to facilitate a child's treatment to take place at regional hospitals, keeping them and family closer to home and to reduce unnecessary trips to Brisbane.

What was achieved through Sporting Chance's Support

Sporting Chance Outreach Nurse

243

new kids were diagnosed with cancer were supported

Through the Sporting Chance Cancer Foundation Outreach Program, patients and families are supported through education and coordination between oncology and palliative care services and supports Regional Case Managers in regional hospitals to take care of sick kids.

The Sporting Chance Outreach Nurse role is central to the program and focuses on enhancing an outpatient service to deliver and implement safe, coordinated, and clinically effective care to allow patients and families to stay at home for as long as possible.

Rebekah Orford continues to work in the role full-time, helping kids with new cancer diagnoses live comfortably at home for as long as possible by:

- Building relationships with cancer patients and their families during their stay in hospital;
- Assisting families with 'going home' education to facilitate earlier discharge back home;
- Support for regional oncology families and rural/regional oncology services;
- Conducting school visits for children in school undergoing cancer treatment;
- Assisting with school visits for those children with particular care needs; and
- Making home visits and attending home visits with the Paediatric Palliative Care Service.

Figure 1 - Bek Orford, Sporting Chance Outreach Nurse

From January 2018 – January 2019, **243 new patients were diagnosed with childhood cancer.** Normally the number of new diagnosis is 180 patients in 12 months.

This is a growth rate of almost 30%.

Kids and families who need the support of trained, clinical nurses like Bek grows every day.

In 2018, with the support of Sporting Chance Cancer Foundation -

- More than **80 education sessions for parents and carers** of newly diagnosed families were conducted including:
    - oral and subcutaneous chemotherapy;
    - central venous line (CVL) dressing management; and
    - nasal gastric tube (NGT) placements, insertions, and management.
- More than **80 schools and kindys received oncology support via phone and face to face visits** across the Brisbane region, along with resource packs and action plans for the school staff;
- More than **170 support calls** were answered from parents, caregivers, and health professionals across regional Queensland addressing questions about chemo, blood counts, infections and more;
- More than **50 new referrals to the Hospital in the Home program** were made – your support has meant Bek working with families to do blood sampling, CVL dressings, administering medication – all of which allows the family to go home rather than return to hospital for these routine tasks;
- Over **60 orders for consumables** were placed (like medication, syringes, and dressings) for regional families so they didn't have to worry about ordering themselves, or travelling to hospital to pick them up;
- Conducted six 'pop-up' visits to regional areas to touch base with both families and staff:
    - Stanthorpe in the Darling Downs area;
    - Noosa and Caloundra on the Sunshine Coast;
    - Gladstone in Central Queensland twice; and
    - Townsville in North Queensland.

80

kids in regional Queensland stayed at home instead of travelling to hospital for routine care

In Brisbane, between 1-2 visits were conducted each week to palliative care patients and their families. Generally, this involves touching base with the families, introducing them to different community teams who support them in their home setting, communicating with them about the end of life, and educating and briefing the community staff.

In 2018, 16 patients supported by Bek and the Palliative Care Team passed away.

Funding from Sporting Chance has meant they and their families were fully supported during this difficult time and had access to the best possible clinical care.

Key Milestones

In 2017 some key objectives were set for the Outreach Role as below, and we are pleased to report three of the four have been achieved, with the fourth completed and awaiting final approval.

Objective	Achieved?
Seek to facilitate 40 or more children returning to home to continue their oncology treatments through the support of regional case managers.	Achieved. More than 80 patients were supported in the calendar year January – January. This includes new patients and existing patients who became ready for transition.
Continue to conduct regular school and home visits.	Achieved. As detailed, more than 80 schools, kindergartens and day-care centres were visited in Brisbane for Health in the Home; approximately 50 visits were conducted for Palliative Care support.
Develop and implement a program for intravenous fluids and certain drugs to be administered by CADD pumps within the child's home.	Ongoing. The policies and procedures for this service have been developed and are awaiting approval from Children's Health Queensland.
Develop and implement a teaching package for central line care for parents to reduce the incidence of central line infections in children and reduce the number of avoidable hospitalisations.	Achieved. CVL management can be complex, so families are individually identified by the Clinical Nurse Consultants as being competent to complete this training and administer the necessary management.

50

kids in regional Queensland with new cancer diagnosis were able to go home this year

Other Achievements

Resource Development

In addition to achieving all the key milestones for this program, the team have been working to update their existing resources for families and compile them into one easy package for parents to take home.

One pack was created for parents, and another for schools so that principals and families could distribute them. Photos of the resources created can be found in Appendix A.

Conferences and Presentations

Bek and the team have, and will be, presenting at conferences through 2018/19 including:

- *Australia & New Zealand Child Haematology/Oncology Group Conference, June 2018.* 'Wig library for teenagers with cancer in Queensland', Philippa Fielden & Rebekah Orford.
- *National Rural Health Conference, March 2019.* 'Never too far: return to country, working with rural Indigenous communities', Karen Joy & Rebekah Orford.
- Become an EPEC (Education in Palliative and End-of-Life Care)-Paediatrics Trainer, March 2019. Professional attendance.

Details of posters are provided in Appendix B.

Meet Missy

Missy was a healthy, normal 10-year-old before her diagnosis. She wanted to be a doctor when she grew up, and spent time with her two older sisters and attending Girl Guides up in Malanda in Far North Queensland.

Missy started having fatigue, stomach pains, bruises and a severe rash.

In August 2016 on a Friday morning, she was sent for a blood test which confirmed she was not just under the weather – Missy had Acute Lymphoblastic Leukaemia (ALL). She and her mum flew to Brisbane the following Sunday to the Queensland Children's Hospital where she spent the next three months of her life.

Missy suffered rare and painful side effects from her chemo treatment, including seizures and nasal infections which saw her spend several days in the Paediatric Intensive Care Unit.

Missy was introduced to Bek almost immediately during her treatment – with the aim to get the family back up north as soon as possible. Missy and her mum Anj missed their other two girls terribly.

"…one nurse stood out above all others. Bek was a shining star from the beginning. She will always be very special to us."

The whole family suffered from being separated for so long. Both Amelia and Freya (14 and 12 at the time) missed their mum and sister, but they "stepped up and became more helpful and self-sufficient" according to Anj.

"… it was invaluable having someone so calm and thoughtful, especially when Missy was not a very nice patient. Bek has the ability to leave behind whatever is going on and be truly focused on her patients and their treatment"

In January 2019 Missy started Grade 7 at Malanda High School with her sisters.

She loves to cook, read and ride her bike. She is a high achiever at school despite the months she missed and enjoys helping her fellow classmates. Now when she grows up she wants to be a clinical researcher to help other kids with cancer.

Missy and her family wanted to extend their thanks and appreciation to Sporting Chance Cancer Foundation for making Bek's role possible, and helping their family navigate such a difficult time.

Figure 2 - Missy on her last day of treatment, November 2018

The video of Missy ringing the bell to signify the end of her cancer treatment is below:

https://www.facebook.com/321313738205184/videos/269545407046406/

Budget Expenditure

Budget January 2018 to January 2019	Amount
Funding awarded to date	$118,000.00
Expenditure to date	$103,097.31
Balance brought forward	$ 14,902.69

The remaining balance in expenditure is due to a slight delay in recruitment for the Outreach Nurse role and will be expended in 2019.

In everything we do, our patients come first. Helping families through every stage of their journey with us is critically important.

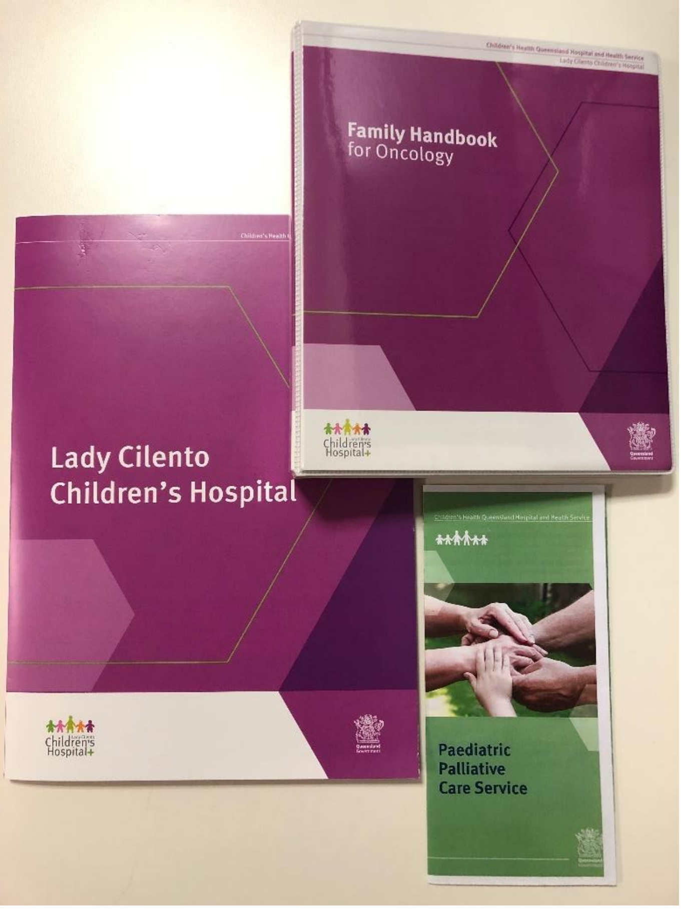
With your continued support, the Children's Hospital Foundation will be able to help even more children and their families as they undergo treatment and hopefully progress on the road to recovery.

Thank you for all that you do for our sick kids in Queensland and northern New South Wales.

Slater was the 2017 ambassador for the Sporting Chance Cancer Foundation's Raelene Boyle Outreach Program. He has just turned 4 and will be starting kindy soon!

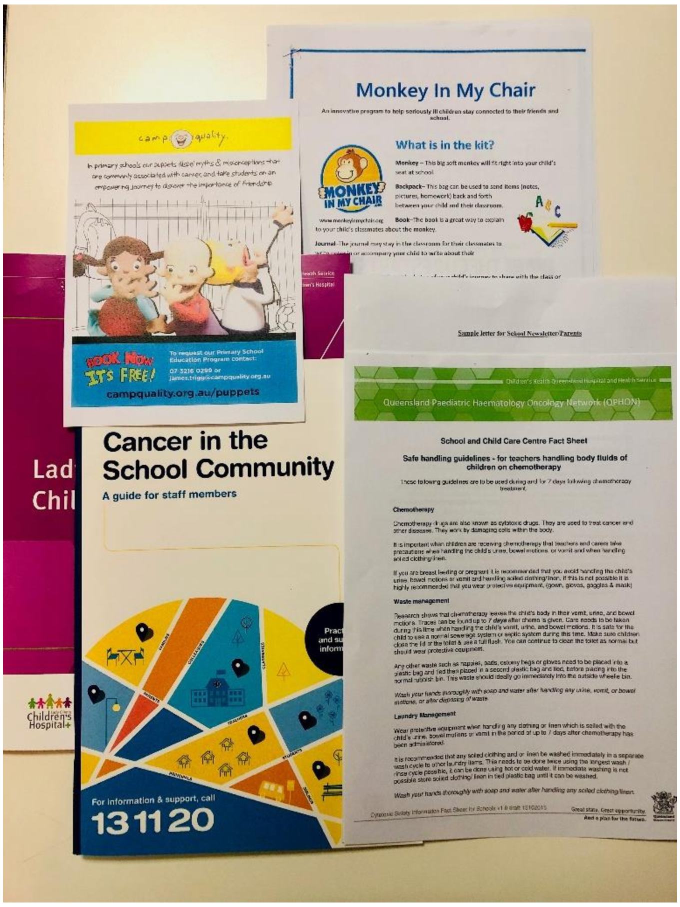
Appendices

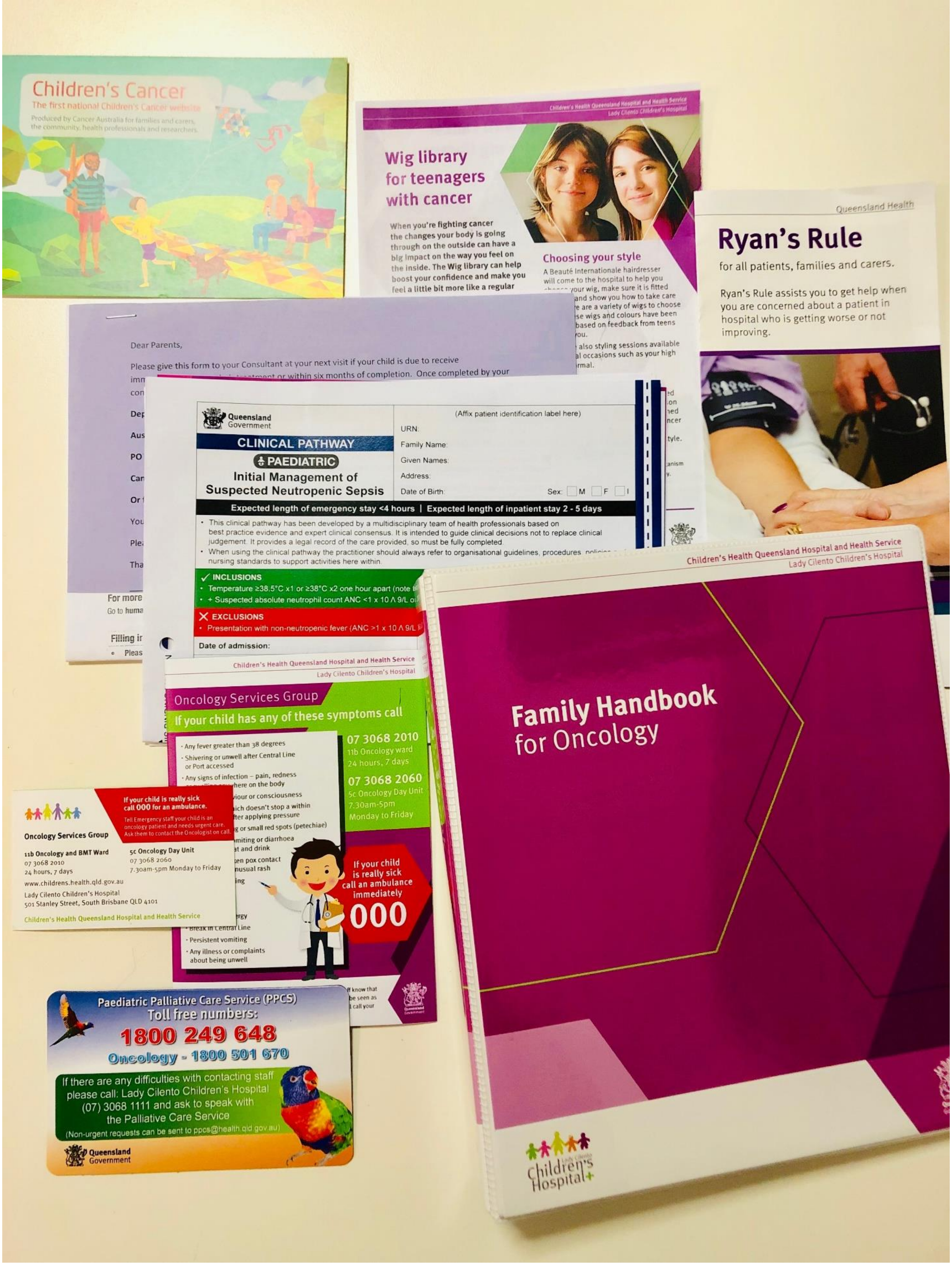
Appendix A – Resources



Left: Schools pack, Family Handbook, and Palliative Care flyer.

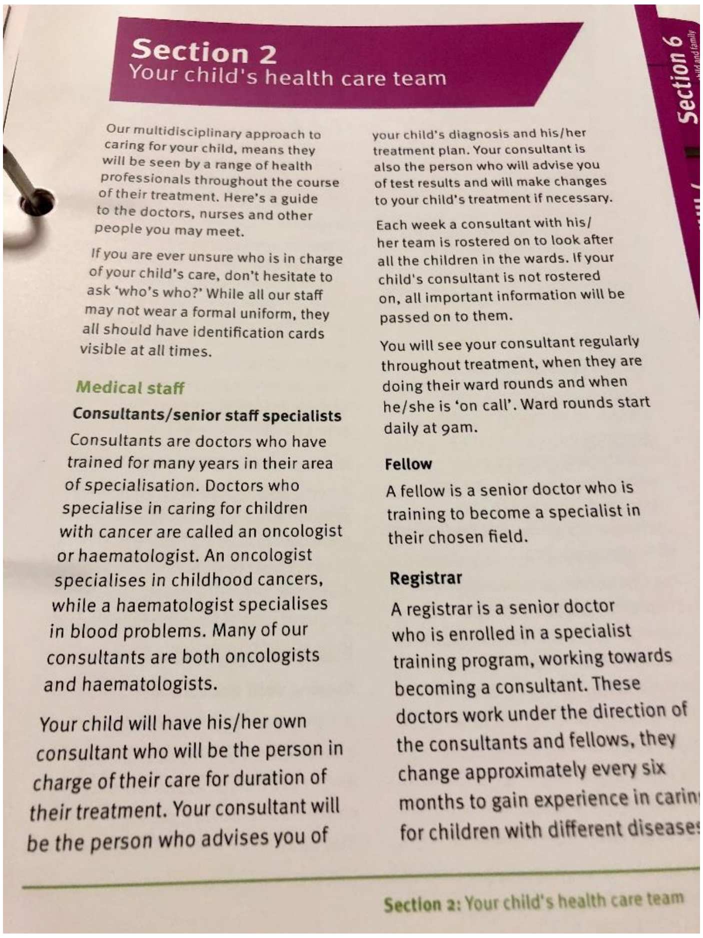
Below: School pack contents





Above: Family Handbook contents

Samples of inside contents of the Family Handbook.



Section 2
Your child's health care team

Our multidisciplinary approach to caring for your child, means they will be seen by a range of health professionals throughout the course of their treatment. Here's a guide to the doctors, nurses and other people you may meet.

If you are ever unsure who is in charge of your child's care, don't hesitate to ask 'who's who?' While all our staff may not wear a formal uniform, they all should have identification cards visible at all times.

Medical staff

Consultants/senior staff specialists

Consultants are doctors who have trained for many years in their area of specialisation. Doctors who specialise in caring for children with cancer are called an oncologist or haematologist. An oncologist specialises in childhood cancers, while a haematologist specialises in blood problems. Many of our consultants are both oncologists and haematologists.

Your child will have his/her own consultant who will be the person in charge of their care for duration of their treatment. Your consultant will be the person who advises you of your child's diagnosis and his/her treatment plan. Your consultant is also the person who will advise you of test results and will make changes to your child's treatment if necessary.

Each week a consultant with his/her team is rostered on to look after all the children in the wards. If your child's consultant is not rostered on, all important information will be passed on to them.

You will see your consultant regularly throughout treatment, when they are doing their ward rounds and when he/she is 'on call'. Ward rounds start daily at 9am.

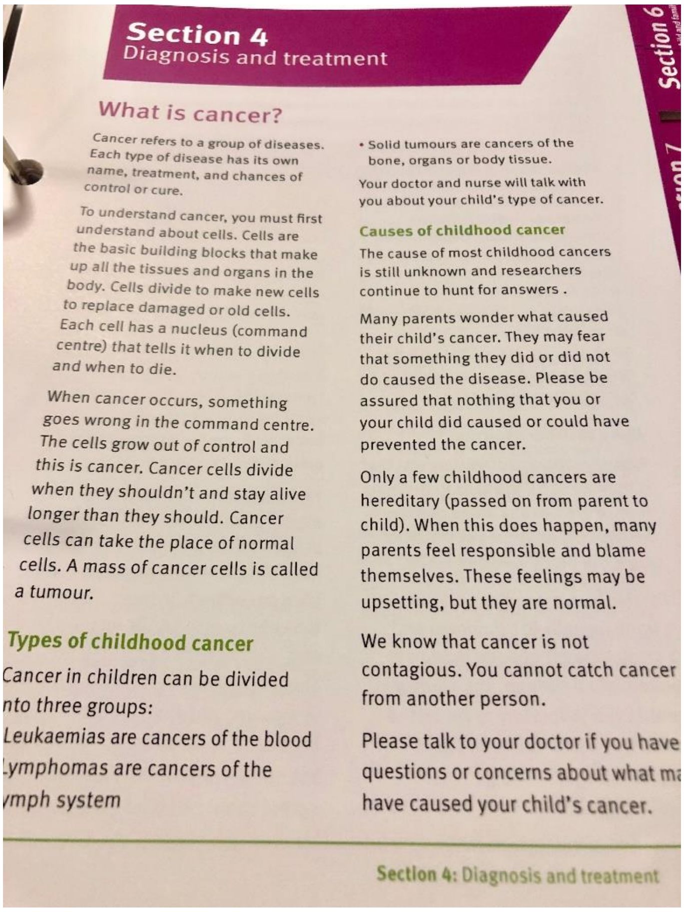
Fellow

A fellow is a senior doctor who is training to become a specialist in their chosen field.

Registrar

A registrar is a senior doctor who is enrolled in a specialist training program, working towards becoming a consultant. These doctors work under the direction of the consultants and fellows, they change approximately every six months to gain experience in carin for children with different diseases

Section 2: Your child's health care team



Section 4
Diagnosis and treatment

What is cancer?

Cancer refers to a group of diseases. Each type of disease has its own name, treatment, and chances of control or cure.

To understand cancer, you must first understand about cells. Cells are the basic building blocks that make up all the tissues and organs in the body. Cells divide to make new cells to replace damaged or old cells. Each cell has a nucleus (command centre) that tells it when to divide and when to die.

When cancer occurs, something goes wrong in the command centre. The cells grow out of control and this is cancer. Cancer cells divide when they shouldn't and stay alive longer than they should. Cancer cells can take the place of normal cells. A mass of cancer cells is called a tumour.

Types of childhood cancer

Cancer in children can be divided nto three groups:

Leukaemias are cancers of the blood

ymphomas are cancers of the ymph system

- Solid tumours are cancers of the bone, organs or body tissue.

Your doctor and nurse will talk with you about your child's type of cancer.

Causes of childhood cancer

The cause of most childhood cancers is still unknown and researchers continue to hunt for answers .

Many parents wonder what caused their child's cancer. They may fear that something they did or did not do caused the disease. Please be assured that nothing that you or your child did caused or could have prevented the cancer.

Only a few childhood cancers are hereditary (passed on from parent to child). When this does happen, many parents feel responsible and blame themselves. These feelings may be upsetting, but they are normal.

We know that cancer is not contagious. You cannot catch cancer from another person.

Please talk to your doctor if you have questions or concerns about what ma have caused your child's cancer.

Section 4: Diagnosis and treatment

Appendix B – Conference Poster Presentation

Children's Health Queensland Hospital and Health Service
Lady Cilento Children's Hospital

Wig library for teenagers with cancer in Queensland

Authors: Philippa Fielden and Rebekah Orford

Background

A diagnosis of cancer as a teenager is a challenging time in an adolescent's life. Not only are they dealing with physical changes, they are also trying to establish their own identity and self-image. For young people with cancer, hair loss can be a devastating side-effect of their treatment which can continue for many months.

Method

The Wig Library for teenagers with cancer was made possible by the Oncology and Queensland Youth Cancer Service CNCs at the Lady Cilento Children's Hospital (LCCH), Brisbane after being successful in a community grant application through Cancer Council Queensland.

Consumer engagement was pivotal in setting up the wig library, 11 teenagers with cancer provided valuable input into wig styles and colours and selected wigs for male and female teenagers aged 13–18 years.

The free wig library provides a selection of over 50 synthetic wigs. A volunteer hairdresser delivers this service and assists teenagers to choose and fit their wig. Written and verbal instructions on how to care for their synthetic wig are provided with a free hairdressing service available to cut the wig to shape the face and style wigs for formals.

When the wigs are no longer required they are returned to LCCH for cleaning. Once appropriately cleaned they are returned back to the wig library therefore offering another teenager with cancer the choice of having a wig. In the case a teenager having a multi-resistant organism wigs cannot be returned to the Wig Library.

Conclusion

This initiative has profound psychological benefits for teenagers with cancer in Queensland, assisting young people to cope with hair loss with the option of wearing a wig regardless of their family's financial circumstance.

Results: January 2016 – February 2018

- Cancer diagnosis includes Rhabdomyosarcoma, Osteosarcoma, Acute Lymphoblastic Leukaemia, Lymphoma, Ewings Sarcoma, Germ Cell Tumour, Medulloblastoma, Astrocytoma and Neuroblastoma
- 51 teenagers were referred to the wig library service
  – 100% attended a consultation for a wig fitting
  – 43 teenagers chose a wig from the wig library
  – 8 teenagers did not take up a wig loan
  – All male teenagers declined consultation and wig fitting
- The wig library has a total of 59 wigs in its database
  – 42 wigs were available upon initial funding at set up
  – 8 wigs since have been purchased with monetary donations
  – 9 wigs have been donated
- Average wig loan is 12–18 months
- The Oncology Services Group at LCCH offers financial assistance towards the purchase of a wig. Between 2010–2015, 66 families accessed this funding. Since the introduction of the wig library, only one family has accessed financial assistance for a wig purchase.

'For me, the hardest part was losing my hair'

These testimonials from teenage patients express how having a wig boosted their confidence and empowered them to continue with normal activities.

'I was heartbroken as I felt that my hair was the one thing that made me feel feminine'

'I now feel normal again'

'It made me feel a lot better because I got really self-conscious from having no hair, it felt much better and secure'

'The wig helps with your self-esteem, you don't look different so you don't feel different'

'My appearance has always been important to me, I'm a 'girly' girl, so it was all about the hair'

'I was worried at first that people would be able to notice it was a wig, but when I got it I was so excited'

'Having a wig gave me the confidence to go out in public places. No one realises the hair on my head is actually a wig'

Teenagers have reported how they appreciated the comfort of being able to play with and touch 'their hair', and how the texture of 'the hair' against their face makes them feel normal.

Acknowledgements

We would like to express special thanks and our very great appreciation to the consumer group of teenagers with cancer for their valuable engagement; Cancer Council Queensland making the Wig Library possible through a community grant; Beaute Internationale providing volunteer hairdressing services and donating supplies; Stefan hairdressers providing professional cleaning of returned and donated wigs to the library and LCCH Oncology Services Group administration support for coordination of the wig library service.