

2007 NSW Health Awards Entry

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| Entry Title (50 characters or less) |
| Children's Cancer and Haematology Service Treatment Passport |
| Abstract (120 Words) |
| <p>All children, adolescents and young adults that have been off treatment for more than five years for their childhood cancer continue to attend the Late Effects Clinic at the Children's Cancer and Haematology Service at John Hunter Children's Hospital where they are educated and receive their Patient Treatment Passport (PTP) at their first visit.</p> <p>The implementation of PTP has provided the increased number of survivors of childhood cancer with a clear and concise document containing the relevant information pertinent to their type of cancer. It also includes treatment and health surveillance recommendations for each individual that may assist with the early detection of any future potential late effects of treatment. This is all contained within the one transportable document that empowers the survivors to be actively involved in their personal health care, maintaining quality of life and independence.</p> |
| Aim (30 Words) |
| <p>To provide survivors of childhood cancer with the relevant information about the type of disease, their treatment and potential long-term consequences in an easy to understand booklet as a reference for future care.</p> |
| Nature of the Problem (100 words) |
| <p>Approximately 750 children and adolescents are diagnosed with cancer in Australia each year and more than 80% are expected to be long-term survivors (Heath 2007). The number of children, adolescents and young adults that have survived childhood cancer requiring follow-up at the John Hunter Children's Hospital (John Hunter Children's Hospital) Late Effects Clinic by 2011 is estimated to be 150 survivors. This number is expected to gradually increase as a result of improved survival rates and referrals from other institutions.</p> <p>Throughout the acute treatment phase when a patient is being treated for their childhood cancer they are educated and well informed of their treatment protocols, progress and future directions. When survivors enter the late effects clinic, five years from completing treatment, continuing education and support is vital to assist survivors to maintain optimal health and well being by increasing their personal responsibility for their own health care. Often the survivor was a young child at the time of treatment and now presenting to the late effects clinic as a teenager or young adult with limited or no recollection of their specific treatment. Parents often have more of an understanding of the treatment received and it is vital that the individual survivor is now empowered with this information and not reliant on their parents. More intense treatment for childhood cancer involves many treatment modalities including chemotherapy, surgery, radiotherapy and stem cell transplantation placing the individual at increased risk for potential treatment related health problems (late effects) and often these therapies occur in more than one location and recorded in medical records at multiple institutions.</p> <p>Advances in paediatric cancer treatments has resulted in a substantial increase in the number of survivors of childhood cancer and many physicians are learning about the long-term consequences of the various cancers and the therapies involved. Survivors of childhood cancer attending the Late Effects Clinic often ask for information about their past history and treatment, expressing a desire to know the possible implications for the future so they can stay in the best health possible.</p> |

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| <p>Extent of the problem (150 words)</p> |
| <p>A substantial proportion of childhood cancer survivors experience serious health problems as young adults, particularly those who received radiation treatment, according to a study in the June 27 issue of JAMA: The Journal of the American Medical Association, a theme issue on chronic diseases of children. It was identified that many patients were very young at the time of treatment and have no or little recollection of their treatment. The population of patients treated at JHCH for cancer had an average age at diagnosis of 7.97 years (range 0-18 years), and with many cancers more common in the 0-5 years age group (Children’s Cancer and Haematology Service Database 2007). Chemotherapy and radiation therapy to the brain can also create learning disabilities, which reduce the patient’s ability to remember their own treatment history. Multiple hospitals can be involved in health care provision of each patient. No two patients have the exact same therapy and individual information is essential to optimal follow-up and surveillance. Patients may be referred to 3 additional public hospitals in NSW for treatment or services not available at the John Hunter Children’s Hospitals as well as private hospitals. On average a patient may see up to 5 medical specialists including treating Oncologist/Haematologist, Paediatric and Adult Surgeons, Radiation Oncologist, Endocrinologist, and Cardiologist who may not work at the same institution. With an average treatment time of up to 2 years and off-treatment follow-up and surveillance a single patient may acquire up to 6 volumes of medical records at one hospital alone and on average most patients will have 3 volumes at the primary treating hospital, stored in multiple locations such as off-site secondary storage areas. The need for a patient treatment passport is compounded by adulthood and the need for correct treatment history; for relapsed patients to prevent organ dysfunction and to enable specialist care during pregnancy to monitor heart function. It was identified from a vast amount of literature review and discussion with other Late Effects Coordinators within Australia, New Zealand and Internationally, that a medical summary record or PTP is an invaluable tool for an improved understanding of the journey patients and their family’s travel.</p> |
| <p>Strategic importance (100 words)</p> |
| <p>This project is aligned with the NSW Health Strategic Direction to: Create better experiences for people using health services. In addition, NSW Health has developed the concept of “Live Life Well” which is a focus on people living healthier lifestyles and avoiding ill health rather than treating symptoms as they occur.</p> <p>The implementation of the PTP demonstrates the philosophy of The Maggie Program (which is HNE Health’s clinical system redesign program) by its commitment to the guiding principles that</p> <ul style="list-style-type: none"> • Care is customised according to individual patient needs • Patients and clinicians have effective partnerships where knowledge is freely shared <p>The NSW Cancer Plan 2007-2010 Accelerating the Control of Cancer’s priorities include: Priority 1. Preventing cancer Priority 2. Detecting cancer early Priority 3. Improving cancer services and professional education</p> <p>Are all reflected in the effective implementation of the PTP by ensuring patients are informed and involved in maintaining quality of life and independence. Childhood cancer survivors are at increased risk of recurrence of disease and second malignancies as a result of their treatment such as radiation therapy to the skin, chest and brain. Health surveillance recommendations included in the PTP encourage survivors to be aware of the need for cancer screening to assist with the early detection and prevention of cancer and ultimately improving survival. Annual skin checks, breast self examination and full blood counts are some of the tests recommended.</p> |
| <p>Planning and implementing solutions (300 words)</p> |
| <p>Following discussions with the other late effects clinics within Australia, New Zealand and Internationally, treatment summaries were reviewed from other hospitals and a draft copy was developed and reviewed by nursing staff, paediatric oncologists/ haematologists and by families with</p> |

a child undergoing treatment and also families with a child, adolescent or young adult five years off treatment. A consumer group of parents had also asked for a summary of treatment.

Current patients and families were informed of the proposal of the PTP and they responded positively reinforcing the need was valid. Feedback was collected and minor changes added with the recommendation of evaluating the document in the future. The content was to be brief, informative and in simple to understand terminology and contact details of the health professionals involved in treating the patient included

The PTP was deliberately designed as an A5 size booklet, which easily photocopies onto a single A4 sheet for inclusion into the patient's current active volume of their medical record, for use as a quick reference to staff. This concise reference was also used by allied health and other medical specialists to reduce the time spent looking for medical information within the density of multiple volumes of records produced for oncology patients.

Many patients had received their treatment at multiple hospitals and the development of the PTP ensured that all relevant medical information was now located in the PTP and in the patient's current active volume of their medical record. Prior to the role of the Late Effects Coordinator the complete medical history was spread across multiple volumes of medical records. The Children's Oncology Group's (COG) most recent recommended guidelines (www.childrensoncologygroup.org) for follow-up monitoring were simplified and included in the passport.

The Late Effects Coordinator is the person responsible for compiling the PTP. Prior to attending their first Late Effects Clinic a letter of introduction is sent to the patient/carer outlining the relevant details of the clinic and introducing the idea of the PTP. At the first visit each patient is given their individual PTP and the contents and its function explained. Yearly contact with their general practitioner is encouraged and they are asked to keep the PTP in a safe place.

Outcomes and Evaluation (200 words)

Review of the PTP occurs on an annual basis with patient and family consumer groups asked to participate. Evaluation indicates that the PTP is time and cost effective as it is retrospectively complied

Prior to 2005, patients did not receive a summary of their medical history. In 2005 the Late Effects Coordinator role commenced and the development of the PTP was completed as part of the pilot project. Each patient entering the Late Effects Clinic was given their PTP and educated regarding the content. They were also asked to review the medical information and inform the Late Effects Coordinator of any discrepancies. A list of patients receiving their PTP was recorded in the Children's Cancer and Haematology Service paediatric oncology database ensuring all recipients receive their copy.

There have been five (5) Late Effects Clinics with seven (7) patients in attendance at each clinic. All thirty five (35) patients/carers have been given their PTP and the following questions asked (requiring a yes/no answer):

- Do you think the PTP is a good idea?
- Do you think it will increase your knowledge regarding previous treatment and reasons for further health surveillance?
- Will you show it to your GP?
- Does it give you a feeling of hopefulness?
- Do you feel an increase willingness to participate in your own health care?

The answer to all the above questions was unanimously positive.

An example of the success of the PTP occurred early in 2007 with the relapse of a young adult requiring further treatment for the recurrence of cancer. The patient can no longer be treated by the paediatric team based on age and will receive therapy at an adult oncology unit. A PTP was compiled

and given to the patient and the treating oncologist/haematologist enabling the patient to receive the most appropriate therapy while reducing the risk of further possible complications as cumulative doses of drugs and their effects documented within the PTP.

Sustaining change (100 words)

Networking with Sydney Children's Hospital and Westmead Children's Hospital has occurred regularly with sharing of feedback and further changes to their medical summaries discussed.

The Guidelines for the Late Effects Clinic (John Hunter Children's Hospital) compiled in 2006 include a section on PTPs. The template for the PTP is included in a word document that can be easily utilised for each new survivor entering the late effects clinic. Nursing, medical and allied staff are attending regular in-service and grand rounds, both paediatric and adult, are educated regarding the PTP.

Future Scope (100 words)

Various groups within NSW Health with chronic health conditions such as, adults with cancer, children and adolescents with developmental and physical disabilities could significantly benefit from the implementation of a PTP. The information included in the PTP would enable them to utilise the most appropriate health services possible and inform their health care providers of their medical history at times of hospitalisation and within the community setting.

Cancer specialists at UCSF Children's Hospital in Texas have developed a pocket sized health passport the size of a credit card (Brown 2006). Which would optimise the amount of people that would have vital information readily available on their person. Introducing a similar concept is considered an idea to contemplate in the future.

A future recommendation would be that the PTP commences at diagnosis and not compiled retrospectively.

References:

Brown, P. Health "Passport" Developed for Childhood Cancer Survivors. USCF Medical Centre. News Office June 2006

Heath, J. Monitoring after childhood cancer- An update for GP's. The Royal Australian College of General Practitioners Vol. 34 No 9 September 2005

Kruk, R.2007 A New Direction for NSW State Health Plan Towards 2010

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Websites

[JAMA: The Journal of the American Medical Association](#)

www.childrenoncologygroup.org (date accessed May 31 2007)

http://www.ucsfhealth.org/adult/health_library/news/2006/06/66907.html-34k (date accessed May 31 2007)