

Patient Treatment Passport

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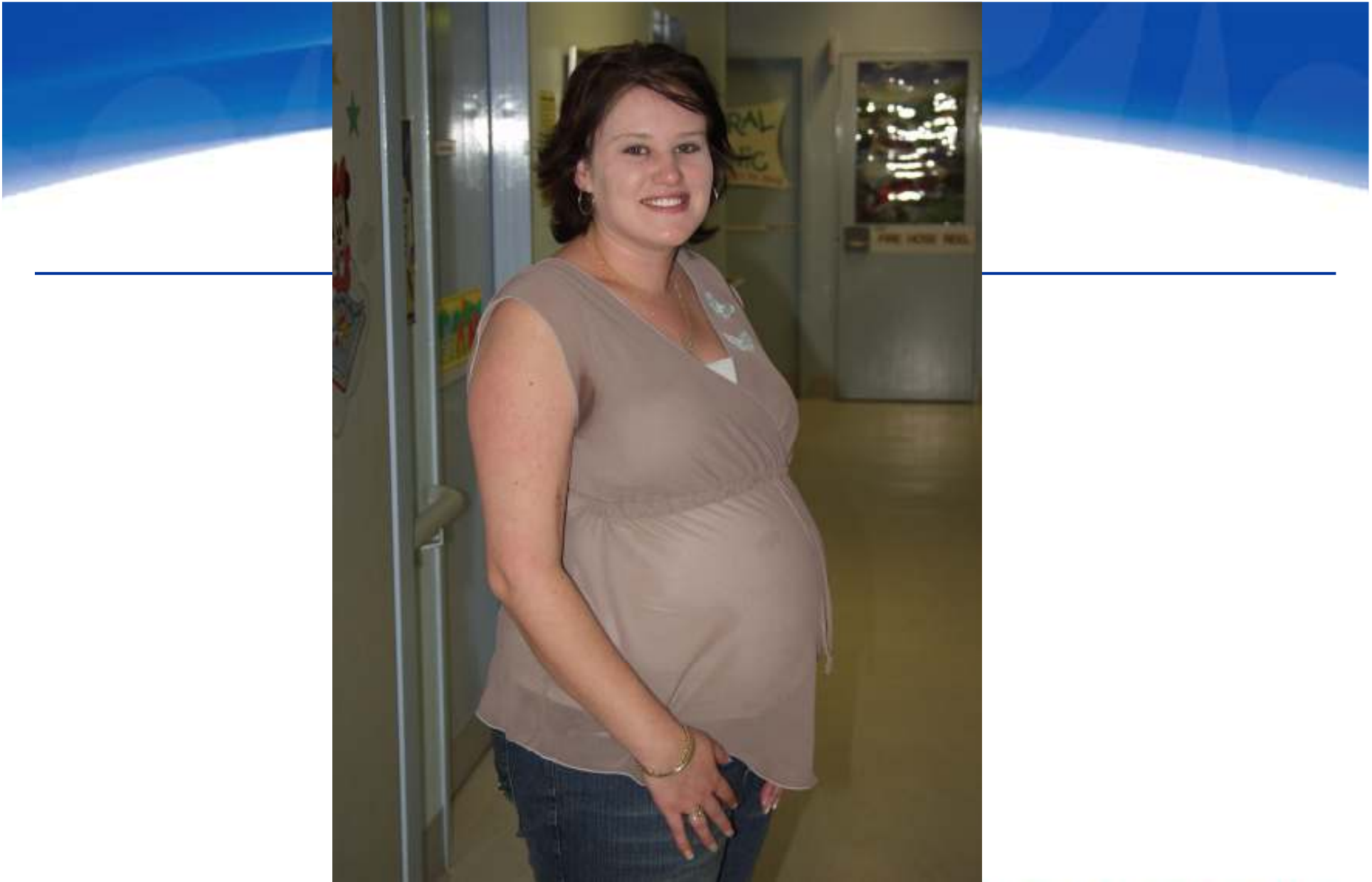
**John Hunter Children's
Hospital**

11th October 2007





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Introduction

- Aim
- Nature of the Problem
- Planning and Implementing
- Outcomes and Evaluation
- Sustaining Change
- Future Scope

Aim

- Develop easy to understand booklet
- Type of childhood cancer
- Treatment
- Potential long term consequences
- Actively involved in their own healthcare



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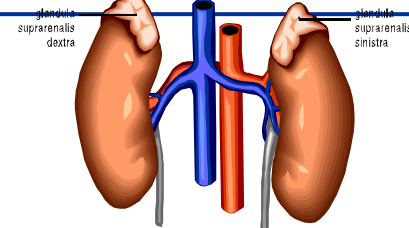
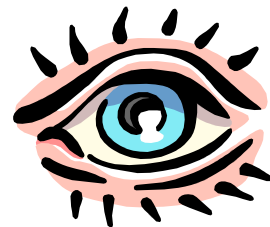
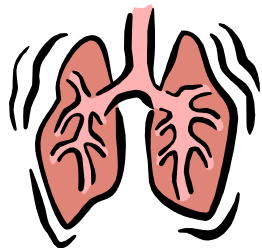
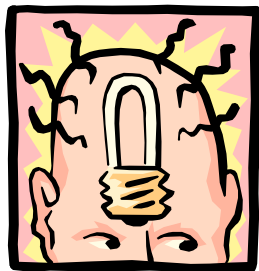
Late Effects

Defined as therapy-related complications or adverse effects that persist or arise after completion of treatment for a Paediatric malignancy.

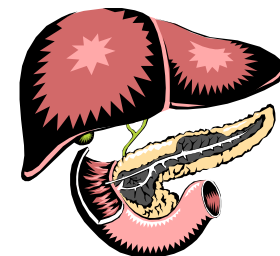
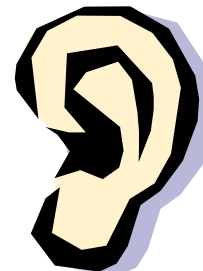
(COG Guidelines, 2004)



Types of late effects



GLANDULAE SUPRARENALIS



Nature of the Problem

Advances in paediatric cancer treatment has resulted in a substantial increase in the number of survivors of childhood cancer.

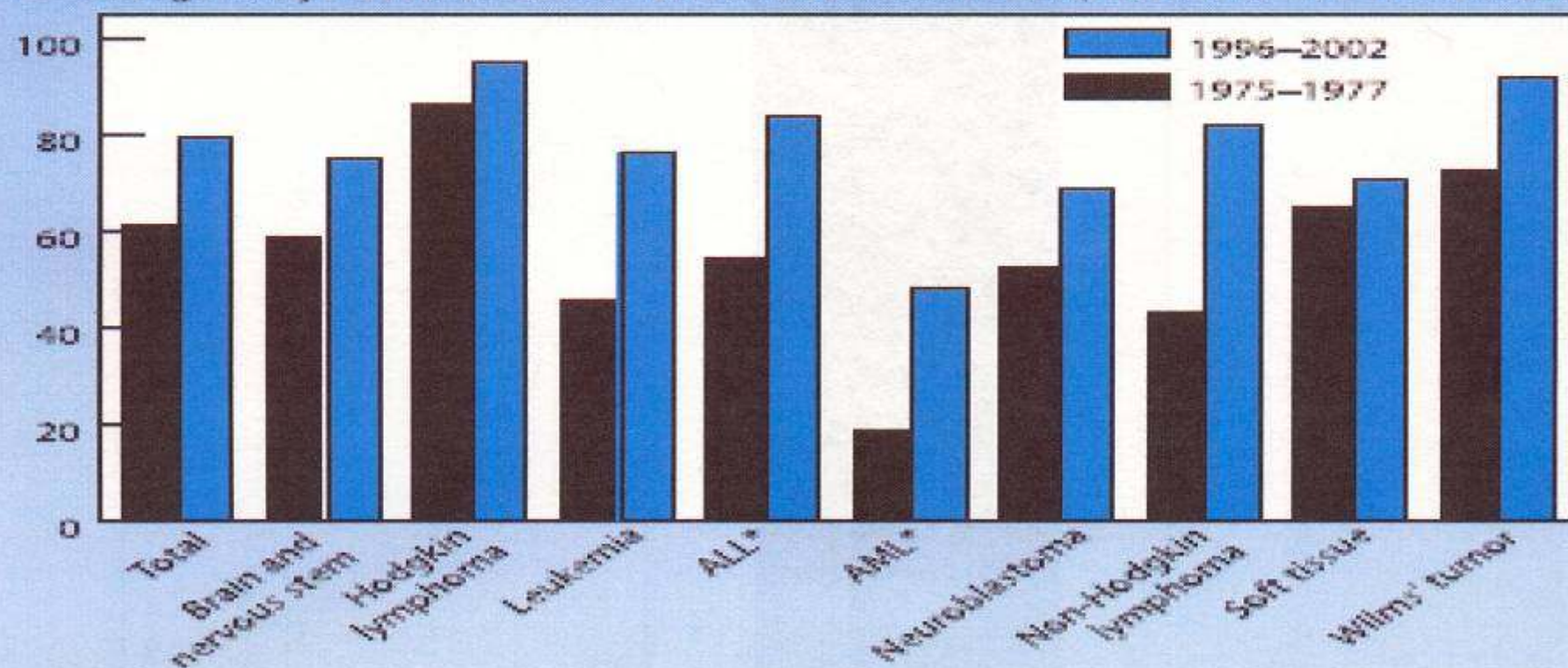
It is estimated that of adults aged 20-34 years, 1 in 570 will be a childhood cancer survivor (CCSS)

- A significant minority of survivors will experience sequelae
- Between 2% and 8% of these will experience second malignancy

Childhood Cancer Survival, 1975–2003

More and more children are surviving cancer. In the last 28 years, for which statistics are available, the percentage of children who survive for five years has increased from 61.5% to 79.5%, and the increase is even higher for certain cancer types. The difference between the 1975–77 relative survival and that in 1996–2002 is statistically significant. In this issue, researchers examine some of the problems childhood cancer survivors have in later life (See p. 890).

Percentage five year relative survival from childhood cancer, 1975–1977 vs. 1996–2002:



*ALL = acute lymphocytic leukemia, AML = acute myeloid leukemia.

Source: SEER Cancer Statistics Review, 1975–2003 (National Cancer Institute); access at <http://seer.cancer.gov>.

Characteristics of survivors of childhood cancer

- Many young at time of treatment
- Little or no recollection of treatment
- Reliant on parents recall of information
- Receive multiple treatment modalities, chemotherapy, surgery, radiotherapy and haematopoietic stem cell transplantation
- Treatment in multiple hospitals
- Cognitive impairment to those that received brain irradiation

This may result in

- Multiple volumes of medical records in multiple hospitals with no central record
- Confusion about treatment
- Allied health unable to locate relevant information
- Patient unable to take over responsibility of own health care

Planning and Implementing

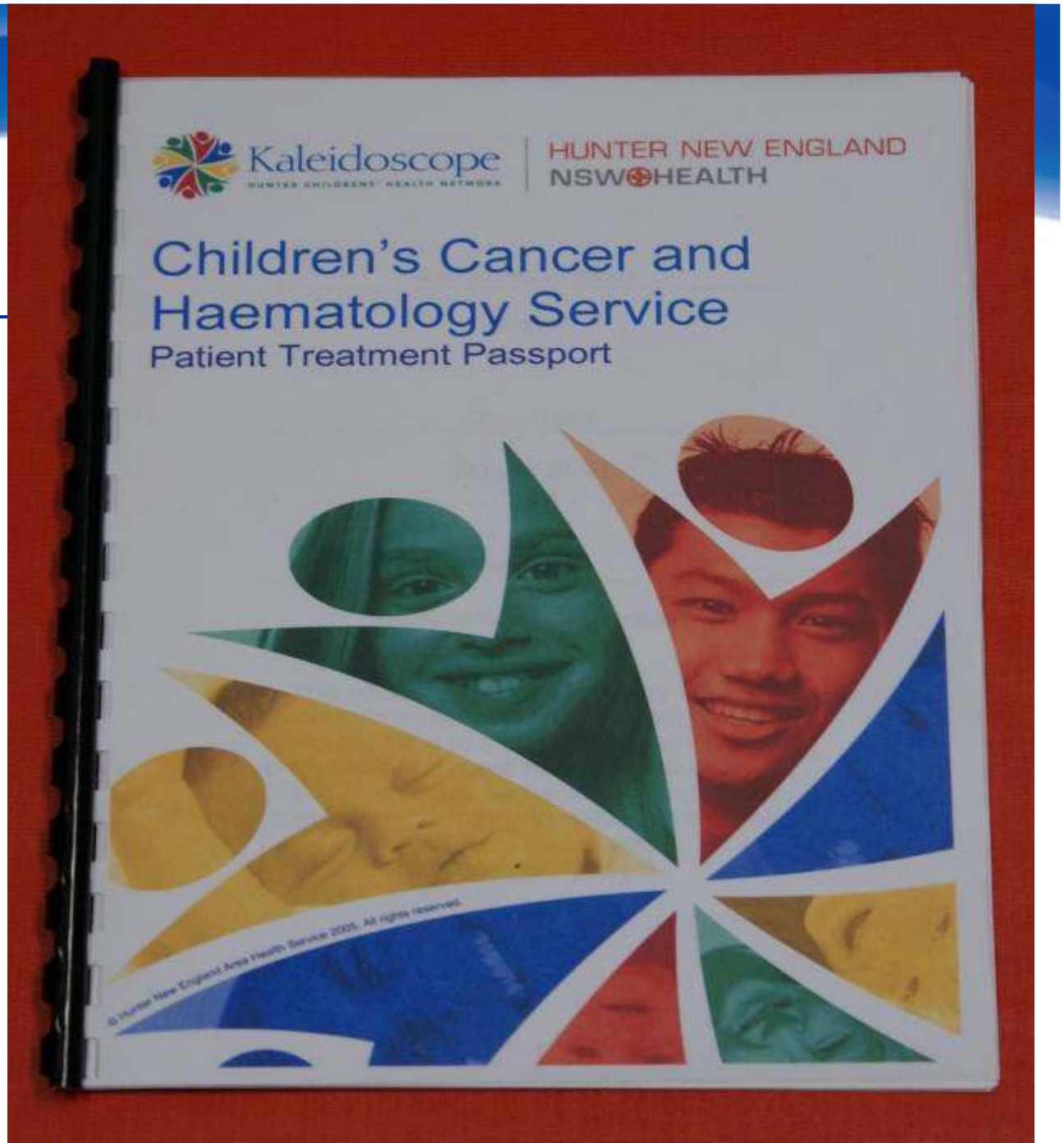
- Consultation with other paediatric cancer hospitals
- Content to be brief, informative and lay language
- A5 booklet
- Health professionals contact details
- Follow-up recommendations included
- Draft copy reviewed by relevant stakeholders



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Patient Treatment Passport



Process now in place

- Patient referred to Late Effects Coordinator by Paediatric Oncologist or CNC
- Review of medical records and consultation with hospitals involved in treatment
- Letter of introduction sent prior to clinic

Outcomes and Evaluation

- Patient Treatment Passport reviewed annually
- Provision of Patient Treatment Passport recorded electronically
- Feedback mechanism in place for any discrepancies
- Verbal satisfaction survey conducted
- More “hands on time”
- Increase time spent on health promotion and health prevention

Strategic Significance

- NSW Cancer Plan 2007-2010
 - Priorities 1, 2 and 3 preventing cancer, detecting cancer early, improving cancer services and professional education
- HNEH Clinical Systems Redesign - The Maggie Program
 - Care is customised according to individual needs & patients and clinicians have effective partnerships where knowledge is freely shared

Sustaining change

- Networking to improve service delivery
 - Sydney Children's Hospital Late Effects Coordinators
 - The Children's Hospital Westmead Late Effects Coordinators
- Patient Treatment Passport included in guidelines for Late Effects Follow-up Clinic
- Concept of Late Effects introduced to patients and families at diagnosis (where appropriate)



Future Scope

- Patient Treatment Passport can be applied to other clinical specialties especially chronic disease
- Possibility of an electronic version similar to a credit card
- Involvement of other medical practitioners to help manage the survivors of childhood cancer as they grow into adulthood



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Active treatment may be over, but a healthy lifestyle requires regular check-ups and recognition of the late effects.

Focus moves from.....



“Cancer patient”to.... “Cancer Survivor”



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References

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