Child and adolescent cancer survivors

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Conflict of interest disclosure

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- No potential COI
Survivorship across the generations
1. Overall cure rates for childhood cancer have increased dramatically in recent decades, but survival rates vary by disease. Five-year survival rate for those with childhood cancers today: 84%, compared to 61% in 1975.

2. Cancer in children is rare, but it's the leading cause of disease-related death in children in the United States. 43 children are diagnosed with cancer every day in the U.S.

3. The number of survivors of childhood cancer continues to grow, but many are vulnerable to late effects of their treatment. Number of childhood cancer survivors in the U.S: 388,500.

4. More research is needed to continue to improve survival and decrease the toxicity of treatment. 4% of National Cancer Institute (NCI) budget is devoted to pediatric cancer.

5. Children die of cancer in the U.S. every day.

To learn more about childhood cancer, visit danafarberbostonchildrens.org
Some facts about young people….

- Cancer in teenagers and young adults (TYA) is rare, <1% of all new cancer diagnoses in England.
- Cancer is a leading cause of death in young people aged 15 – 24 years.
- Spectrum of cancer types distinct from children and older adults.
- Outcomes are inferior to those in children or older adults.
Survival rates are very good

- Cure, but at what cost?

- Treatment induced late effects are diverse
- Approx. 50% of survivors report one late effect
- CCCS-62% had at least 1 chronic condition
  - 28% had severe/life threatening illness
  - Cumulative incidence of a chronic condition at 25 years was 67%
- Survival after treatment is dependent on the risk of late recurrence and organ damage
The long-term goal of the cure and care of the child with cancer is that he/she become a resilient, fully functioning, autonomous adult with an optimal health-related quality of life, accepted in the society at the same level of his/her age peers.
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The goal is survival…that means….

- **Young people need to:**
  - **Negotiate and renegotiate**
    - Continually visit a history of a serious illness to make sense of current and possible health and psychosocial consequences
  - Accommodate cancer related influences on their life course
  - **Manage uncertainties**
    - Survival not necessarily a simple end to a cancer story
    - Limited knowledge of illness history hinders plans for the future

“Re-establishing a ‘normal’ existence floored me……cancer had stifled my life……it had hijacked what should have been my formative years……I could not go back to the life I led before cancer….life had moved on” Alan Pitcairn (2008)

“I found re-integration very hard….I had lost so much confidence through treatment……I no-longer knew how to interact with my own age-group…..I still fear check-ups, in fact it gets worse every time I visit” Kelly Denver (2008)
Being a cancer survivor……

- Re-establishing an individual, social and sexual identity
- Renegotiating relationships with family and friends
- Re-engaging with life after treatment
- Coping with the after effects of treatment
- Transition, in terms of life-stage, and new identity
- Engage with follow-up care
Requirement for survivorship care

Coordination of care
Prevention and surveillance:
- New recurrent cancers
- Late effects
Interventions for cancer/treatment consequences

Physical  Psychological  Social  Spiritual  Cultural

Giffith et al 2010 Seminars in Oncology Nursing
National Cancer Survivorship Initiative

Right Care, Right Patient, Right Time, Right Place


- Improve the quality and effectiveness of service delivery
- Improve quality of life for those living with and beyond cancer
- not only adding years to live, but adding life to years
Vision statement-2010 described 5 key shifts in care

<table>
<thead>
<tr>
<th>Acute cancer treatment</th>
<th>A focus on recovery, health and well-being after cancer treatment</th>
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<tbody>
<tr>
<td>One-size fits all follow-up</td>
<td>Personalised care planning, based on individual needs, risks and preferences &amp; provision of information</td>
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<tr>
<td>Clinically-led approach</td>
<td>Supported self-management, based on individual needs and preferences, with appropriate clinical assessment, support &amp; treatment</td>
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<td>Single-model of follow-up</td>
<td>Tailored support, to allow early detection of late effects of treatment</td>
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<td>Measuring clinical activity</td>
<td>New emphasis on measuring experience and patient reported outcomes</td>
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In essence what this meant was...a shift....

<table>
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<tr>
<th>From</th>
<th>To</th>
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<tr>
<td>Follow up care</td>
<td>Personalised care</td>
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<tr>
<td>Survivor at year 5</td>
<td>Survivor at day 1</td>
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<tr>
<td>Hospital setting</td>
<td>Self management</td>
</tr>
<tr>
<td>Predominantly health focus</td>
<td>Health/educational/employment/well being</td>
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<tr>
<td>Survivor pathway inconsistently defined</td>
<td>Survivor pathway theory well defined/accessible</td>
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WHY????
Well.....

1. We have an expanding population:
   - More than 40,000 cancer survivors in UK
   - 50% are adults
   - 1 in 750 are young adults
   - Expanding by 1250/yr

2. Because young people requested a change:
   - Need for a clearer definition of survivor: ‘you become a survivor the day after diagnosis-you have survived day 1’.
   - Improved services and support on treatment around education/employment/fitness to reduce long-term issues.
   - Improve the range of services available to ensure they are both ‘age and stage’ appropriate.
3. And services needed to change………

- Childhood cancer survivors should be followed-up for life
  - Little consensus as to how best to achieve this
  - Variation in practice
  - Evidence lacking
  - Focus on surveillance

- Increasing number of survivors, puts strain on service provision
  - Has important resource implications
  - Potential to save £3.25 million over the next 5 years on unnecessary OPD visits

- Patient choice not always considered
  - May foster unnecessary dependence
  - Lost to follow up
Emerging principles of survivorship care (1)

- Risk Stratified pathways of care rather than one size fits all

- Dynamic **personal care plan** which arises from an assessment of the disease, the treatment, and the individuals personal circumstances

- **Information provision** should meet individual needs and should be timely, accessible and promote confidence, choice, and control

- Individuals should be **encouraged to self manage with support** and rapid access to appropriate professional when problems arise
Emerging Principles of survivorship care (2)

- Introduction of care plans and **treatment summaries**
- Emphasis on **individualised care** for all cancer survivors
- **Alternative continuous aftercare** rather than traditional models of care
- Planned and informed **transition**
- Safe, informed **self management**

Better use of technology to meet the needs of individual patients.
We need to do all we can to achieve our goal...

Number of survivors will continue to increase, our focus is on

– Reducing the costs of therapy
– Providing continued ‘surveillance’ and support
– Creating flexibility in health care delivery
– Providing and tailoring developmentally appropriate information about cancer and associated health-risks
– Providing resources to deal with concerns about fertility and sexuality
– Support academic and vocational functioning
Five-year survival rates exceed 80% for the 45,000 children with cancer in high-income countries (HICs) but are less than 30% for the 384,000 children in lower-middle-income countries (LMICs).
We still have some work to do, thank you for listening

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