Childhood cancer survivors

New follow-up clinic in Iceland

PNAE meeting in Iceland
October 17, 2017

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Nurse BS, MS
The new follow-up clinic for childhood cancer survivors in Iceland is a project funded by the Icelandic Childhood Cancer Foundation for three years.
**Childhood cancer**

- The incident for malignancies from birth to 18 years old each year in Iceland is around 15/100,000 (10-12 children each year)

- With improvements in cancer treatment and supportive care, the survival of children and adolescents diagnosed with cancer has increased by 40% over the last four decades with the compiled five-year survival rate now being approximately 80%

- Growing number of individuals who are likely to experience some degree of adverse health consequences and quality of life issues because of the cancer treatment

(Offinger, 2006; Robison & Hudson, 2014; Trausti Óskarsson et.al., 2010a).
Some of the issues that are faced by survivors of childhood cancers

(Robison & Hudson, 2014, p. 43)
Specific cancer treatments have been linked to specific long-term health complications

(Figure 3: Therapeutic exposures and adverse events. Specific cancer treatments have been linked to specific long-term health complications. SOURCE: Bhatia presentation, March 9, 2015.)

(Nass & Patlak, 2015, bls. 58)
Aging and risk of severe, disabling, life-threatening, and fatal events in the childhood cancer survivor study (treatments USA 1970-1986)
Follow-up after childhood cancer
The Gothenburg model

Patient finishes treatment

Cancer recurrence and side effects
5 years

Standard follow up after treatment

Collaboration with other health care services

Late effect follow-up

Rehabilitation/ work/education
Fertility
Orthopedic
Endocrine
Teeth
ENT
Nutrition
Gynecological
Psychiatry

Heart
Kidney
Eye
Neurology
Skin

Primary- and other health care services

18 years
Surgery alone and low risk chemo

Chemotherapy and low dose cranial radiation (<24Gy)

Radiotherapy (except low dose cranial) and Megatherapy

Models of care to achieve better outcomes for children and young people living with and beyond cancer.

(NHS Improvement, 2011, page 27)
Guidelines for support

• International Guideline Harmonization Group for Late Effects of Childhood Cancer

• Swedish guidelines regarding follow up and survivorship passport
Follow up in Iceland - For whom?

- From 18 to 25/30 years old
- Cancer diagnosed before 18 years
- Treatment finished 2-5 years ago
- Cured from cancer/treatment finished
- Treatment from 1981
Who are we?

• The follow-up is prepared by a nurse and doctors from the pediatric oncology team

• References to professionals within the adult service, inside and outside the hospital, are a big part of the follow-up
How often?

• Individualized!

• For many a regularly follow-up every 1-2 years until 25-30 years of age

• Those who are over 25 years old and were treated in 1981 or later are invited to come for at least one visit
Purpose of follow-up

• Improve health and quality of life with risk based health assessment, support and education

• Give informations regarding common late effects after certain treatments – **Survivorship passport!**

• Increase the likelihood of detecting late effects early and advise on timely interventions

• Establish continued health surveillance

• Promote healthy living
Survivorship passport

- Contains information regarding the cancer diagnosis and treatment

The passport is intended to empower people after treatment
• The purpose of the passport is to support individualized long-term follow-up by informing survivors and health care providers about:
  
  ➢ possible health related risk after treatment

  ➢ how often and what kind of health assessment is needed

  ➢ ways to keep better health
Before the visit:

- Asked to participate in a **study** before coming – online questionnaire (RedCap)
- Make **passport**
- Send home **AYA** psychosocial screening tool
- Blood and urine sample the week before
Adolescent and Young Adult Psychosocial Survivorship Screening Tool (AYA)

• Developed in Australia - adapted from the NCCN distress thermometer 2011
• To help identify topics to be addressed in the follow-up and to guide the care plan for survivors aged 15-25 years old
• Clinicians administering this tool have as a minimum a degree in nursing, psychology, social work or medicine
AYA

**Distress Thermometer:** Scores of 4 or more indicate levels of higher distress that needs more attention.

**Needs Assessment:** Physical; Emotional; Social; Concentration; Fertility; Impact of experience; Family; Lifestyle; Survivorship; Employment; Education.

**Future Goals:** Support survivors to get on with live after cancer in the best way they can.

**Information Required:** Tick box gives the survivors an opportunity to identify areas where further information is needed.
### Samantekt eftir krabbameinsmeðferð

**Greining:**
- C81.9 - Hodgkins disease, unspecified
- Classical nodular sclerosis

**Stigur:**
- 11-B

### 14 ára við greiningu

<table>
<thead>
<tr>
<th>Dagsetning greiningar:</th>
<th>Dagur 1.</th>
<th>Mónudur</th>
<th>Ár 1992</th>
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### Staðsetning, sjá mynd

Ettilastækkanir vinstra megin á hælsi og í miðmæti.

### Meðferð

<table>
<thead>
<tr>
<th>Meðferðarskemtl</th>
<th>ABDV</th>
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<tbody>
<tr>
<td>Byrjablót</td>
<td>5. desember 1992</td>
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<td>Laus:</td>
<td>6. júlí 1993</td>
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### Aðgerð

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<tr>
<th>Sýnataka úr etli á hælsi vi. megin</th>
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### Íhlutir

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<tr>
<td>CVK/lyfþurnur</td>
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<td>Gastrostomía</td>
<td>x</td>
<td></td>
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<tr>
<td>Íhlutir</td>
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**Tegund ventils**
<table>
<thead>
<tr>
<th>Krabbameinslyf</th>
<th>Samanlagður skammtur mg/m²</th>
<th>Athugasemdir</th>
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<tbody>
<tr>
<td>l.v. Vincristin 1,25mg/m² x 14</td>
<td>17,5 mg/m²</td>
<td>Protocol 1,5mg/m², hämark 2 mg i skammti</td>
</tr>
<tr>
<td>l.v. Adriamycin 64mg/m² x 4</td>
<td>160 mg/m²</td>
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<tr>
<td>l.v. Etoposid 125 mg/m² x 10</td>
<td>1250 mg/m²</td>
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<tr>
<td>l.v. Taxol 250 mg/m² x 12</td>
<td>3000 mg/m²</td>
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<tr>
<td>l.v. Cyclophosphamid 500 mg/m² x 8</td>
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<th>Geislameðferð höfst</th>
<th>12. júní 1993</th>
<th>Allri geislameðferð lokið</th>
<th>30. júní 1993</th>
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<tbody>
<tr>
<td>Stáðsetning: skammtar/dagar Gy</td>
<td>Samanlagður skammtur Gy</td>
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<tr>
<td>Háls og brjóstsædi</td>
<td>1,8 Gy x 17</td>
<td>= 30,6 Gy</td>
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<th>Ónnur meðferð:</th>
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<tr>
<td>P.o. Decortin H (Prednison)</td>
<td>= 1500 mg/m²</td>
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General recommendation

Survivors treated with anthracyclines and/or chest radiation and their providers should be aware of the risk of cardiomyopathy.

Who needs cardiomyopathy surveillance after anthracycline chemotherapy?

Cardiomyopathy surveillance is recommended for survivors treated with high dose (≥ 250 mg/m²) anthracyclines.

Cardiomyopathy surveillance is reasonable for survivors treated with moderate dose (≥ 100 to < 250 mg/m²) anthracyclines.

Cardiomyopathy surveillance may be reasonable for survivors treated with low dose (< 100 mg/m²) anthracyclines.

Who needs cardiomyopathy surveillance after anthracycline chemotherapy and chest radiation?

Cardiomyopathy surveillance is recommended for survivors treated with moderate-high dose anthracyclines (≥ 100 mg/m²) and moderate-high dose chest radiation (≥ 15 Gy).

http://www.ighg.org/
At what age should breast cancer surveillance be initiated?

Initiation of breast cancer surveillance *is recommended* at age 25 years or ≥8 years from radiation (whichever occurs last) for female childhood, adolescent and young adult cancer survivors treated with ≥20 Gy chest radiation.

Initiation of breast cancer surveillance *is reasonable* at age 25 years or ≥8 years from radiation (whichever occurs last) for female childhood, adolescent and young adult cancer survivors treated with 10-19 Gy chest radiation.

Initiation of breast cancer surveillance *may be reasonable* at age 25 years or ≥8 years from radiation (whichever occurs last) for female childhood, adolescent and young adult cancer survivors treated with 1-9 Gy chest radiation.

http://www.ighg.org/
Research

Late effects in adult survivors of childhood cancer
A population-based study

Project accepted for a doctoral degree in the Faculty of Nursing at the University of Iceland
AIM: Obtain information regarding health and wellbeing of childhood cancer survivors in Iceland.

POPULATION: 18 years and older treated for cancer before 18 years of age in Iceland since 1981 (N = 226). Those who are invited to accept service at the late effect center are invited to participate.

METHOD: Observational design and mixed approach.

BENEFIT: Studies support mapping consequences of treatment and help to meet the needs of this group. No such study has been conducted on the Icelandic population.
Research
Late effects of childhood cancer treatments

- Background
- Knowledge about cancer, treatment and late effects
- Current follow-up
- Physical and mental health
- Life quality
- Lifestyle
- Influence on life and family
- Education and support from health care providers
With longer survival, studies provide important knowledge concerning both late effects and the wellbeing of survivors

- Studies give healthcare professionals a glimpse of what to expect for certain types of cancer treatment and therefore make long-term follow-up more effective.

- Studies can also affect future protocol changes, in some cases by reducing the doses of drugs that have been associated with serious health problems.

- As long as cancer treatments continue to change, research will be a necessary part of childhood cancer survivors follow-up.
Enjoy Iceland
Resources


NHS improvement (2011). Models of care to achieve better outcomes for children and young people living with and beyond cancer.

