Uppsala Health Summit: Long term care for cancer survivors
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Childhood cancer

- Rare disease 16/100000 (< 18y)
- Improved prognosis >80%
Childhood cancers - Estimated numbers of five-year survivors alive at the end of successive calendar years, by attained age in years.

Great Britain, 1971-2005

Modified from Charles Stiller 'Childhood Cancer in Britain' 2010
Late complications after childhood cancer
Aging and risk of severe, disabling, life-threatening, and fatal events in “the childhood cancer survivor study“
(treatments 1970-1986)
Limited knowledge among

- Patients
- Health care providers
- Social security systems
- Educational system
- Workplaces
Swedish National Cancer strategy 2009

”To increase survival time and to improve the quality of life among cancer survivors”
Swedish guidelines

- International guidelines
- Treatment protocols
- Original scientific papers and reviews
- Co-opted experts
- Adapt to Swedish health care conditions
The process of National guidelines

National societies of the medical specialities and presumed user organizations

Proposal from the national working group

Revised proposal from the national working group

Revised proposal from the national working group

Health care authorities in county councils and regions

Regional Cancer Centres

Regional Cancer Centres

Implementation
Långtidsuppföljning efter barncancer
Nationellt vårdprogram

http://cancercentrum.se/samverkan/cancerdiagnoser/barn/vardprogram/
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Detailed data of the treatment.
• Cumulative doses of chemotherapy
• Radiotherapy
• Surgery
• CVC
• Complications during therapy.
• Etc.

To empower patients after treatment
To inform health care providers

SALUB-register

Health status at age of 18.
Final height
Education level
Organ functions
Fertility preservation.
Etc.

Survivorship Passport

Recommendations for follow-up.

Event report form

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Pediatric oncology Gothenburg

2 million inhabitants
90-100 new pediatric cancer patients/year
almost 2000 adult childhood cancer survivors

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Expectations from patients

"To get knowledge about the cancer diagnosis and treatment"

"To be aware about possible problems that may occur"

"To feel that the staff are professional and competent"

"To get advice about healthy lifestyle"

"To get medical, and psykosocial help with treatment related problems"

"To get a summary of the cancer treatment and help with a care-plan if it is needed"

"Be listened to and be taken seriously on my questions and get sincere answers"

"To get support"

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Health economics 2009-11

- More than twice as many out-patient visits to hospital than expected.
- The total cost three times higher than expected.
- Hospitalizations 2-3 times higher frequency than expected.

(Verified by the Nordic ALLICCS study: de Fine Licht PLoS Med 2017)
Children and Young People National Cancer Survivorship Initiative - Levels of Care

LEVEL 1
Characteristics may include:
- No routine outpatient attendances
- Information on prescription and/or an educational intervention
- Automated surveillance tests with results by telephone or post
- Ability to reaccess system with or without reference to GP

LEVEL 2
Characteristics may include:
- Planned review of care e.g. hospital, community, face to face or telephone
- Clinical examination if required
- Patients with co-morbidities
- Those who are unable/decline to self manage

LEVEL 3
Characteristics may include:
- Complex rapidly changing health
- Complex treatment complications or symptomatic needs
- Complex ongoing treatment regimes
- Other input required e.g. cardiology, haematology, gastroenterology
- Requiring regular MDT reviews

Potential care model being tested
LTFU-clinic in Gothenburg

Provide knowledge to patients and health care providers
Risk-based individual planning of follow-up
Screening in some cases
Psychosocial support
Health literacy

Concerns people’s knowledge, motivation and ability to access, understand, evaluate and to practice information about health.

- To make assessments and to take decisions in daily life.

- To relate to health care, health prevention and health promotion.

- To maintain and improve quality of life throughout the life.

Sorenson et al, 2012
We are coming to understand health not as the absence of disease, but rather as the process by which individuals maintain their sense of coherence (i.e. sense that life is comprehensible, manageable, and meaningful) and ability to function in the face of changes in themselves and their relationships with their environment.

— Aaron Antonovsky —