



Experiences with Lukashuset

The first hospice for children and adolescents in Denmark.

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Lukashuset

Respite, symptom control and end of life care for children and young adults.





Why Lukashuset?

- Before Lukashuset: No formal palliative care services to children and young adults in Denmark
- International experience: There is a need
 - World's first children's hospice – Helen House, Oxfordshire, UK, 1982
 - First Australian hospice – Very Special Kids, Melbourne, 1996
 - First Nordic hospice – Lilla Erstagården, Stockholm, 2010
- Sankt Lukas Stiftelsen: Christian (diakonal) organisation.
 - Began with a children's welfare project in 1900
 - Denmark's first hospice, 1992
 - Denmark's first home hospice team, 1997
 - Denmark's first children's hospice, Lukashuset, 1. Nov 2015



Establishment of paediatric palliation in Denmark

Before 2015

- No formal services
- The first national meeting in paediatric palliation DK (2014)
- ”...paediatric palliation doesn't yet exist in Denmark as a specialised field with it's own strategies, guidelines and centres” (Mette Raunkiær, REHPA 2015)

2018

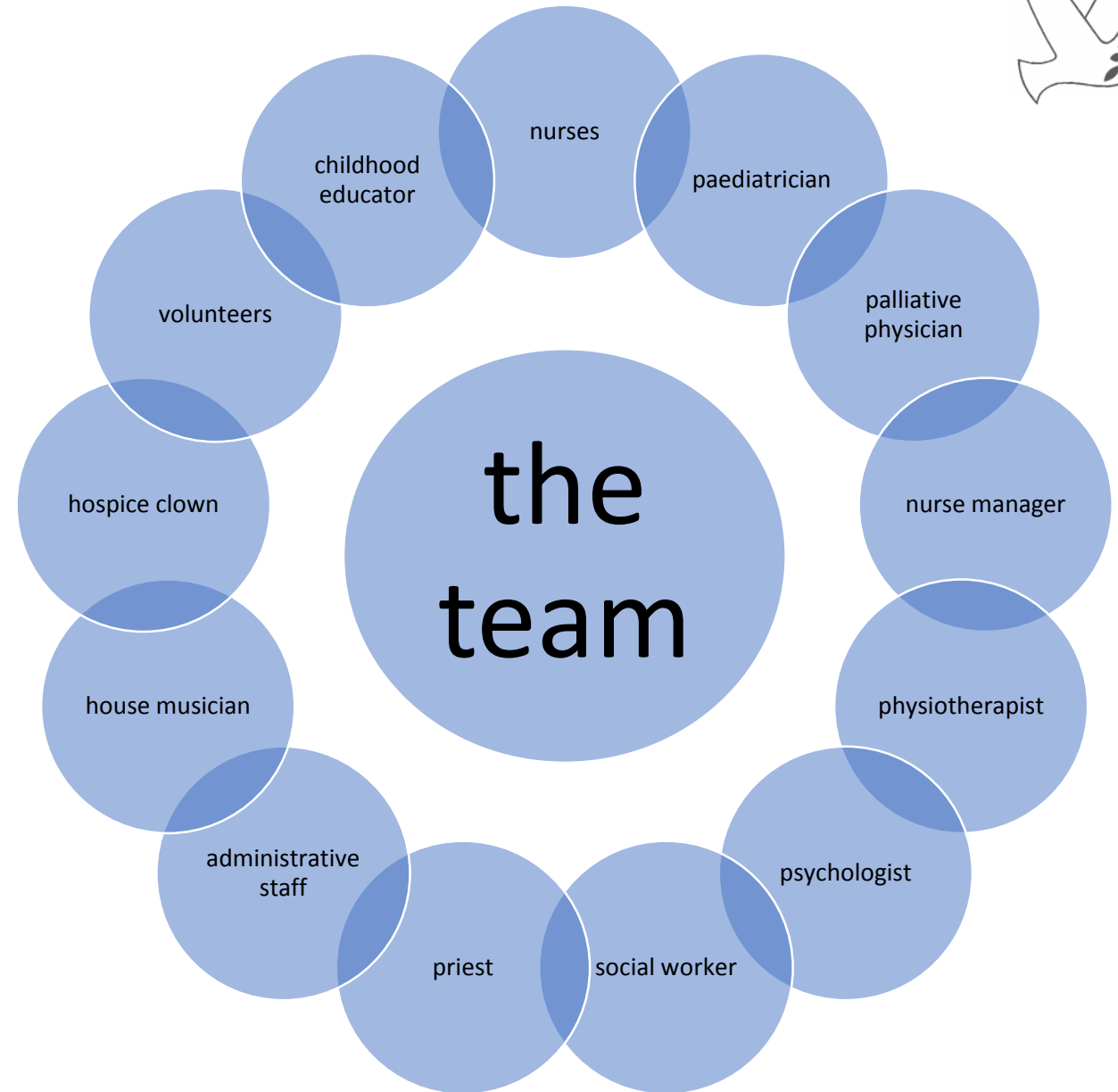
- Lukashuset (2015)
- Familie Fokus (2016)
- Regional teams (5 for children and adolescents (2016-2017))

Lukashuset - the house



- Facilities for 4 children and their families
- Kommunal kitchen, dining, and livingrooms
- Shared bathrooms/toilets, spa bath
- Physiotherapy room
- Verandah
- Playground and garden

Lukashuset – the team





The children - demographics 2015 - 2018

- 36 children
 - 21 male
 - 15 female
- Ages
 - Range 11 days to 26 years

Ages	Number
< 1	13
1-3	5
4-9	10
10-17	5
18+	3

- 47 admissions
 - Range 1 - 4
- Length of stay
 - Range 3 days - 14,5 months
 - Median 27 days
- Bed occupancy

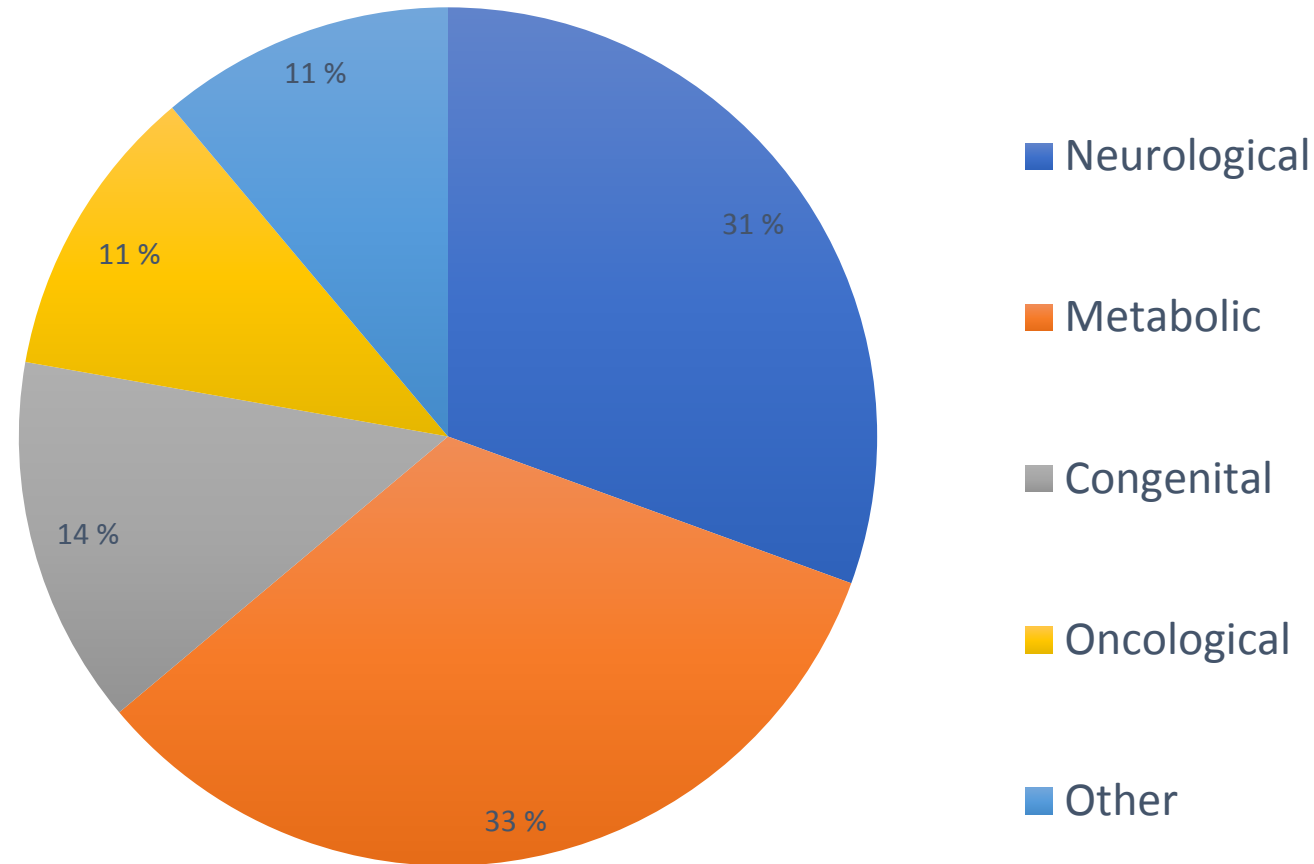
Year	%	Comment
2015	36,5	Nov - Dec
2016	67,75	
2017	79,6	
2018	66,27	Jan - July

- Ethnicity
 - 13 (36%) non Danish background
- 26 discharged
- 10 children have died in Lukashuset

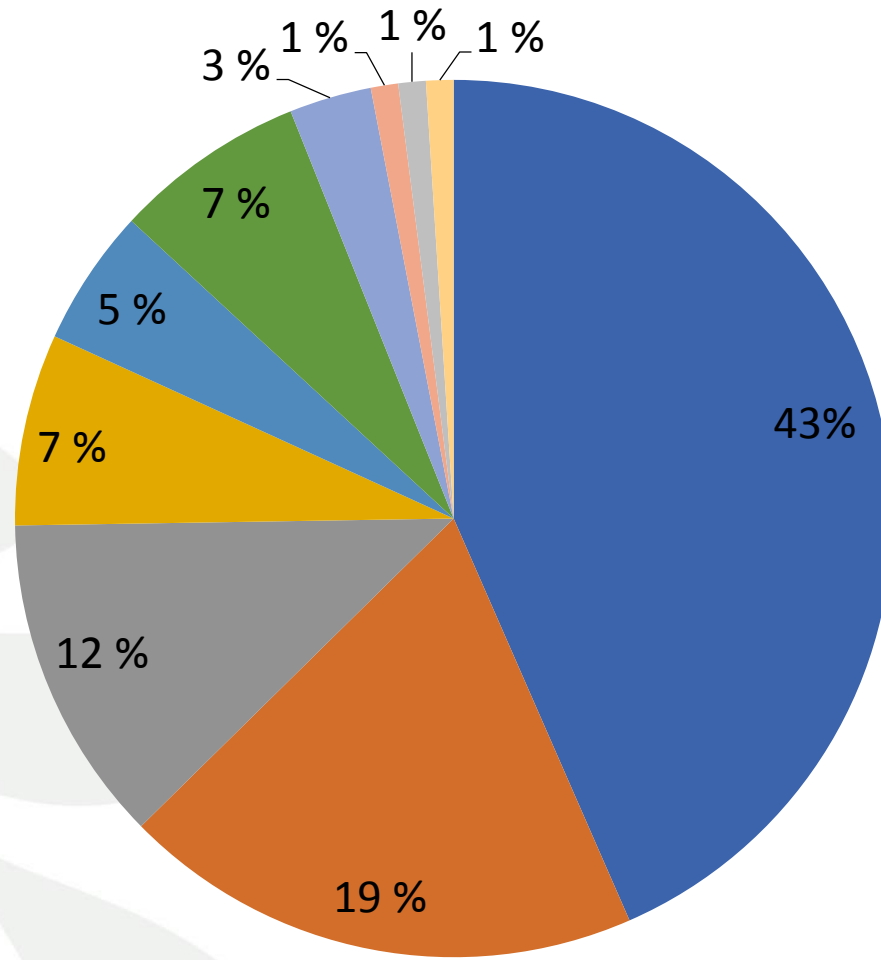




Diagnoses of the first 36 children admitted



Diagnoses of 2478 children admitted to UK hospices in 2011/12



- Neurology
- Congenital
- Oncology + Haematology
- Metabolic
- Perinatal
- Other eg. transplant rejection
- Respiratory
- Cardiovascular
- Genitourinary
- Gastrointestinal

Devanney, C et al 2012

Lukashuset/Sankt Lukas Stiftelsen



Lukashuset - Economics

- Running costs - 12,5 million kroner per year
 - 10 -15 % > an adult hospice bed
 - 10% < a specialised childrens department bed
- Who pays?
 - Free for the families
 - 2016 and 2017 – 2 mill. kroner from the "satspulje"
 - 2018 – Total of 7,9 mill. from the government.
 - 6,3 mill. kroner from "finansloven"
 - 1,6 mill. from the "satspulje"
 - 2019 – 7,5 mill. From "finansloven"
 - Sankt Lukas Stiftelsen and charity
 - Fundraising and lobbying



Case 1.

3 month old boy - 4 month admission

Symptom control and respite

- Epidermolysis bullosa simplex – Butterfly child
- Pain – Severe - Skin and GI tract
- Dressings – GA/ 4 hours – 2 nurses + mother.
- Traumatized, exhausted parents
- QOL - child and family
- 2 weeks of 24 hour respite
- DNR to full resuscitation



Case 2.

19 year old girl – 3 month admission

Symptom control, respite and end of life care

- Astrocytoma with hydrocephalis and leptomeningeal involvement
- Wheelchair bound
- Blindness
- Neurogenic pain
- Isolation – physical and social
- Room for all the family
- Progression – end of life care



Case 3.

2.5 month old boy – 14,5 month admission

Respite and symptom control. End of life care?

- Molybdenum cofactor deficiency and Hydrocephalus
 - Epilepsy
 - Severe psychomotor retardation
 - Pain/cerebral irritability
- Respiratory problems
- Family from Pakistan
- Social problems
- Psychiatric problems
- Plan 1: Respite, symptom control, EOLC? – 5 months
- Plan 2: EOLC??? – Father psych./ Mother visa - 5,5 months
- Plan 3: "Stable" – discharge – 4 months
- Plan 4: At home – pall. team and home nurses – 4 months. Pneumonia – admission to hospital
- Plan 5: Readmission to LH. Resp deterioration – CPAP, oxygen. EOLC???



Lukashuset – lessons learned

- Children's palliation is very different from adult palliation
 - Unpredictable
 - Cancer patients – 11% LH population.
 - Neurological and metabolic patients are in the majority
 - More respite and symptom control than end of life care.
 - The family has a much larger role
- Why hospice?
 - Complex symptoms
 - Home physical environment not suited – space, access
 - Families with fewer social resources
 - Need for respite
- "It takes a village to raise a child" – we need a team to help our patients and their families
- A children's hospice is a necessary part of palliative services to children in Denmark



Lukashuset



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References

- Raunkiær, M (2015) PALLIATIV INDSATS TIL FAMILIER MED BØRN OG UNGE MED LIVSBEGRÆNSENDE ELLER LIVSTRUENDE TILSTANDE – ET LITTERATURSTUDIE
- Devanney C, Bradley S and Together for Short Lives (2011/12) Count Me In: Children's Hospice Service Provision