

# Support to siblings



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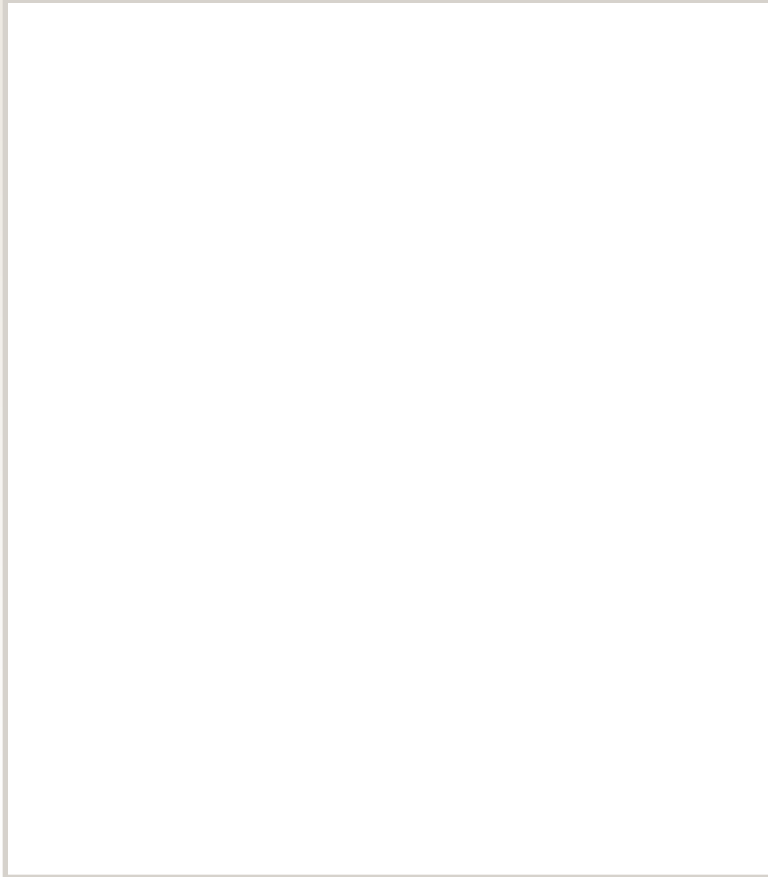
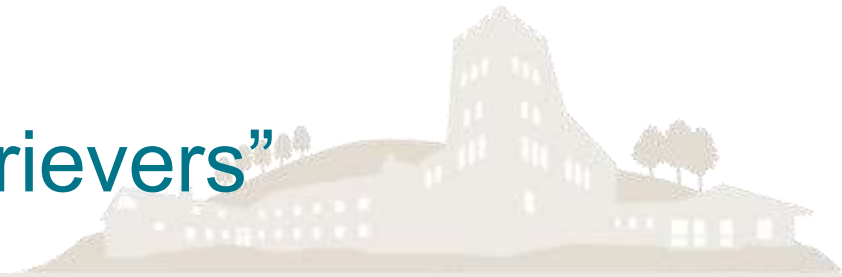


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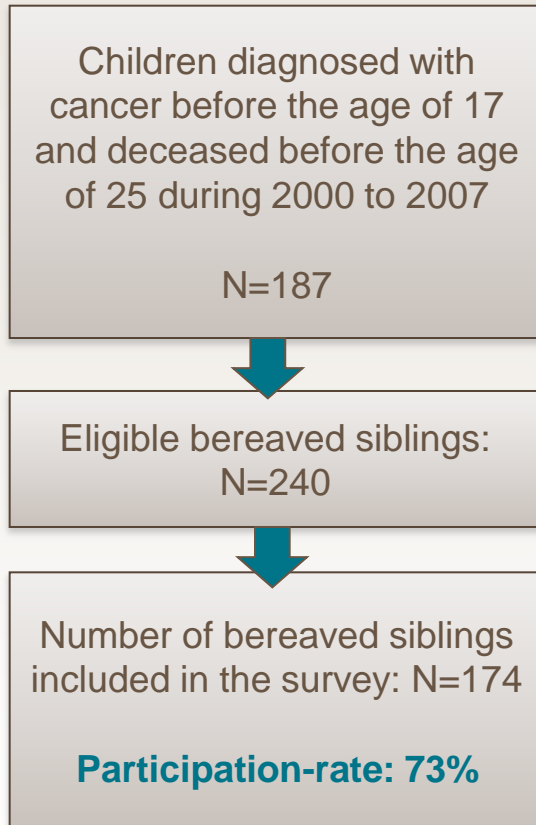


# "The forgotten grievers"

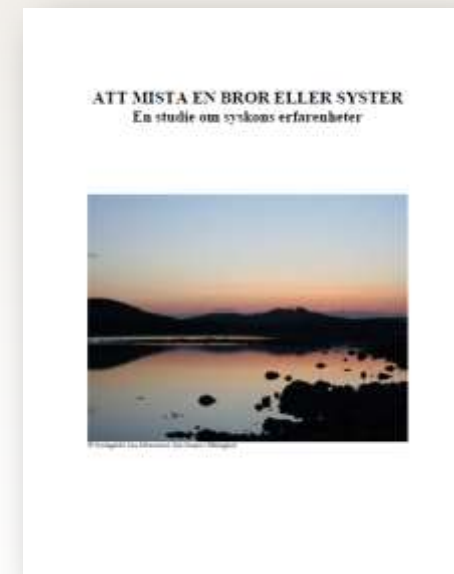


Siblings often stand  
outside the spotlight  
of attention and care

# Siblings' experiences of losing a brother or sister to cancer



- Nationwide survey in Sweden 2009
- Psychological health including grief
- Care- and family factors
  - Information
  - Participation
  - Communication
- Time of death
- After death
- Social support, etc...



## Insufficient communication and anxiety in cancer-bereaved siblings: A nationwide long-term follow-up

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## Cancer-bereaved siblings' positive and negative memories and experiences of illness and death: A nationwide follow-up

MARY-ELIZABETH BRADLEY EILERTSEN, R.N., PH.D.,<sup>1,2</sup> MALIN LÖVGREN, R.N., PH.D.,<sup>3,3</sup>  
ALEXANDRA EILEGÅRD WALLIN, R.N., PH.D.,<sup>4</sup> and ULRIKA KREICBERGS, PH.D.<sup>1,2</sup>

## Siblings' experiences of their brother's or sister's cancer death: a nationwide follow-up 2–9 years later

Malin Lövgren<sup>1,2\*</sup>, Li Jalmell<sup>3,4</sup>, Alexandra Eilegård Wallin<sup>2</sup>, Gunnar Steineck<sup>5,6</sup> and Ulrika Kreicbergs<sup>1,7</sup>  
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<sup>7</sup>Ersta Sköndal University College, Palliative Research Centre, Stockholm, Sweden

## They still grieve—a nationwide follow-up of young adults 2–9 years after losing a sibling to cancer

Josefin Sveen<sup>1,5\*</sup>, Alexandra Eilegård<sup>1,3,4</sup>, Gunnar Steineck<sup>2,3</sup> and Ulrika Kreicbergs<sup>1,3,4</sup>  
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<sup>4</sup>Sophiahemmet University, Stockholm, Sweden  
<sup>5</sup>Institute of Neuroscience, Psychiatry, Uppsala University, Uppsala, Sweden

## Care at End of Life Influences Grief: A Nationwide Long-Term Follow-Up among Young Adults Who Lost a Brother or Sister to Childhood Cancer

Malin Lövgren, PhD,<sup>1,2</sup> Josefin Sveen, PhD,<sup>1</sup> Tommy Nyberg, MSc statistician,<sup>3,4</sup>  
Alexandra Eilegård Wallin, PhD,<sup>2</sup> Holly G. Prigerson, PhD,<sup>5</sup>  
Gunnar Steineck, PhD,<sup>2,3</sup> and Ulrika Kreicbergs, PhD<sup>1,2</sup>

Psycho-Oncology

Published online 20 February 2012 in Wiley Online Library (wileyonlinelibrary.com). DOI: 10.1002/pon.3053

## Psychological health in siblings who lost a brother or sister to cancer 2 to 9 years earlier

Alexandra Eilegård<sup>1,2,4\*</sup>, Gunnar Steineck<sup>3,1</sup>, Tommy Nyberg<sup>4</sup> and Ulrika Kreicbergs<sup>1,2,4</sup>  
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<sup>3</sup>Division of Oncology, Sahlgrenska University Hospital, Gothenburg, Sweden  
<sup>4</sup>Division of Oncology, Sahlgrenska University Hospital, Gothenburg, Sweden

## Impact of Social Support on Bereaved Siblings' Anxiety: A Nationwide Follow-Up

Mary-Elizabeth Bradley Eilertsen, PhD, RN<sup>1</sup>, Alexandra Eilegård, PhD, RN<sup>2</sup>,  
Gunnar Steineck, MD, PhD<sup>2,3</sup>, Tommy Nyberg, MSc<sup>2</sup>,  
and Ulrika Kreicbergs, PhD, RN<sup>2,4</sup>

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## Bereaved Siblings' Advice to Health Care Professionals Working With Children With Cancer and Their Families

Malin Lövgren, PhD, RN<sup>1</sup>, Tove Bylund-Grenklo, PhD, MSc<sup>1,2</sup>, Li Jalmell, MD, PhD<sup>3,4</sup>,  
Alexandra Eilegård Wallin, PhD, RN<sup>5</sup>, and Ulrika Kreicbergs, PhD, RN<sup>1,6</sup>

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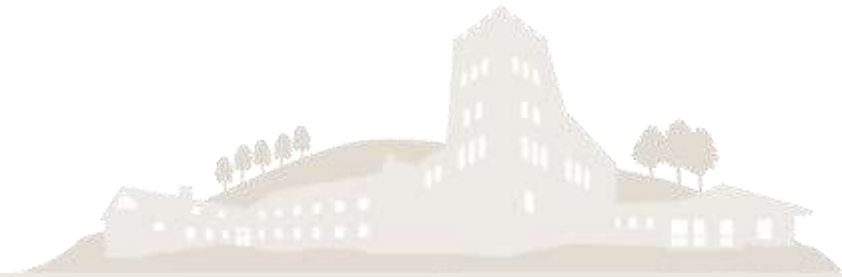
Ulrika Kreicbergs, RN, Professor; Alexandra Eilegård Wallin, RN, PhD; Gunnar Steineck, MD, Professor; Li Jalmell, MD, PhD; Josefin Sveen, Psychologist, Associate Professor; Mary-Elizabeth Bradley-Eilertsen, RN, Associate Professor; Tove Bylund-Grenklo, PhD; Holly G Prigerson, MD, Professor.



# Bereaved siblings' health

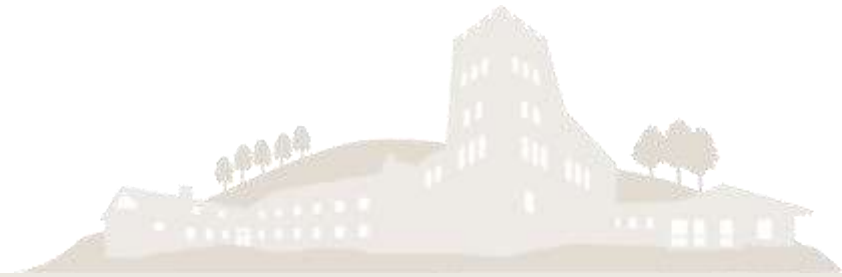


- Not more likely to report anxiety or depression
- Experience more psychological distress
  - Increased risk of:
    - low self-esteem
    - low level of personal maturity
    - difficulties falling asleep
- Negative experiences during illness/death increase the risk for long-term distress
- Losing a brother/sister in childhood = increased risk for mortality\*



## Focus for this presentation

- Care- and family factors during illness, at time of death and after death that are modifiable and/or avoidable
- Knowledge about these factors can help health care staff, family and friends to SUPPORT siblings



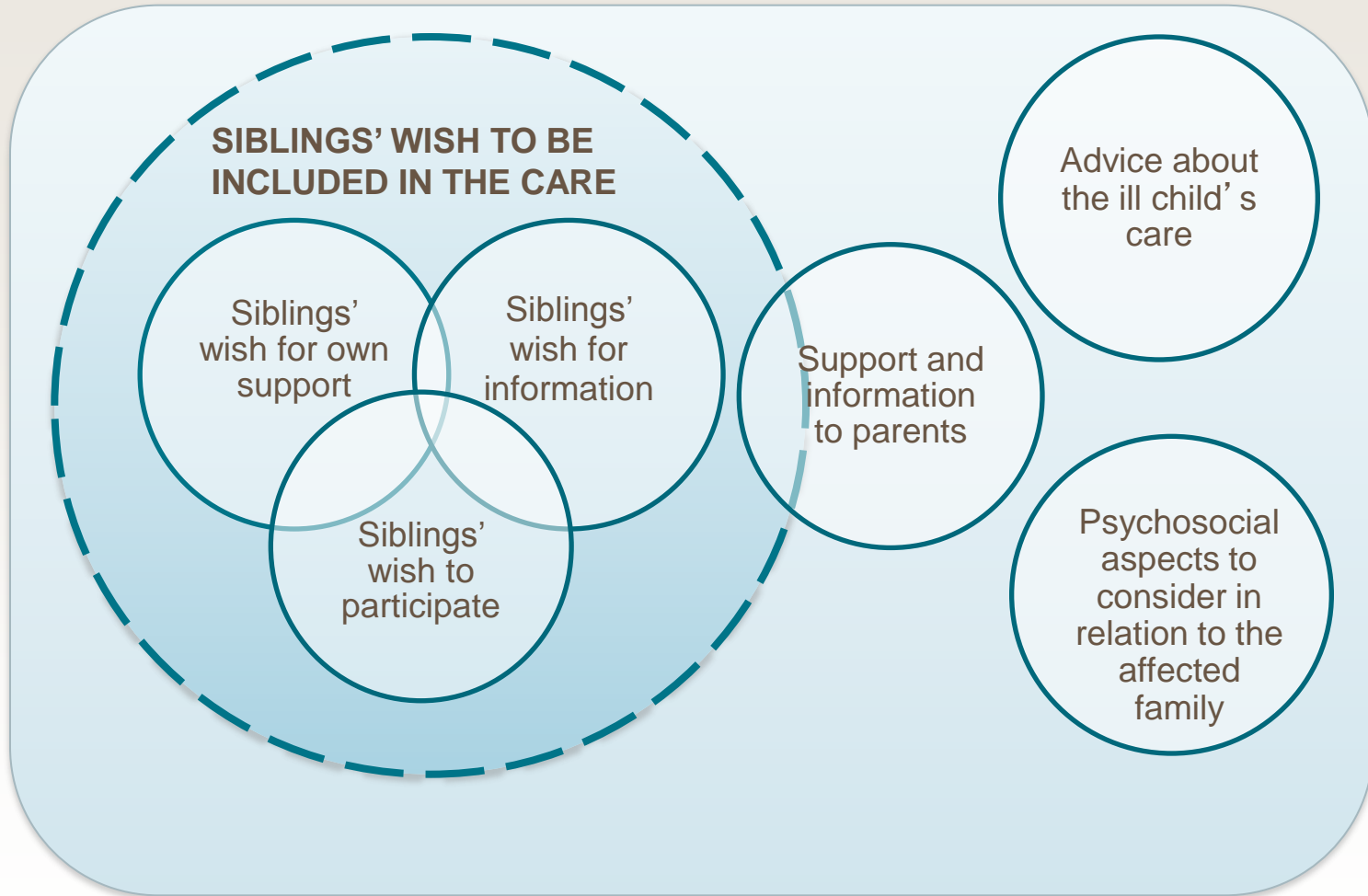
# Bereaved siblings' advice to health care staff







# Siblings' advice to staff



A total of 245 pieces of advice!

# Siblings' wish for own support

	<b>EXAMPLES OF ADVICE</b>
<b>To be seen and get attention</b>	<i>"Don't forget the siblings", "Pay more attention to the siblings"</i>
<b>To talk to a professional</b>	<i>"Offer contact with counselor/psychologist at different time points", "Need for counseling both after the death and later on"</i>
<b>To participate in support groups and other activities for siblings</b>	<i>"Meet others who have lost a sibling", "Suggest activities at the children's ward"</i>
<b>Other advices</b>	<i>"Stop by with a game, a sticker, tea etc. for siblings", "Help with homework".</i>



*“It’s hard for a parent to find energy, time, willingness and opportunity to sit down and help with homework and so on. Or now the class is going on a class field trip and everything has be gotten ready and things need to be done (...) It would be good to get support from someone else.”*

Siblings had a wish for support in daily life, e.g. homework, school activities, hobbies.

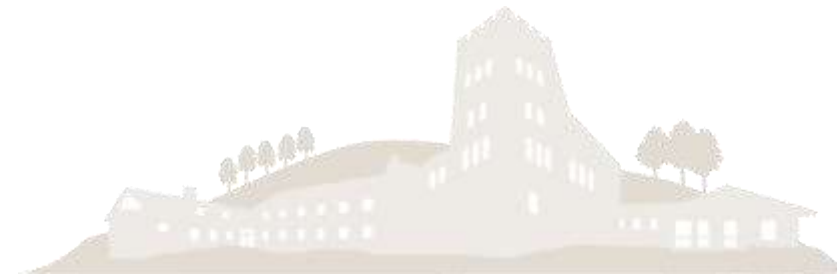
# Siblings' wish for information

- Disease
  - Treatment
  - Prognosis
  - Available support
- 
- The same info as the parents
  - With and without parents
- 
- On a suitable level
  - In a playful way

*“A what? A counselor? What’s that? Is it some kind of sports car or something... you don’t quite get it.”*

*“They came in with a book for me, with a bunch of happy cartoons (...) They had drawn in a bunch of smileys and things and they sort of like leafed through it for me and told me exactly how cells worked.”*

Diagnosis -----> After bereavement

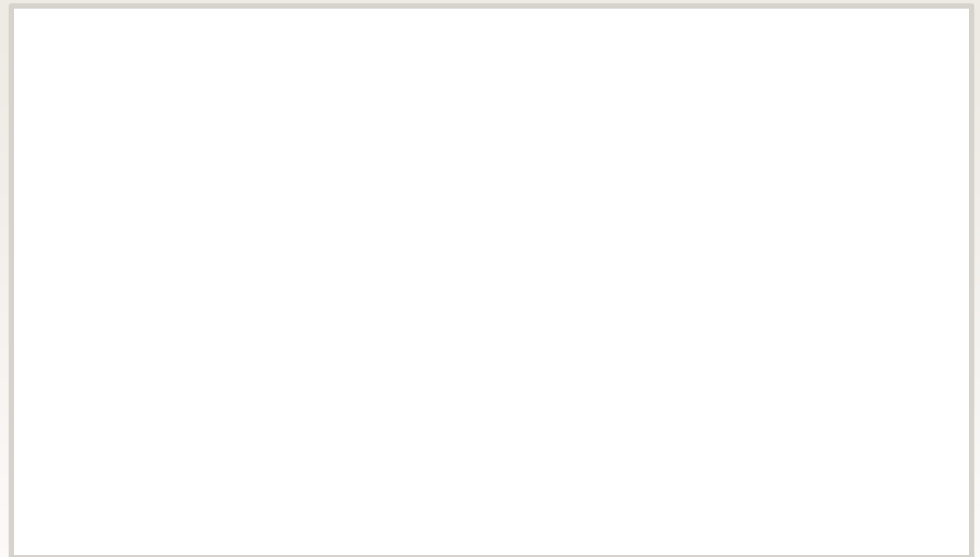


- *“Talk to me directly”*
- Parents sometimes excluded information
- They used their parents’ facial expressions to interpret information
- Hard to ask the parents - brought up negative emotions

*“I felt like I didn’t want to ask her (the mother) because I sensed that no, she shouldn’t have to explain when she’s sad enough already. She shouldn’t have to explain it because I think the doctors should do that.”*

- Practical participation

*“It’s actually possible to be involved in a fun way. I did that once with a nurse, and then I could help her punch the buttons, like. I thought that was pretty fun; like I was giving my brother his medicine.”*



- The siblings felt **important, good and needed** when they participated in the care.

# Support and information to parents

*"Inform parents about how much distress siblings experience, even though it's nobody's fault, so parents can be more aware of that."*

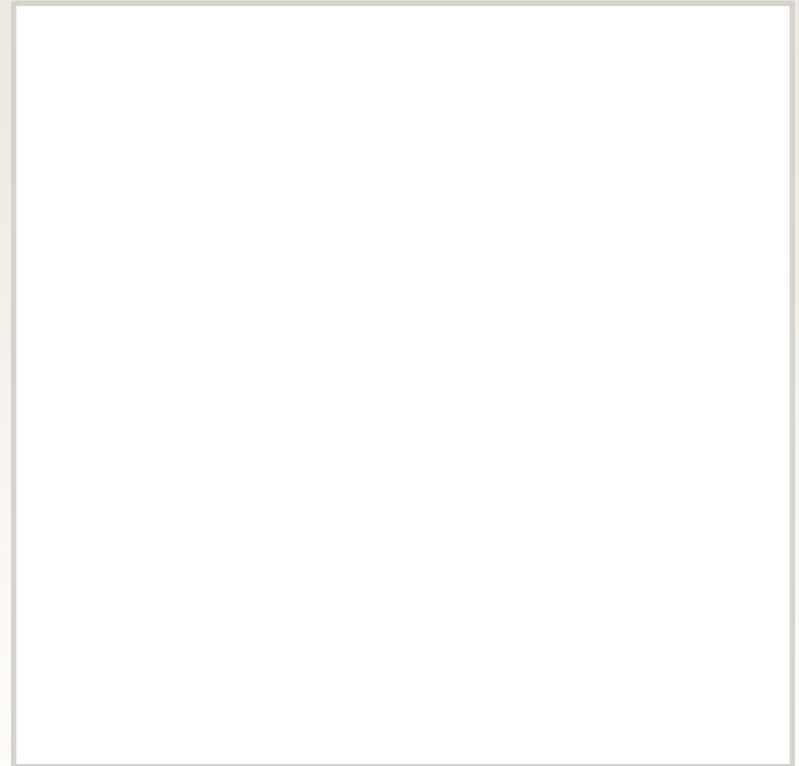
*"Give support to parents"*

*"Give the parents help in how to involve the siblings more"*

# Advice about the ill child's care



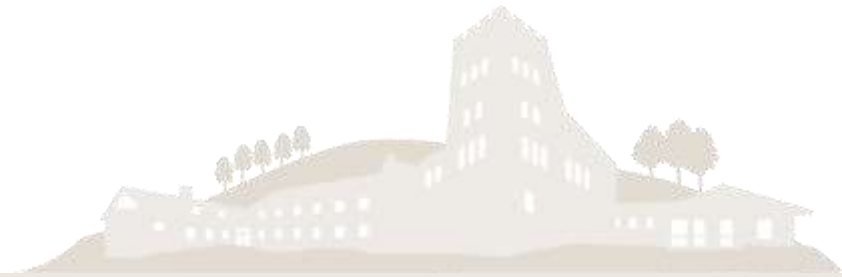
- *“Let the sick child be as normal as possible”*
- Ask how they want to be cared for
- Communication about death:  
*“Those who have fallen ill don't want to hear constantly that they are going to die”*



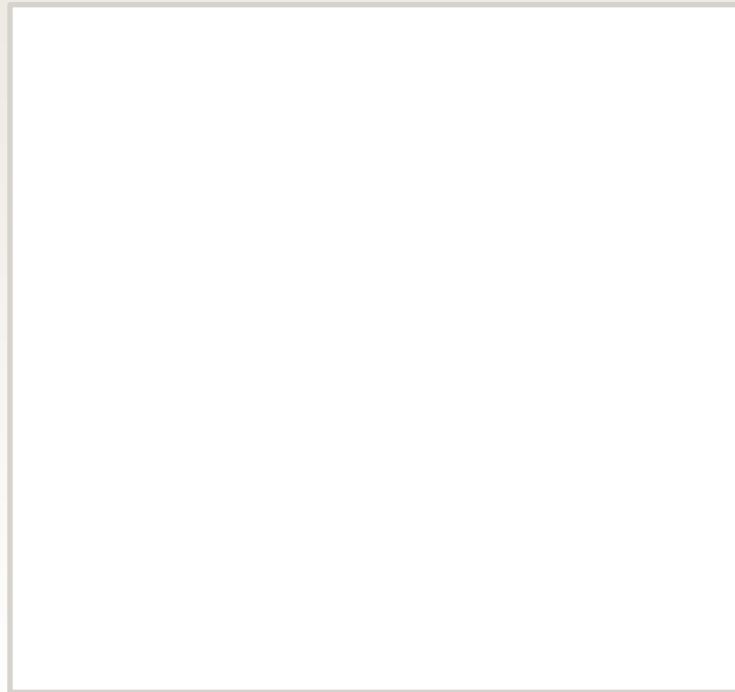


# Psychosocial aspect to consider in relation to the family

	EXAMPLES OF ADVICE
<b>Mediate positivity, hope and happiness — realism and honesty</b>	<i>"Be honest", "Be positive and cheerful", "Be encouraging, strengthen hopes, but don't give false hopes"</i>
<b>Be empathic and responsive</b>	<i>Put yourself into their situation", "Show empathy"</i>
<b>"Be natural, be yourself"</b>	<i>"Be yourself", "Do things in a natural way", "Be normal – dare to laugh, for example"</i>
<b>Other advices</b>	<i>"Be patient", "Treat everyone warmly", "Don't butt in, but be nearby", "That staff members are patient and don't just do the same things as they've always done"</i>



# Bereaved siblings' experiences of their brother's or sister's cancer death



Before death — At time of death — After death

# Experiences closely before death

Did you get the chance to say goodbye to your sibling before he or she died?

Yes	53%
No	47%

Did you notice if your sibling was suffering during his/her last hours of life?

Yes	<b>70%</b>
No	30%
<i>Was not present, N=41</i>	

Did anyone tell you what to expect when your sibling was going to die?

Yes	<b>17%</b>
No	84%

Nobody told the sibling what to expect when the brother/sister was going to die



Higher level of anxiety 2-9 years later



- Sudden or gradual deterioration

*“In less than a week he got drastically worse and ended up in intensive care. No one realised how it was going to end until the last day.”*

- Emotional reactions

*“Watching your brother suffer that much is incredibly painful for an older sister. You feel so powerless when you can’t make it better or help.”*

- **Absence during illness**

*“I wish I had been there that last month, but I didn’t know that it was the last month so I was 1250 km away studying”*

- **Poor knowledge about death**

*“Looking back on it now it would have been good to talk to someone about how death can be and what was going to happen.”*

# Experiences at time of death

## Were you present when your sibling died?

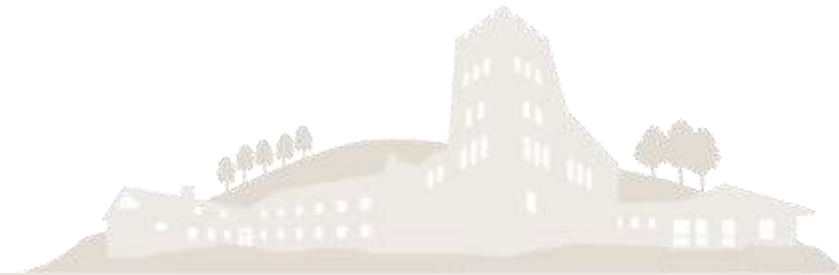
Yes	55%
No	45%

## Do you regret being present when your sibling died?

Yes	1%
No	99%

## Do you regret not being present when your sibling died?

Yes	76%
No	24%



- Presence vs. Absence
- **Observing physical changes**
- **The atmosphere in the room**
- Emotional reactions

*“At about 12:00 my mother called and said that a taxi was on its way to pick up my sister and I. It was critical, but we came too late.”*

*“When she took her last breath I had my hand on her chest and felt her heart slow down.”*

*“There were quite a lot of us around the bed then. It was very calming and nice that everyone was there.”*

*“He was suffering so much that it was a relief to see him go to a better place.”*

# Experiences closely after death

**Did you see your sibling after he/she died?**

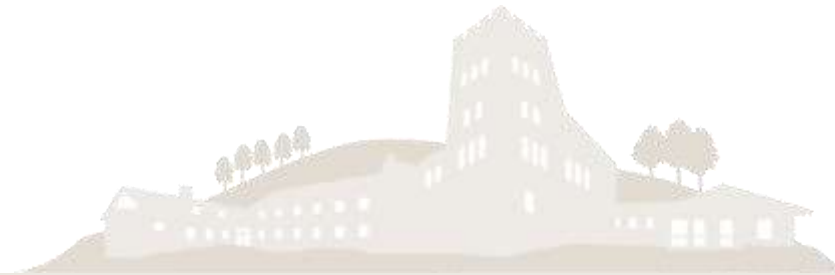
Yes	90%
No	10%

**Do you regret seeing your sibling after he/she died?**

Yes	2%
No	98%

**Did you talk to anyone about your siblings' death?**

Yes	72%
No	28%



- Being together afterwards
- Emotional reactions
- **Blaming others**
- **Experiences that facilitated or complicated the grieving process**

*“Then the family gathered at my brother’s bed and cried and said goodbye.”*

*“Afterwards it felt so terribly empty. But at the same time nice for him to not have to suffer anymore.”*

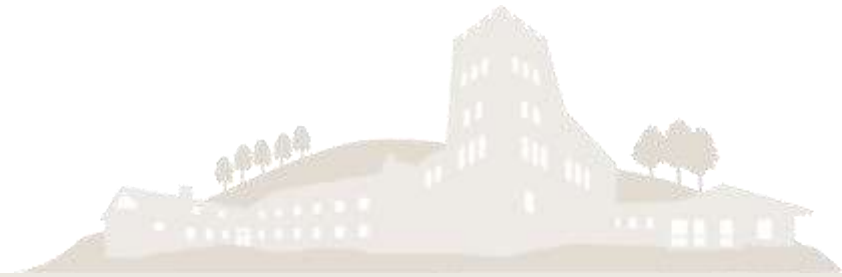
*“I can’t help blaming this on the doctors after they did such a stupid ‘experiment’.”*

*“I felt a little in the way, I didn’t want to show the extent of my own grief when I thought of how mum and my step father were so busy with their own grief and with my little brother.”*





# To consider...



- More knowledge about death among siblings = lower risk for anxiety and regrets later on!
- Talk about the time frame & the uncertainty
  - Give them possibility to:
    - Be present during illness
    - Be present at time of death
    - To say goodbye
- Bodily changes: what happens to the body when we die?!!!

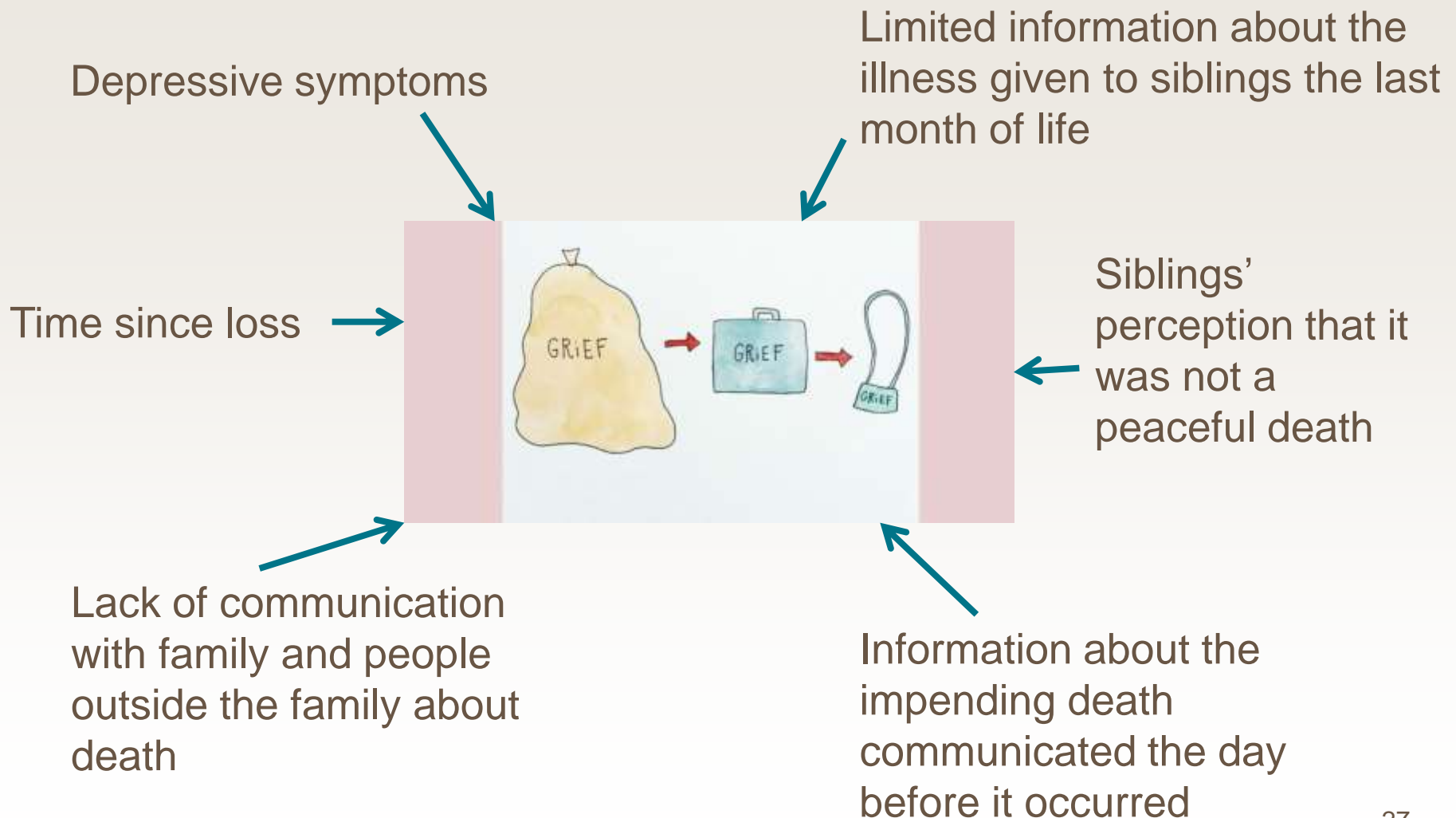
# Siblings still grieve!

- A majority of cancer-bereaved siblings still grieve 2-9 years after the loss



- *“Grief never, ever leaves you. It just becomes a bit more manageable”*

# Factors influencing long-term grief among siblings



# Increased risk for long-term anxiety among siblings



Parents and neighbors did not care for siblings after death

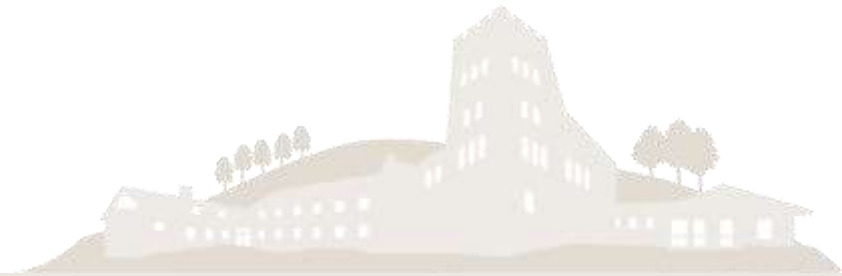
Siblings did not talk to their family after loss

Nobody told the sibling what to expect when the brother/sister was going to die

Siblings did not talk about their feelings during illness

Siblings avoiding staff for fear of being in their way (during illness)

Siblings' social support was unsatisfied during illness



## Siblings' ways of coping with grief

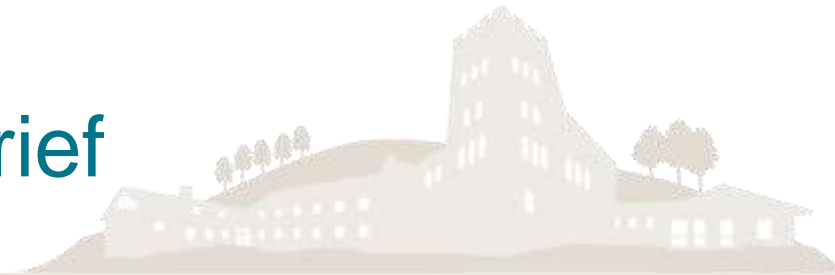
### Dual Process Model of coping\*

- Loss-oriented
- Restoration-oriented

\*Stroebe, M., & Schut, H. (2010). The dual process model of coping with bereavement: a decade on. *Omega (Westport)*, 61(4), 273-289.



# Coping with grief



**Thinking of the dead brother/sister, feeling the grief and expressing it**

*“Look at photos and movies we have recorded. Make photo albums of the photos”, “Internet and that I have been able to write down my thoughts and feelings”.*

**Distracting or occupying themselves**

*“Just do something that makes me think of something else”, “I have been riding a lot of motocross and enduro”.*

**Engaging in spiritual and religious beliefs/activities**

*“Strong belief that (we) meet again has given me the strength to move on”, “I think everyone can expect something amazing on the other side of death”, “My belief”.*

**Waiting for time to pass**

*“That time passes. It alleviates the worst of the pain”, “Time heals all wounds, some anyway...”*

# Religious beliefs & Spirituality



Siblings who had used spirituality, religious beliefs and activities to cope were more likely to have worked through their grief than those who had not

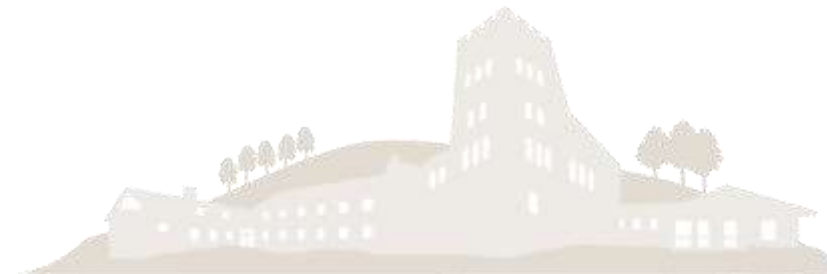
# Continuing having a sibling-bond



- ~~Visit the grave~~
- Alternative places
- Having reminders

- Include the dead brother/sister in the family, e.g. special place at the table





# Parents' experiences of the care of their child with severe spinal muscular atrophy (SMA)



Freja  
FOTOGRAF NINA

THE JOURNAL OF PEDIATRICS • www.jpeds.com ORIGINAL ARTICLES

**Parents' Experiences and Wishes at End of Life in Children with Spinal Muscular Atrophy Types I and II**

Malin Lövgren, RN, PhD<sup>1,2</sup>, Thomas Sejersen, MD, PhD<sup>3</sup>, and Ulrika Kreicbergs, RN, PhD<sup>1,2</sup>

**Objective** To explore experiences and wishes of bereaved parents concerning end-of-life care for their child with severe spinal muscular atrophy.

**Study design** A follow-up survey was conducted in 2013 on parents of deceased Swedish children who were born between 2000 and 2010 and later diagnosed with spinal muscular atrophy type I or II (n = 48). The questions used in this study covered location of death (LoD), support from health care staff, and parents' wishes and concerns

EUROPEAN JOURNAL OF PEDIATRIC NEUROLOGY 20 (2016) 830–838

Official Journal of the European Paediatric Neurology Society

Original article

**Information and treatment decisions in severe spinal muscular atrophy: A parental follow-up**

Malin Lövgren <sup>a,b,c,\*</sup>, Thomas Sejersen <sup>c</sup>, Ulrika Kreicbergs <sup>a,b</sup>



# Denmark - Sweden

- Nationwide surveys
- Parents' perception of the care

## Included parents:

- Sweden: Children born 2000-2010
- Denmark: Children born 2003-2013
- Diagnosed with SMA type 1 & 2 + respiratory support was discussed

## Response rate:

- Sweden: 61/70, 87%
- Denmark: 34/43, 79%

### HEALTHCARE EXPERIENCE AS A PARENT

For parents of a child with  
spinal muscular atrophy

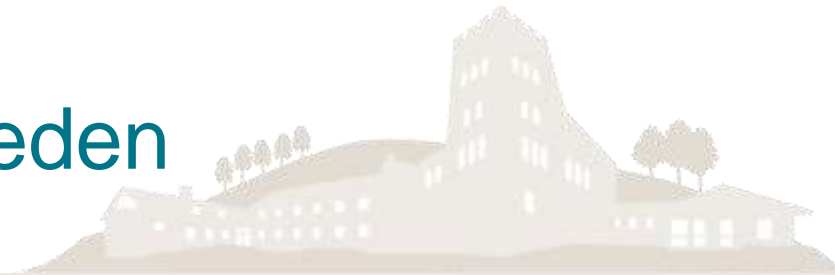


### HEALTHCARE EXPERIENCE AS A PARENT

For parents who have lost a child with  
spinal muscular atrophy



# Denmark - Sweden



	Denmark N=18	Sweden N=28	Total N=46 (%)
<b>Siblings 3 yrs and older</b>			
<b>Sibling given information about their sister or brother's illness</b>			
Yes, by parents	16	19	35 (76)
Yes, by parents + other way	2	3	5 (11)
Yes, by a physician	-	2	2 (4)
Sibling(s) too young	-	4	4 (9)
<b>Siblings received professional psychological support</b>			
Yes	3	1	4 (9)
No	14	24	38 (83)
Sibling(s) too young	1	3	4 (9)

**Communicated WITHIN the family!!!**



# Summary

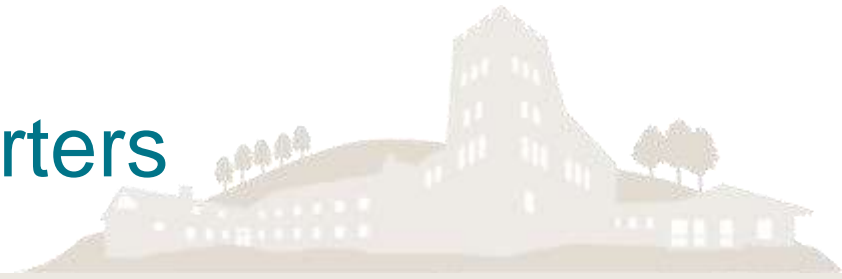
## COMMUNICATION

- Own support to siblings- make them visible!
- Better medical information during illness, at time of death and afterwards
  - Directly to siblings
  - Illness - Prognosis
  - The dying process
  - Prevent: to blame others, regrets, unresolved grief, anxiety, etc.
- Support to parents = support to siblings
- Practical participation in the care

- Facilitate the grieving process
  - Information
  - Peaceful death
  - Communication with family and people outside the family
  - Religious and spiritual coping: how can we help siblings with this?
- Be aware of siblings way of grieving
  - “Go in and out”
  - Different from adults
  - Sibling-bond
- Prevent long-term anxiety
  - Information
  - Communication (health care staff, family, neighbors, etc.)
  - Social support
- What is our responsibility as health care professionals?



# Sibling supporters

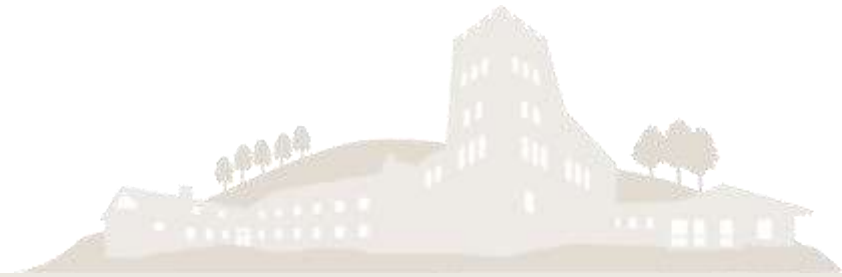


Jonna and Kerstin, siblings supporters at Lilla Erstagården (the Children's hospice in Sweden)

# Palliative Care in Pediatric Oncology



April 27-28,  
2018 in  
Stockholm,  
Sweden



# Thank you for your attention!

