

**the  
CHURCHILL  
fellowship**



## *Children as Next-of-Kin*



**Dr Steve Marshall  
Churchill Fellow 2020**

## Executive summary

The aim of this Churchill Fellowship was to learn about legislation enacted in 2010 in Norway and Sweden, giving rights to children as ‘next-of-kin’: when a parent has a serious illness in these countries, their dependent children now have the right to information and support. The Fellowship enabled me to interview and shadow health and social care professionals in both countries and learn how the 2010 legislation is incorporated into clinical practice. The main finding was that Norway and Sweden are countries that are fundamentally child-focused, where it is acknowledged that to ensure the wellbeing of the adult population, all vulnerable children must be identified and offered appropriate support. Despite some challenges, the 2010 legislation has been incorporated into clinical practice and provides a framework for a pioneering approach that puts the needs of dependent children at its core.

The recommendations from the Fellowship are grounded in the UK’s legislation around young carers and are focused upon four levels:

- Team level – I intend to work with my palliative care colleagues around making a change to how dependent children are conceptualised and supported by the team.
- Organisational level – I plan to develop a network of ‘Children’s Champions’ across King’s College Hospital, to encourage the identification and support of all patients’ dependent children.
- Local level – I intend to collaborate with colleagues from local hospices and local young carers’ groups to identify children who would be considered young carers.
- National level – I plan to develop a national network of professionals and organisations that can advocate for the needs of children living with parental illness.

The recommendations are intended to increase the visibility of children and young people living with parental life-limiting illness in the UK and to support health and social care professionals to ensure that the basic human rights of this vulnerable group are not denied.

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## Cover image

'Death in the Sickroom' by Edvard Munch (1893), original displayed in the National Gallery, Oslo.

## Acknowledgements

Thank you to the Churchill Fellowship for funding this project and to King's College Hospital for supporting my travels to Norway and Sweden. I would also like to thank all of the professionals in Norway and Sweden who were so welcoming and gave their time so willingly (and were so gracious about speaking to me in English). Many people went above and beyond, inviting me into their homes and being such hospitable hosts. I will not mention everyone by name for fear of forgetting anyone, but you were all amazing. Thanks also for the invitation to the annual 'Children as next-of-kin' Nordic Network Meeting 2022 in Denmark. Thank you to my Churchill Fellowship mentors Andrew Rowland and Olwen Minford. And finally a big thank you to Mike for supporting my Scandinavian adventures (and even joining me for some of them).

## About the author

Steve Marshall is a social worker in the palliative care team at King's College Hospital in South London, and also holds an honorary senior lecturer position in the Cicely Saunders Institute at King's College London. Steve has a special interest in supporting families with children under the age of 18 and has recently completed a Marie Curie-funded research project on this subject. This Churchill Fellowship complements and builds upon his clinical and academic work with children whose parent has a life-limiting illness.

## Introduction

### *Background*

Children under the age of 18 who have a parent with a life-limiting illness are at increased risk of negative outcomes as they grow up and become adults.<sup>1</sup> The death of a parent during childhood is likely to have a long-term impact, negatively affecting psychological wellbeing,<sup>2</sup> educational attainment<sup>3</sup> and employment prospects.<sup>4</sup> Every classroom in the UK is likely to contain at least one child who has experienced the death of a parent and approximately 41,000 children are bereaved of a parent each year in the UK.<sup>5</sup> These children have described feeling marginalised, unnoticed and isolated as their parent is dying,<sup>6,7</sup> with limited and inadequate input from healthcare professionals.<sup>8,9</sup> The result is that these children are not appropriately supported at a time of increased vulnerability,<sup>10,11</sup> which may be a contributory factor in their increased risk of negative outcomes in adulthood.

As a social worker in palliative care, I have worked with many patients with a life-limiting illness who have children under the age of 18. My current position is at King's College Hospital, a specialist centre for trauma, haematology and liver disease, meaning that a large proportion of our patients are younger and have dependent children. This can be an emotive and challenging part of the work of a palliative care specialist and many professionals can feel unskilled when working with these families.<sup>12,13</sup> However, I found that there were no evidence-based guidelines to support healthcare professionals struggling with this aspect of their work. Funded by the Marie Curie Research Grant Scheme (grant *MCRGS-20171219-8008*), I was able to undertake primary data collection and interview 32 children and young people about their experience of having a parent with a life-limiting illness. These interviews formed the basis of recommendations and guidelines for any professionals working with dying patients who have children under 18.<sup>14,15</sup> I am currently in the process of disseminating these recommendations and supporting colleagues across the UK to implement changes to their practice.

Whilst undertaking the Marie Curie-funded research, I became aware that the Nordic countries (Denmark, Finland, Iceland, Norway and Sweden) take a pioneering approach towards the needs of children when a parent has a serious physical illness, has a mental health illness or abuses substances.<sup>16</sup> The Nordic countries use the term 'next-of-kin' to delineate these children and perceive them as a discrete and vulnerable cohort requiring additional support. These countries show a commitment to the United Nations Convention on the Rights of Children (UNCRC), the 1989 international human rights treaty expounding the civil, political, economic, social, health and cultural rights of all children.<sup>17</sup> Article 12 of the UNCRC states that children have a right to be involved in all matters affecting them. The Nordic countries are pioneering internationally by acknowledging the rights of children affected by the illness of a parent. In 2010, Norway and Sweden enacted legislation placing a duty on healthcare professionals to consider the needs of children as next-of-kin.<sup>18,19</sup> In the context of my clinical practice and the dissemination of the recommendations from the

Marie Curie-funded research, learning how the 2010 Norwegian and Swedish legislation works in practice seemed to be the next logical step for me.

### *Aims and objectives*

The aims and objectives of this Churchill Fellowship were as follows:

- to develop an understanding of the Norwegian and Swedish 2010 legislation establishing children as next-of-kin;
- to develop an understanding of how this legislation works in clinical practice;
- to adapt this knowledge into recommendations applicable to the UK.

### *Purpose of the report*

The purpose of this report is to summarise the findings from the Churchill Fellowship and outline how the Nordic countries apply the concept of children as next-of-kin. These findings are then adapted into clear and achievable recommendations that can be implemented in the UK context.

### *Methods*

This report was completed after travelling to Norway and Sweden in August and September 2022. The towns and cities visited are detailed on the map in *Appendix A*. The travels included meeting with health and social care professionals across both countries, all of whom work with the issue of children as next-of-kin. Meetings were held with professionals from a range of backgrounds, including clinicians working in palliative care and oncology, children's grief support workers, children as next-of-kin co-ordinators, child protection specialists, policymakers, researchers and academics. A full list of the meetings and the professionals are detailed in *Appendix B*.

Additional information was obtained by shadowing clinical teams in palliative care and oncology. I was able to attend home visits with several families who have young children, and *Appendix C* details the social work assessment from one of those visits. The report was also informed by documentation provided by the teams visited. *Appendix D* provides an example of information developed by a team in Norway for seriously ill parents and carers of children under the age of 18.

I was also able to attend the annual 'Children as next-of-kin' Nordic Network Meeting which took place in Odense in Denmark in September 2022. This enabled me to network with colleagues from the other Nordic countries (Denmark, Finland and Iceland) and learn how they approach the issue. The agenda for this two-day meeting can be found in *Appendix E*.

## Findings

The findings have been arranged into three themes, which will be illustrated with examples from the Fellowship.

### *Theme 1: Being fundamentally child-focused*

It became apparent during the interviews that Norwegian and Swedish healthcare professionals are fundamentally child-focused. Children are perceived as individuals with their own basic human rights, rather than being 'junior' citizens with fewer rights than adults. Knowledge of, and commitment to, the UNCRC was evident across organisations and across different professional backgrounds. Children are also seen as having rights independently of their parents. There is a recognition that identifying and providing appropriate support to vulnerable children will help to ensure their wellbeing in adulthood. Examples of this child-focused perspective are:

- One palliative care doctor was surprised that this issue required a Fellowship. He took for granted that the needs of children would be addressed when a parent is referred to his service and assumed that all other countries had a similar approach.
- An oncology social worker stated that addressing the needs of dependent children was not questioned by anyone in her team and she remarked: *'Everyone realises that we have an obligation towards the children.'*
- Sweden has recently updated its national guidelines for palliative care.<sup>20</sup> The guidelines contain five recommendations for the initial palliative care assessment. One of the five recommendations highlights the importance ascribed to identifying the needs of children: *'map the patient's relationships with special regard to minor children as relatives'*.
- A Norwegian academic remarked that it is essential to ask every patient (regardless of their age) about dependent children on admission to hospital. This ensures that the needs of no children are overlooked.
- A Swedish oncologist stated that: *'Disease affects the whole family.'* She therefore offers to speak with the dependent children of all of her patients and encourages children to attend all hospital appointments, including any treatment.

The focus in Norway and Sweden appears to be weighted towards the wellbeing of all children rather than simply the protection of children. The child protection team in Gothenburg had a focus on identifying issues early and supporting the family, rather than simply becoming involved when the child is at risk. At the Nordic Network meeting I attended, the team from Denmark outlined their 'early intervention focus', which aims to detect potentially vulnerable children well before they are at risk. It also appears that school nurses across Norway and Sweden have a large remit for ensuring the welfare of children and most schools have their own social worker to support children in need. Prioritising the needs of children and ensuring that potentially vulnerable children are identified and supported appears to be intrinsic to the work of health and social care professionals across the Nordic countries.

## *Theme 2: The impact of the 2010 legislation*

Although they already consider themselves to be child-focused, many interviewees stated that the 2010 legislation provides a framework and justification for the consideration of children's needs. Examples of the impact of the legislation are as follows:

- Every hospital now has two new roles: a 'Children's Ombudsman' and 'children responsible personnel'. The Children's Ombudsman is the designated lead person for children as next-of-kin, ensuring that these children are identified and supported across the hospital. This role also has to regularly report on the hospital's progress with regards to this issue. One professional in every clinic and ward is assigned the duty of 'children responsible personnel', with allocated time each week to focus on ensuring the needs of children as next-of-kin are met. Children responsible personnel receive support, advice and training from the Children's Ombudsman.
- The responsibility of every ward and clinic to identify and support children as next-of-kin is well established and accepted. A psychologist working in oncology stated that: *'Every unit needs to have a child perspective.'*
- There appears to be a widespread awareness of the rights of children as next-of-kin, including members of the public. The Children's Ombudsman in Gothenburg related an example of a complaint they had received. The surviving partner of a deceased patient complained to the hospital, as they felt that their 10-year-old child had not been involved or informed as their father was dying, and that the child's rights under the legislation had been contravened.
- The 2010 legislation is actually referred to in clinical practice. When shadowing a social worker, reference was made to the rights of the dependent children and how the practitioner had a duty to consider the needs of the patient's two children (see the case study in *Appendix C*).
- In a Swedish palliative care team, every patient referred to the team with dependent children is automatically contacted by one of the social workers to discuss the children's needs.
- The legislation is also referenced in information for health and social care professionals. *Appendix F* shows a leaflet entitled *Våga Fråga!* (meaning *Dare to Ask!*), which is distributed across a hospital in Sweden, encouraging professionals to ask all patients if they are responsible for any dependent children. The leaflet refers to the 2010 legislation on the second page, subtly reminding professionals that they have a legislative duty to do this.

It would appear that the 2010 legislation has provided the legal responsibility and justification for embedding children as next-of-kin within clinical practice.



### *Theme 3: Obstacles and challenges*

Although everyone who was interviewed was in agreement that the 2010 legislation had made positive changes, some obstacles and challenges were described:

- Patient confidentiality can be a barrier and takes precedence over the legislation around children as next-of-kin: a patient must always consent to their children knowing about their illness. Despite encouragement from professionals, some parents will never agree for their child to be involved. The palliative care team at Akershus University Hospital outside Oslo gave the example of a patient who had sent his 12-year-old daughter to live with relatives in another town when he was diagnosed with cancer. Due to his beliefs around children, the patient refused for his daughter to even know that he was unwell. Despite a gentle and sensitive intervention from the team, the patient would not allow for his daughter to be informed or involved in any way.
- Some interviewees described units and professionals that have a 'tick-box' mentality towards the legislation. Whilst acknowledging their duty towards children as next-of-kin, certain professionals and teams were seen as providing limited support to families with dependent children. This was attributed to the wording of the 2010 legislation being vague and open to interpretation.
- Addressing the issue in hospitals can be easier than in the community, as the 2010 legislation only puts the duty on healthcare professionals in hospitals. The role of 'children responsible personnel' only exist in hospitals and was described by an academic in Norway as a '*poorly described role*'. A Children's Ombudsman questioned how much could realistically be achieved to support dependent children, given that most hospital in-patient admissions are now very short.
- There was no consistency about where to document details of dependent children on a patient's notes. Some Norwegian hospitals have a section on every patient's record to document about their children. Due to patient confidentiality and access to personal medical records, in Sweden it is not permitted to document any details about children on a patient's notes.

Despite the child-focus and legislation around children as next-of-kin, there still appear to be challenges around ensuring that this vulnerable cohort is provided with support.

## Recommendations

The UK does not currently have any plans to introduce legislation around children as next-of-kin and is unlikely to do so in the near future. However, the UK does have legislation around young carers (within the *Care Act 2014*<sup>21</sup> and the *Children and Families Act 2014*<sup>22</sup>). Young carers are defined as someone under the age of 18 who helps to look after a relative with a disability, illness, mental health condition, or drug or alcohol problem. Young carers have the right to an assessment from their local authority, which must take into account the impact of the caregiving duties on their wellbeing and development. If the care being provided by a child is assessed as 'excessive or inappropriate', the local authority has a duty to intervene.

There is considerable overlap between the Nordic concept of children as next-of-kin and UK legislation around young carers: they both recognise the vulnerability of children living with a parent with a serious health condition and the listed conditions are the same across both UK and Nordic legislation. Therefore the recommendations from this Churchill Fellowship will use the UK's existing legislation around young carers as a foundation. The recommendations will be organised into four different levels and discussed individually: team level; organisational level; local level; and the national level.

My intention is to work through the recommendations, starting at the team level, and then using the learning from this level to move up to the next level. However, the levels are interconnected and there will be flexibility and hopefully opportunities to implement some recommendations at all levels concurrently.

### *Team level*

My plan is to provide an education session to my colleagues in the palliative care team about how the Nordic countries approach the issue of children of parents with a life-limiting illness. This session will include clarification of the UK's legislation around young carers. My intention is to support a change in how children are conceptualised by the team.

Recommendations following this education would be to encourage the team to:

- identify any children (under the age of 18) who are impacted by the life-limiting illness of a patient.
- document as much information as possible about the children, ideally full name, date of birth and school attended.
- inform patients that their dependent children would be considered to be young carers and would therefore be entitled to support.
- develop information about children as young carers that can be given to all families that have young children.
- provide information for patients about the right to a young carer's assessment, how to access an assessment from their local authority and what support is available to young carers in their local area.

- consider the impact of culture and faith on how children may or may not be perceived as young carers.
- share as much information as possible about the children with other healthcare professionals when discharging a patient.

### *Organisational level*

My plan is to encourage and support other teams within King's College Hospital to incorporate the recommendations from the team level. My intention is to begin by approaching the haematology, renal and liver teams, who have a high proportion of younger patients with children under the age of 18.

Recommendations would be to:

- develop a network of Children's Champions within the hospital. Following the model of 'children responsible personnel', to encourage each unit or ward in the hospital to identify a member of staff who is interested in this issue and would like to develop support for patients' children.
- nurture a core of senior staff within the hospital who consider this issue to be a priority and will ensure the issue has backing at a senior level.
- deliver education on children's rights and the approach to children as next-of-kin taken by Nordic countries.
- provide regular updates and support to the Children's Champions, such as a regular newsletter on the topic.
- develop educational resources for all members of staff, for example developing and trialling an e-learning resource.
- work with IT to consider documentation and ensure GDPR compliance.
- develop resources similar to *Våga Fråga!* (Appendix F) that can be distributed around the hospital.

### *Local level*

Being based in a palliative care team in central London, I have a network of local colleagues with whom we work closely. My intention is to approach these colleagues and ask them to consider ways in which we can collaborate and incorporate the findings from this Fellowship. I will also offer to provide education and training around children as next-of-kin, children's rights and how we can learn from the Norwegian and Swedish approaches. I plan to approach the following:

- our local hospices, which are St Christopher's Hospice and Royal Trinity Hospice. This will also be an opportunity to assess whether the recommendations work outside the acute sector or need to be adapted to different settings.
- Lambeth and Southwark Young Carers Groups, the two local groups to King's College Hospital. Having expertise from young carers groups will help to promote the needs of young carers with a parent with a life-

limiting illness and overcome some of the challenges with identifying young carers.

Young Carers Action Day is on 15 March 2023. I plan to work with our local young carers' groups, to organise an event in King's College Hospital to raise awareness of the needs of our patients' dependent children and how they are entitled to support from young carers' groups.

### *National level*

My intention is to frame the national recommendations as a children's rights issue, whereby children living with parental life-limiting illness in the UK are not being identified as young carers and are therefore being denied support. My recent Marie Curie-funded research will provide a foundation for these national recommendations, as of the 32 children who were interviewed for this study about their experience of living with parental life-limiting illness, only four had been identified as a young carer.<sup>14</sup> My plans are as follows:

- Using the network developed by the Cicely Saunders Institute, I intend to approach and inform people of influence, including policymakers and politicians.
- I plan to publish these findings in an academic journal.
- I will network with colleagues from the Association of Palliative Care Social Workers. (I have been asked to give an education session on my Fellowship to this forum in February 2023.)
- I intend to submit the findings for presentations at national and international conferences. (I have already been able to give a presentation at an international forum on 14 October 2022, please see *Appendix G*.)
- Working with colleagues from other organisations, I plan to develop a national network of children's champions. I have already approached the Childhood Bereavement Network and Hope Support to begin planning this network.
- I intend to approach organisations working with young carers and discuss the overlap in our work.
- I plan to liaise with organisations working with children's rights such as UNICEF.
- I will approach colleagues from the fields of psychiatry and substance abuse, to enquire if these fields are making any advancements with regards to children as next-of-kin.
- I intend to approach academic experts in the field of young carers and in the field of children's rights.
- I plan to advocate for the perspective of children to be incorporated into all areas of palliative care, including the research agenda.
- I intend to collaborate with colleagues from the Cicely Saunders Institute at King's College London and discuss how the organisation can become recognised as a children's rights respecting organisation, along the lines of UNICEF's rights respecting schools and child-friendly communities.<sup>23, 24</sup>

## Conclusion

Norway and Sweden have a progressive approach towards supporting children and young people whose parent has a life-limiting illness. This approach was formalised by legislation in 2010, giving rights to children as 'next-of-kin'. Health and social care professionals in both countries have incorporated the legislation into their practice, and their approach can be similarly incorporated into clinical practice in the UK. The UK's legislation around young carers has an overlap with the Norwegian and Swedish 2010 legislation. By educating health and social care professionals about this Nordic approach and supporting them to adapt their practice, young carer legislation can be employed as a foundation to instigate change. This report outlines recommendations at a team, organisational, local and national level that can easily be implemented. It is my intention to work on these recommendations and try to influence change at all levels. The model of children as 'next-of-kin', as practised across Norway and Sweden, is the goal to be worked towards. Children and young people living with parental life-limiting illness in the UK are a vulnerable group who are often hidden and do not have a voice. Their rights under the UNCRC are not being recognised and they are at increased of long-term negative outcomes in adulthood. The aim of this Churchill Fellowship is therefore to increase the visibility of this cohort, raise awareness in UK health and social care professionals of their needs and improve the support provided to them.

Appendices

*Appendix A*

Map of Norway and Sweden with places visited during the Fellowship



## Timeline listing meetings and the professionals met during the Fellowship

<b>Kristiansand, Norway</b>	
30 August 2022	<p><i>Introduction to The Multicenter Study and BarnsBeste Research Network</i> Dr Bente Birkeland, Associate Professor, University of Agder <a href="https://www.uia.no/en/kk/profile/benteh15">https://www.uia.no/en/kk/profile/benteh15</a></p>
	<p><i>Introduction to BarnsBeste Coordinator network</i> Eivind Thorsen, Barnsbeste <a href="https://sshf.no/helsefaglig/kompetansetjenester/barnsbeste">https://sshf.no/helsefaglig/kompetansetjenester/barnsbeste</a></p>
	<p><i>Children Under the Radar Project</i> Vibecke U. Vallesverd and Linn Berge, Barnsbeste <a href="https://sshf.no/helsefaglig/kompetansetjenester/barnsbeste">https://sshf.no/helsefaglig/kompetansetjenester/barnsbeste</a></p>
31 August 2022	<p><i>Introduction to Co-ordinator for Children as Next-of-Kin role in the specialist health service</i> Siren Wettrhus Knutsen, Sørlandet Sykehus <a href="https://sshf.no/">https://sshf.no/</a></p>
	<p><i>Introduction to BarnsBeste municipality network</i> Mary-Ann Esperaas, Barnsbeste <a href="https://sshf.no/helsefaglig/kompetansetjenester/barnsbeste">https://sshf.no/helsefaglig/kompetansetjenester/barnsbeste</a></p>
	<p><i>Tour of Andreas Hus, Children's Hospice</i> Natasha Pedersen, General Secretary, Foreningen for barnepalliasjon <a href="https://www.andreashus.no/">https://www.andreashus.no/</a></p>
1 September 2022	<p><i>Meeting about the Treffpunkt programme (children aged 6-16 with a parent with cancer)</i> Kreftforeningen Kristiansand <a href="https://kreftforeningen.no/">https://kreftforeningen.no/</a></p>
	<p><i>Children's Nurse and Relative Contact at the Association for Children's Palliation</i> Nina Vigre, Barnesykepleier og Pårørendecontact i Foreningen for barnepalliasjon <a href="https://barnepalliasjon.no/">https://barnepalliasjon.no/</a></p>
	<p><i>Support for siblings as next-of-kin</i> Bella and Natasha Pedersen, Foreningen for barnepalliasjon <a href="https://barnepalliasjon.no/">https://barnepalliasjon.no/</a></p>

<b>Oslo, Norway</b>	
5 September 2022	<p><i>How a palliative care team manages the issue of children as next-of-kin</i> Mona Irene Skaug, CNS, Palliative Care Team, Akershus universitetssykehus <a href="https://www.ahus.no/">https://www.ahus.no/</a></p>
	<p><i>Support for Norwegian children who have been bereaved</i> Anett Sanne, Specialist Nurse Akershus universitetssykehus HF, Sorgbehandling Poliklinikk <a href="https://www.ahus.no/avdelinger/medisinsk-divisjon/sorgstotte">https://www.ahus.no/avdelinger/medisinsk-divisjon/sorgstotte</a></p>
	<p><i>Young carers in Norway</i> Ellen Katrine Kallander, Researcher, Children and Family Agency, Oslo Municipality <a href="https://www.oslo.kommune.no/english/welcome-to-oslo/children-and-families/#gref">https://www.oslo.kommune.no/english/welcome-to-oslo/children-and-families/#gref</a></p>
6 September 2022	<p><i>How a palliative care unit manages the issue of children as next-of-kin</i> Britt Carlsen, Physiotherapist and Lisa Schibert, CNS Lovisenberg Lindring og Livshjelp <a href="https://lovisenbergpsykehus.no/avdelinger/medisinsk-klinikk/lovisenberg-lindring-og-livshjelp">https://lovisenbergpsykehus.no/avdelinger/medisinsk-klinikk/lovisenberg-lindring-og-livshjelp</a></p>
7 September 2022	<p><i>Children whose parent has cancer and the use of the Fuelbox tool (remote meeting)</i> May Aasebø Hauken, Professor, Senter for krisepsykologi/Center for Crisis Psychology, University of Bergen <a href="http://www.uib.no/sfk">www.uib.no/sfk</a></p>
	<p><i>Support for siblings and the Child Talks+ intervention</i> Yngvild B. Haukeland, Psychologist/PhD, Voksne for Barn <a href="http://www.vfb.no">www.vfb.no</a></p>



<b>Gothenburg, Sweden</b>	
12 September 2022	Meeting with the Palliative Care Social Work Team Högsbo Sjukhus <a href="https://www.sahlgrenska.se/for-dig-som-ar/patient/kartor-over-vara-sjukhus/karta-hogsbo-sjukhus/">https://www.sahlgrenska.se/for-dig-som-ar/patient/kartor-over-vara-sjukhus/karta-hogsbo-sjukhus/</a>
	Meeting with the Children's Ombudsman Sahlgrenska Universitetssjukhuset <a href="https://www.sahlgrenska.se/">https://www.sahlgrenska.se/</a>
13 September 2022	Tour of Kålltorps Hospice <a href="https://goteborg.se/wps/portal/enhetssida/kalltorps-hospice">https://goteborg.se/wps/portal/enhetssida/kalltorps-hospice</a>
	<i>How children as next-of-kin are documented in medical notes</i> Linda Sandin, Kurator/socionom, Sahlgrenska Universitetssjukhuset, Palliativa sektionen <a href="https://www.sahlgrenska.se/for-dig-som-ar/patient/kartor-over-vara-sjukhus/karta-hogsbo-sjukhus/">https://www.sahlgrenska.se/for-dig-som-ar/patient/kartor-over-vara-sjukhus/karta-hogsbo-sjukhus/</a>
	Meeting with the Child Protection Team <a href="https://www.vgregion.se/halsa-och-var/dvardgivarwebben/amnesomraden/barnskyddsteam/">https://www.vgregion.se/halsa-och-var/dvardgivarwebben/amnesomraden/barnskyddsteam/</a>
14 September 2022	<i>Home visit with a social worker from Högsbo Sjukhus</i> Emelie Fasth, Kurator/socionom, Sahlgrenska Universitetssjukhuset, Palliativa sektionen <a href="https://www.sahlgrenska.se/for-dig-som-ar/patient/kartor-over-vara-sjukhus/karta-hogsbo-sjukhus/">https://www.sahlgrenska.se/for-dig-som-ar/patient/kartor-over-vara-sjukhus/karta-hogsbo-sjukhus/</a>
	<i>Resources that have been developed to support parents, families and children known to the palliative care team</i> Linda Sandin, Kurator/socionom, Sahlgrenska Universitetssjukhuset, Palliativa sektionen <a href="https://www.sahlgrenska.se/for-dig-som-ar/patient/kartor-over-vara-sjukhus/karta-hogsbo-sjukhus/">https://www.sahlgrenska.se/for-dig-som-ar/patient/kartor-over-vara-sjukhus/karta-hogsbo-sjukhus/</a>
<b>Östersund, Sweden</b>	
15 September 2022	Meeting with the Palliative Care Team Östersund Hospital <a href="https://www.regionjh.se/omoss/ostersundssjukhus">https://www.regionjh.se/omoss/ostersundssjukhus</a>
	<i>Home visit with a social worker from Östersund Hospital</i> Tommy Berglund, Kurator/socionom, Palliativa sektionen, Östersunds sjukhus - Region Jämtland Härjedalen <a href="https://www.regionjh.se/omoss/ostersundssjukhus">https://www.regionjh.se/omoss/ostersundssjukhus</a>

15 September 2022	Tour of Östersund Hospital <a href="https://www.regionjh.se/omoss/ostersundssjukhus">https://www.regionjh.se/omoss/ostersundssjukhus</a>
16 September 2022	Attendance at the Palliative Care Team MDT Östersund Hospital <a href="https://www.regionjh.se/omoss/ostersundssjukhus">https://www.regionjh.se/omoss/ostersundssjukhus</a>
	Meeting with Dr Oskar Knutsson Palliative Care Team, Östersund Hospital <a href="https://www.regionjh.se/omoss/ostersundssjukhus">https://www.regionjh.se/omoss/ostersundssjukhus</a>
	Meeting with Helena Sjostrom, CNS Palliative Care Team, Östersund Hospital <a href="https://www.regionjh.se/omoss/ostersundssjukhus">https://www.regionjh.se/omoss/ostersundssjukhus</a>
<b>Umeå, Sweden</b>	
20 September 2022	Introduction to the team at Palliativ Medicin Umeå Norrlands Universitetssjukhus <a href="https://www.1177.se/hitta-var/d/kontaktkort/Palliativ-medicin-Umea/">https://www.1177.se/hitta-var/d/kontaktkort/Palliativ-medicin-Umea/</a>
	Meeting with palliative care doctors in Umeå and Skellefteå Norrlands Universitetssjukhus <a href="https://www.1177.se/hitta-var/d/kontaktkort/Palliativ-medicin-Umea/">https://www.1177.se/hitta-var/d/kontaktkort/Palliativ-medicin-Umea/</a>
	<i>Using the Family Talk Intervention with families referred to palliative care</i> Johanna Backström, CNS, Palliativ Medicin Umeå Norrlands Universitetssjukhus <a href="https://www.1177.se/hitta-var/d/kontaktkort/Palliativ-medicin-Umea/">https://www.1177.se/hitta-var/d/kontaktkort/Palliativ-medicin-Umea/</a>
	<i>Working with bereaved children</i> Rune Åberg, Kurator/Socionom, Palliativ Medicin Umeå Norrlands Universitetssjukhus <a href="https://www.1177.se/hitta-var/d/kontaktkort/Palliativ-medicin-Umea/">https://www.1177.se/hitta-var/d/kontaktkort/Palliativ-medicin-Umea/</a>
21 September 2022	Meeting with Mirjam Bergknut, Kurator och Leg. Psykoterapeut med inriktning KBT, Cancercentrum, Norrlands universitetssjukhus <a href="https://regionvasterbotten.se/organisation-och-verksamheter/sjukhusvard/a-d/cancercentrum-umea">https://regionvasterbotten.se/organisation-och-verksamheter/sjukhusvard/a-d/cancercentrum-umea</a>

	Meeting with Sara Lilliehorn, Lecturer, Dept of Social Work, Umeå University <a href="https://www.umu.se/personal/sara-lilliehorn/">https://www.umu.se/personal/sara-lilliehorn/</a>
	Meeting with Anne Andersson, Senior Oncologist, Norrland University Hospital, Umeå University <a href="https://www.umu.se/personal/anne-andersson/">https://www.umu.se/personal/anne-andersson/</a>
<b>Stockholm, Sweden</b>	
23 September 2022	<i>The Family Talk Intervention in clinical practice</i> Malin Lövgren and Tina Lundberg, Researchers at Marie Cederschiöld University <a href="https://www.mchs.se/">https://www.mchs.se/</a>
	Tour of Lilla Erstagården Children's Hospice <a href="https://www.erstadiakoni.se/verksamheter/sjukvard/hospice/hospice-pa-ersta-sjukhus/lilla-erstagarden/">https://www.erstadiakoni.se/verksamheter/sjukvard/hospice/hospice-pa-ersta-sjukhus/lilla-erstagarden/</a>
	<i>Meeting the needs of children when a parent is diagnosed with cancer</i> Tina Sundholm, Psychologist and Psychotherapist, Psycho-Oncology Department, Karolinska University Hospital <a href="https://www.karolinska.se/om-oss/hitta-till-karolinska/karolinska-solna/">https://www.karolinska.se/om-oss/hitta-till-karolinska/karolinska-solna/</a>
	Tour of the Karolinska Institute <a href="https://ki.se/">https://ki.se/</a>
27 September 2022	Meeting with Professor Ulrika Kreicbergs, Professor in Palliative Care for Children and Youth at Marie Cederschiöld University <a href="https://www.mchs.se/arkiv/listning-anstallda/anstallda/ulrika-kreicbergs.html">https://www.mchs.se/arkiv/listning-anstallda/anstallda/ulrika-kreicbergs.html</a>
	Meeting with Tove Bylund Grenklo, Senior Lecturer, Dept. of Nursing Science, Gavle University <a href="https://www.hig.se/Ext/Sv/Organisation/Akademier/Akademin-for-halsa-och-arbetsliv/Forskning-vid-akademin/Forskarpresentationer/Medicin-och-vardevetenskap/Tove-Bylund-Grenklo.html">https://www.hig.se/Ext/Sv/Organisation/Akademier/Akademin-for-halsa-och-arbetsliv/Forskning-vid-akademin/Forskarpresentationer/Medicin-och-vardevetenskap/Tove-Bylund-Grenklo.html</a>
<b>Odense, Denmark</b>	
29–30 September 2022	<i>Children as next-of-kin</i> Nordic Network Meeting 2022 (Agenda in <i>Appendix E</i> )

Social work assessment from a home visit in Gothenburg

*Medical:* 43-year-old male, diagnosed with metastatic neuroendocrine and rectal cancer <3 months ago, previously fit and well. Recent acute admission to hospital with liver failure, now at home with support from district nurses around pain management. Reports has lost 25kg in the last six months. Mobile and self-caring, some support with activities of daily living from wife and mother. To commence palliative chemotherapy in the next week.

*Psychological:* Fully informed about disease and limited prognosis, wants to remain optimistic. No report of any psychological concerns.

*Social:* Croatian origin, came to Sweden in 2019 to work in construction. Wife and two children came to live in Sweden in 2020, son aged 10 and daughter aged 3. Son attends school, daughter at nursery. Son is aware that his father has a serious illness but not the limited prognosis. Parents keen to protect and shield children from the illness. No family in Sweden, patient's mother currently visiting from Croatia since diagnosis and is helping with childcare. Limited Swedish, can communicate in English, but would prefer Croatian interpreter for more complex discussions.

*Practical:* Live in 3-bedroom privately rented accommodation on the 8<sup>th</sup> floor of a block with lift access. Property is level access with a walk-in shower. Currently on sick leave, no benefits. Wife has recently started her own cleaning business. No financial concerns at present. Patient reports that he finds it difficult to sleep on current mattress, would like support with a mattress raiser.

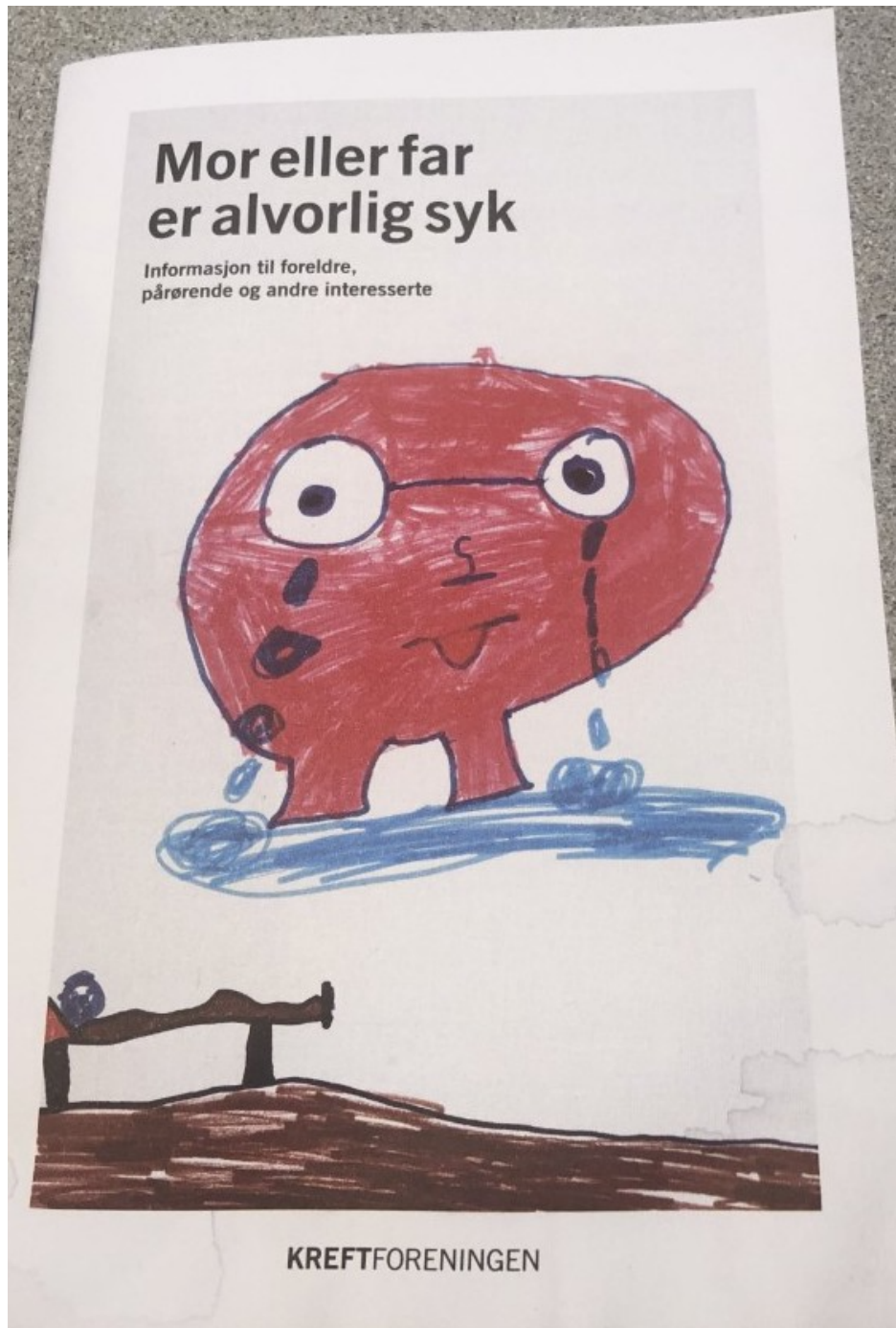
*Spiritual:* Roman Catholic faith but not practising.

*Social work plan:*

- Relationship building with the family.
- Financial advice and support when requested.
- Support accessing mattress raiser.
- Ongoing discussions around the needs of the children.

Information leaflet developed by a team in Norway for seriously ill parents and carers of children under the age of 18

[The title translates as *Mother or father are seriously ill: Information for parents, carers and other interested parties*]



## Agenda from 'Children as next-of-kin' Nordic Network Meeting



### The National Board of Social Services

Edisonsvej 1  
5000 Odense C  
Tel.: +45 72 42 37 00  
info@socialstyrelsen.dk  
www.socialstyrelsen.dk

Case no.:  
2022 - 4016

Date:  
September 2022

### Meeting in the Nordic Network 2022

*The 29th-30th of September 2022 in Odense, Denmark*

#### **Agenda day 1** (10.45-16.30 local time)

- 10.45-11.00. **Meeting point:** The reception (where you will get a guest-card). Address: *Socialstyrelsen, Edisonsvej 1, 5000 Odense C*. Link: [Edisonsvej 1 Google Maps](#). There is about 15 min. walk from the railway station to *Socialstyrelsen* (The National Board of Social Services)
- 11.00-12.00. **Welcome, lunch and presentation** of network members
- 12.00-12.30. **Joint review of the mandate** - Children as next of kin in the Nordic countries. Everyone has read and reflected on the terms of the mandate prior to the network meeting (mandate attached).
- 12.30-12.45. **Break**
- 12.45-13.30. **Since the last meeting part 1** (15 min. per country incl. questions for discussion). Facilitated by Denmark:  
A short presentation from Finland, Iceland, Norway (approx. 10 min. per country) with headlines regarding significant occurrences since the network meeting in 2021 in terms of support for children who are next of kin.  
Each country concludes its presentation with a question for discussion in the network. In addition, there is an opportunity for other countries to ask questions. (Time for questions for discussion is approx. 5 min. per country).
- 13.30-13.45. **Break**
- 13.45-14.15. **Since the last meeting part 2.** Short presentation from Sweden and Denmark (15 min. per country incl. questions for discussion)
- 14.15-14.45. **The experience of children as next-of-kin in the UK.** Dr Stephen Marshall, Senior Lecturer, King's College London, will give a short presentation on the experience of children as next-of-kin in the UK, together with examples from his recent research about children and young people, who are living with a dying parent. In continuation of the presentation, there is an opportunity for the network to ask questions.
- 14.45-15.00. **Break**



- 15.00-16.30. **The EU Strategy on the Rights of the Child and the EU Child Guarantee and Youth Guarantee** (including a break). Facilitated by Sweden:
  - A) Elizabeth Hanson will give an introduction and overview of the strategy.
  - B) Short report by each country explaining where they are up to in implementing these EU policies, especially in relation to children who are next of kin (10 minutes for each country).
  - C) Group discussion.(Elizabeth will gather all the relevant EU literature in English, together with the general links to the national language versions. This material will be sent to participants prior to the meeting).

Late afternoon / evening: opportunity to explore the city of Odense: <https://www.visitodense.com/>

**Agenda day 2** (9.00-14.30 local time)

- 09.00-09.30. **Welcome and short summary of day 1**
- 09.30-12.15. **Involving children as next of kin in policy, research and development and practice.** Facilitated by Denmark:
  - A) 09.30-09.45: Elizabeth Hanson and Lennart Magnusson will give an introduction to and set the context for this topic.
  - B) 9.45-11.15: Examples by each country explaining if and in what ways they are involving children as next of kin in their work - any examples of innovative practices in this area (15 minutes for each country incl. questions). (Including a break).
  - C) 11.30-12.15: Walk n' talk about the examples just given from each country – special trends across countries?
- 12.15-12.45. **Lunch**
- 12.45-14.00. **Examples of projects and research in Denmark** with support for children who are next of kin (incl. time for questions)
- 14.00-14.30. **Thank you** for this year's network meeting. Agreement on the presidency for 2023 and dates for the 2023 network meeting.

Flyer produced by Västra Götalandsregionen  
[The title *Våga Fråga!* translates as *Dare to Ask!*]

VÄSTRA  
GÖTALANDSREGIONEN

# VÅGA FRÅGA!

**UPPMÄRKSAMMA**  
Har patienten barn? Använd barn- och familjeformuläret.

**INFORMERA**  
om varför barnet behöver information, råd och stöd.

**STÖD**  
patienten att själv informera barnet om situationen när så är lämpligt. Var beredd att hjälpa.

**DOKUMENTERA**  
i patientens journal vad som är gjort och vad som återstår.

**KONTAKTA**  
utsedd personal på din arbetsplats om barnet och familjen behöver mer stöd och hjälp.

§ 5kap 7§ hälso- och sjukvårdslagen säger att ett barn vars förälder har en allvarlig sjukdom, skada, psykisk störning eller psykisk funktionsnedsättning, ett missbruk eller beroende eller avlider har rätt till information, råd och stöd utifrån sitt och familjen behov

VGR5888





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## Childhood bereavement: An international symposium on rights and support

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### Agenda

Friday, 14<sup>th</sup> October 2022

09:30 – 10:00      **Registration and coffee**

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10:00 – 10:20      **Opening chair**  
Professor Richard Harding, King's College London, UK

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10:20 – 10:50      **The rights of children when a parent is dying**  
Baroness Ilora Finlay, Professor of Palliative Medicine, and member of the House of Lords, UK  
*There will be opportunity for questions with Baroness Finlay.*

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10:50 – 11:10      **Children as next-of-kin in the Nordic countries**  
Dr Steve Marshall, King's College Hospital and King's College London, UK

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11:10 – 11:30      **Break**

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11:30 – 11:50      **Navigating parental cancer at end of life: parental, healthcare and funeral director perspectives**  
Dr Jeff Hanna, Ulster University, UK

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