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*Modelli di imprenditorialità sociale al servizio della
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The Danish hospice model - By Ole Bang and Susanne Paulsen 2007

The Danish hospice model

By Ole Bang and Susanne Paulsen

This article is based on the paper held by Ole Bang then chairman of the Danish NPO, *Danish Hospice Forum*, at the “Blended Values” conference in Bologna in November 2005. The development within the hospice area over the last two years from the conference took place has been added but a part from that no major changes have been made. The emphasis is on the development of hospices in Denmark – as a significant part of the complete palliative effort – but other palliative areas of effort are left out.

I. The historical development in the hospice area in Denmark 1967-1992

Early debates about the right to a dignified death

From St. Christopher’s Hospice was established in 1967 until the first Danish hospice was built 25 years passed. During this period the hospice idea slowly became the topic of debate.¹ The reason for this was not least the Danish welfare model. Behind the establishment of the Danish welfare state was a fundamental wish that access to all welfare benefits – including health benefits – should be equal for everybody. The intention was to move away from previous charity systems, where people with limited means had to become beggars and subsequently depend on private initiatives. For many years this caused a shying away from initiatives placed outside the established health system – and therefore also the hospice movement.²

¹ As demonstrated by Susanne Paulsen in *Et godt sted at dø. En nuancering af medikaliseringens syn på hospitaliseringen af døden*, Københavns Universitet (2005).

² *Pleje og omsorg for alvorligt syge og døende*, Sundhedsstyrelsen (1985), p. 57-58.

However, the shying away from the hospice idea did not result in avoiding the actual discussion of the treatment offered to dying patients by the health system, altogether. As death was gradually hospitalised during the 20th century, that is increasing numbers of people died in hospital rather than at home, as earlier, hospital staff was increasingly confronted with death, as well. The result was that hospital employees began discussing the conditions for dying patients and in this way put the issue on the agenda.³

Initially two particular issues carried weight in the public debate; those were the discussions about life wills and compassionate leave at the end of the 1970es. The life will contained a declaration that the testator did not wish to be kept alive artificially in case of incurable disease and that the testator wished to die at home, if at all possible.

The debate about the introduction of compassionate leave for relatives to enable them to take care of dying relatives at home took place a couple of years later. The common thread for both was that a hospitalised death was considered problematic and dying at home was seen as the dignified alternative. Even though there was a wish to change conditions for the dying in the hospitals in this country, it was at the same time emphasised that it should be relatively easy to implement these solutions within the existing health system.⁴

The hospice debate

Only in the mid-eighties did the serious debate about establishing independent hospices gain momentum.⁵ Until then the hospice philosophy had been regarded as a source of inspiration only. In the 1970es representatives from various branches of the health sector started going on study trips to the English hospices, and they returned from there with a wealth of different tools, like for example palliative care, which improved the quality of life of the dying significantly, but also the attitude to the patients which was increasingly coloured by openness around the situation of the patient. Therefore the health staff became more and more influenced by the hospice

³ Paulsen, *Et godt sted at dø*, p. 37-40.

⁴ Paulsen, *Et godt sted at dø*, p. 47-8, 52, 54.

⁵ Paulsen, *Et godt sted at dø*, p. 49-50, 57-60.

philosophy, which they saw as a catalogue of ideas which could be picked with great advantage.⁶

Until the mid-eighties it was only a minority who considered it necessary to establish independent hospice institutions, but from then on the picture started to change. More doctors and nurses joined the band of supporters of the establishment of an experimental hospice which became a reality in 1992. When it took 25 years for the first hospice to be established in Denmark, it was partly because the Danish model was not geared towards initiatives at the interface between the public and the private sphere. So it was not because there was an intention to ignore the discussion concerning a dignified death that the hospice debate was slow at gaining momentum, but because there was a historically based reserve regarding initiatives, which were outside the established health system.

2. Landmarks in the Danish hospice history

In 1992 the first hospice in Denmark, Sankt Lucas Hospice, Copenhagen, opened. It was based on the English model and was a 12 beds in-patient unit. Three years later, in 1995, two more hospices opened bringing the total number of beds up to 34 palliative beds. The first home unit was established by the Sankt Lukas Hospice in 1997. In 1999 the fourth hospice opened (12 beds in-patient unit). In the same year the Danish governmental institution, Sundhedsstyrelsen (The National Board of Health), published “Professional guidance for Palliative Care”⁷ and described among other things which professional standards should be adhered to within hospices and the palliative care in Denmark. Attention was called to a likely need for around 250 palliative beds. This was important as it was the first time the authorities recognized the vast need for palliative care. The following year the “free choice of hospice” was introduced by law from the 1st of July.⁸ To begin with this only included the first three hospices.

⁶ Paulsen, *Et godt sted at dø*, p. 50-1, 60-1.

⁷ *Faglige retningslinier for den palliative indsats. Omsorg for den alvorligt syge og døende*, Sundhedsstyrelsen (1999).

⁸ *Forslag til lov om ændring af lov om sygehusvæsenet. (Hospicer og frit sygehusvalg)*, L 234, (1999-2000), http://www.ft.dk/Samling/19991/lovforslag_fremsaettelse/L234.htm

An expert report from 2001 compiled by the Ministry of the Interior and Health, the union of county councils, Danish Regions, and the national municipal union, Local Government Denmark, called attention to a need for 257 palliative beds in Denmark.⁹ At this moment there were only 63 beds dispersed on five hospices.

Hospice Forum Danmark

During the first decade politicians had been showing little or no political will to support establishing financial structures and legislation within the hospice area. Many hospice groups had worked voluntarily for years, with no obvious results. A popular protest emerged and informal contacts were established among the projects (altogether eight) which had been met with strong political resistance, at this time.

All the mentioned eight groups had become aware that a common mouthpiece had to be created in relation to the Government and the Parliament, if there was to be any realistic hope of establishing more hospices. At that moment just over half of the Danish Parliament was against the idea of establishing hospices outside the established hospital environment – or simply against.¹⁰ Subsequently Hospice Forum Danmark was established in September 15th 2001 as an umbrella organisation for Danish hospice projects providing opportunity for the established hospices to join as members and at the present the association includes around 25 projects or hospice support groups including 14 established hospices and others.¹¹

Hospice Forum Danmark (NPO) attends to the common interests of its members and works as a professional support organisation for the many groups for hospice improvement in the whole country, where there is a significant interest for the hospice idea.

The association aims to support the palliative effort in relation to the political system and the public countrywide, including assisting in:

- * Developing and securing quality
- * Education, publicising, research and
- * Continual development of the hospice culture

⁹ *Hjælp til at leve til man dør. Rapport fra arbejdsgruppe om palliativ indsats i amter og kommuner*, Amtsrådsforeningen, Sundhedsministeriet and Kommunernes Landsforening (2001).

¹⁰ [http://www.ft.dk/Samling/20001/salen/B58_BEH1_42_9_\(NB\).htm](http://www.ft.dk/Samling/20001/salen/B58_BEH1_42_9_(NB).htm)

¹¹ For an up to date list, see <http://www.hospiceforum.dk/page395.aspx>

The association gathers and publicises knowledge and experience concerning palliative effort and hospice offers.

The purpose of Hospice Forum Danmark is working with the specific purpose of promoting the hospice philosophy and of improving conditions in Denmark for the terminally ill and dying people and their relatives by influencing decisionmakers. The efforts of volunteers are invaluable in the work of the association. The primary goal of the association is to assist in the establishing of at least one hospice in each county in Denmark with reference to the possibility of these becoming non-profit institutions.

Achievements – the need for a strong organisation

In 2002 Hospice Forum Danmark succeeded in influencing the government and its supporting parties so that earmarked resources on the state budget were set aside for the actual establishing of more hospices and more palliative beds from 2003. For 2003 modest 20 million kroner were set aside (3 million Euro), in 2004 the amount was 30 million kroner (4.5 million Euro). For 2005 60 million kroner were set aside (9 million Euro). For the following years it was decided to set aside further 40 million kroner (6 million Euro) per year, starting from 2006.

A considerable part of the honour for this public financial injection towards the improvement of the conditions for the terminally ill and dying in Denmark can be attributed to Hospice Forum Danmark. Altogether 150 million kroner (22.5 million Euro) during the six years since the association was established in 2001.

In the autumn of 2004 the Hospice Forum Danmark took the initiative to meet with the spokespersons of each of the political parties in Parliament which led to the passing of an epoch-making law with the support of all members in Parliament in December 2004, imposing on each of the then 14 counties in the country to establish a minimum of 12 palliative beds in co-operation with the “non-profit” working, private, independent institutions.¹²

After 4 years intensive work the primary goal of Hospice Forum Danmark had been reached to a high degree. However, we continue working towards increasing the number of hospices. In 2007 65 more beds will be added meaning that the number of beds will reach 190. In this way the number of beds has tripled since the establishing

¹² *Forslag til lov om ændring af lov om sygehusvæsenet. (Driftsoverenskomster med hospicer og frister for tilbud om alkoholbehandling)*, L 111, (2004-2005), <http://www.folketinget.dk/doc.aspx?/Samling/20041/lovforslag/L111/index.htm>

of Hospice Forum Danmark in 2001. However, the uncovered need for a hospice bed is still big. Presumably 40 % of all applications are being turned down.

So far the focus has been on terminally ill cancer patients. Different organisations and experts have recognised the need for hospice beds for other groups as well and has put a lot of pressure on decisionmakers in order to establish a new hospice for terminal patients with lung- and heart diseases. Plans for such a specialised hospice combined with a rehabilitation center for patients with chronic diseases, *Hospice Mariager Fjord og Center for Lindrende Indsats*, have now been approved and the new rehabilitation- and hospicecenter is planned to open in 2009/2010.¹³

Nearly all the work in the association Hospice Forum Danmark is voluntary and unpaid – however, it may not be realistic to maintain this, because the activities and the tasks are growing significantly, as described.

The good hospice in Denmark

As more hospices were being built the need for developing and securing quality in the Danish hospices grew. The Realdania Foundation in Denmark therefore offered the hospice movement and the palliative associations a project, which aimed at strengthening the pool of knowledge regarding the establishing of new hospice buildings in Denmark.¹⁴ The idea was the development of “The good hospice in Denmark” project with the central questions being: How does the good hospice look, and how can optimal and dignified frameworks for the dying be created?

The goal of the project was to work out a programme for establishing the optimal hospice with the physical structures as a focus. Among other things the programme aimed at putting forward concrete suggestions for the distribution, sizes and types of rooms. The hospice programme would also include ideas about how to create spaces which further growth and well-being; suggestions about the kind of

¹³ For more information on the project:

<http://www.hospicemariagerfjord.dk/123/?m=1&cid=49&nid=68> (in Danish)

¹⁴ Fonden Realdania, *Årsberetning 2005*, p. 19,

<http://www.realdania.dk/Presse/Pressemeddelelser+2007/Arkiv/Pressemeddelelser+2005/Pressreleases/Hospice+30-06-05.aspx?q=hospice>

<http://www.hospiceforum.dk/Default.aspx?id=5&newsid5=239> (in Danish and English)

atmosphere to be found in particular rooms, whether these were private rooms for patients, rooms for reflection, social interaction, lectures, grieving groups, party – or music arrangements or rooms for visitors and relatives.

In this way the programme showed how for example light, colours and design in the individual room can heighten the quality of life during this last chapter in life and through peace and harmony create a space, in which patients and relatives can feel at home during a difficult time.

The actual compilation of the programme was based on thorough research and analyses of the conditions and situations partly from existing hospices in Denmark, partly from “ideal models” of hospices in other countries. A steering group for the project was formed as well as a reference group, which provided ongoing sparring, involvement and publicising of knowledge about the project.

The compilation of the programme for the good hospice was completed by the end of February 2006.¹⁵

3. The Danish model as a role model?

The Danish hospice model distinguishes itself from that of most other countries because it is purely financed out of public funds. This is due to the strong tradition of the welfare state. This financial model is more or less vital for the hospice development and the hospice culture in Denmark, as a lot of money is needed and money is extremely hard to access via fundraising because there is no tradition for this, as there is for instance in England.

This financial model has assured that the hospices maintain their autonomy in a considerable way and at the same time – due to the voluntary element – the public support. The professional element will now, with the physical framework in place, take over the running of the hospices, so that Hospice Forum Danmark can continue to develop and secure high standards in the offers to the patients and their relatives. This balance between total public funding and voluntary assistance characterises the Danish hospice model.

¹⁵ Ole Bang (among others), 2006: *Programme for the Good Hospice in Denmark. An outline for the hospice as a part of palliative care*, Realdania (translated into English 2007 with support from Lions Club, Soeborg, Denmark, (Member of The International Association of Lions Clubs)).

http://www.hospiceforum.dk/media/DetGodeHospice_engelsk.pdf

Apart from the establishing resources it has also become legally possible to acquire resources to secure the running of the many new beds, as it rests on the counties and the municipalities to pay the entire operation in future. The free choice of hospice in Denmark is getting close to a real choice, whereas it was more illusory than real when it was introduced in 2000. The public has been heard – the common mouthpiece has worked, in the form of an association. The voluntary effort has been worth its weight in gold. This has provided the needed respect, when the political decisions were taken.

The next big challenge is to make the hospice an even more integrated institution in the established health system and to define what kind of role the hospice should play in the palliative effort. Together with other organisations, Hospice Forum Danmark is therefore working towards the establishment of a national palliative council.

Hospice Forum Danmark has proved to be a success. The success is probably also due to the fact that Denmark is a small country with only 5.5 million inhabitants but nevertheless the “common mouthpiece” strategy together with a strong and concrete focus on the goal has shown its strength. Therefore, the role of Hospice Forum Danmark as an umbrella organisation could become an example for the hospice development in other countries.

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Susanne Paulsen is an historian, cand.mag. from the University of Copenhagen as well as a M.A. in social history from the University of Lancaster and has written about the development of the Danish hospice movement. She is a freelance editor and writer.