# How a hospital room is able to palliate dying

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Hospitals should embrace death. Ria Martens' message in a nutshell. She is conducting doctoral research at Hanze University of Applied Sciences in Groningen where she investigates comfortable spaces and services in palliative care for the terminally ill. "My concern is: what can we do when death becomes inevitable?"

VUmc Cancer Center, Amsterdam, D/DOCK

What makes a hospital room a comfortable place to pass away? This is the key concern that drives Ria Martens' research efforts. A weighty subject matter. Twenty years ago, she had never thought this would ever be an area that would occupy her mind. "Back in the day, I studied tourism", she tells us. "But travelling became laborious and a bit of a nuisance. There came a point when I found myself at a different stage with my family. Which was when I switched to the world of education. Now I'm a university college lecturer in hospitality management. Which is all about hospitality in the service industry."
Personal circumstances eventually led her to palliative care, i.e. nursing seriously ill people for whom death has become inescapble. "The first seed was planted in 2008, when eight people close to me passed away. The first of whom was the small child of a lady friend of mine. The last person that same year being my own mother."
All of which proved very different situations which she experienced in how palliative care works. "In the case of my lady friend's little boy I saw how important it is not to make those horrid chemo sessions the entire focus and how much courage that takes. It is almost unbearable that recovery is no longer on the cards, not just to the family but also to the doctors and nurses."

WE NEED TO SET UP PALLIATIVE WARDS AGAIN INSIDE OR CLOSE TO HOSPITALS

## More attention

Just how difficult the end of life can be is something she found out for herself that same year when her own mother passed away. "She greatly struggled to face the

fact that recovery was no longer an option. To her mind, there were no other options than to receive treatment. So that was her entire focus. Every now and then, I would try and initiate a different kind of conversation. At which point was enough enough for her?"
The subject was off limits. "The question simply didn't assert itself in her mind. I believe that, because of this, she faced needless anxiety and frustration. Which is why it is so important that we break the taboo, and make it possible to simply have a conversation about that topic. We are all going to die, no matter how sad and grim the thought. And we do want it to be a good death."
Since then, Martens sees a change in people's mentality. "There is a lot more attention going out to seriously ill people who have no prospects of getting better. On telly for instance. A lot of Dutch hospitals have a palliative consultation team nowadays. The whole purpose of this team is to get the people away from the hospital, as hospitals are not fitted out to deliver palliative care for the terminally ill. Yet a lot of people continue to pass away in hospital. There is no reason to assume that this number will decline."

> THERE NEEDS TO BE SPACE TO SHIFT THINGS AROUND, TO ADD BITS OF FURNITURE AND TO PERSONALISE THE DECOR

## Home environment

The question is: if we have to die in hospital, how can we make it as comfortable as possible for the patients? How can the delivery of care and the interior help to achieve this aim? Yet, Martens feels that there is a fault line between hospitals and dying. "Hospitals aren't intended as places where people can pass away. They're even required to publish mortality figures. If, as a patient, you've noticed a lot of people dying at a particular hospital, you're bound to think: what are they doing wrong in their delivery of care."
Add in the fact that people really do not wish to die in a hospital. "In literature too, the assumption is that people all want to die at home. In theory, there is no reason why you wouldn't want that: at home in your own bed, that would be perfect. But in a lot of cases, that's simply not possible. In some case, there simply isn't a sufficiently broad social support network. Or the patients' partners are elderly."

The next step says Martens is to say: people want a home environment. "There are hospices that have a homely feel. But in The Netherlands, these are often voluntary schemes. So it's a question of being fortunate enough to happen to live somewhere close to a hospice. A lot of people cannot afford it and the funding arrangements are complicated."

## Relaxation and distraction

Which means hospitals too need to embrace death. "Given the ageing population, the urgency only becomes more pressing. Speaking for myself, I would say: we need to set up palliative wards again inside or close to hospitals. Terminal patients often die in hospital in a clinical environment. Grey walls, white lights and rooms which by no means all have windows."
The rooms where patients die are cold and detached. "In regular patient rooms, patients lie in bed, with a wall behind them, where - if you're lucky - you can hang up a couple of 'get well soon' cards which the patient is unable to see for him/herself. Next to the bed is an array of beeping equipment. Which is frightening and distressing to patients. The things that need to check out are the view, the lighting, the sound and hygiene."
This could be a view overlooking greenery, some woodland or small parks. "This brings many positive effects, delivering relaxation and distraction, which also has a knock-on effect on patients' mental well-being. These things have been repeatedly borne out by research. And it also applies to non-palliative patients – let's not lose sight of that. In addition, the rooms should have some mood lighting or a shaded light. And there are hospitals where the equipment has been tucked away into units so it is out of sight. It can be done. Only, it requires the interior designer to be alive to this sort of thing."

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## Atmospheric and flexible

Colour is another element that plays its parts. “Obviously, painting all rooms bright blue all of a sudden is not exactly the most sensible thing to do. What is important is for the rooms to be atmospheric and flexible. So you need space to shift things around, to add bits of furniture and to personalise the decor. A lot of people enjoy having things from home. Sometimes all it takes is a single picture frame, sometimes it’s a painting or a comfy chair. It’s about personal items that differ from one patient to the next.” Needless to say most patients enjoy all of these elements – including people who are on the mend. “But once they have been treated, the latter get to go home. They don’t care one way or the other if there is space to wheel in a comfy chair. In some cases, it may even be a good thing that the environment is not entirely welcome, as this also fuels a kind of drive in the patient to head back home, to his safe and familiar surroundings. So things certainly don’t need to be changed right away. The important thing is to strike a certain balance.”

## Follow up research

Cleaning staff too may contribute the dying patient’s well-being. “The only thing is, they often don't feel equipped to engage in a sociable natter. In some cases they’ll avoid getting drawn into a chat even though they could be a major part of the process, provided they are sociable, friendly and have a calming presence. And give them some time! Sometimes they have as little as six minutes to clean the room, before they’re expected to move on to the next room.”

Another element are meals. “People often like to have some of their favourites while they still can: a nice bit of fish, some chips or a croquette. Getting a meal like that served in a hospital where everything is uniformly regimented is a challenge and a half. You should think yourself lucky if you have family that will arrange that for you.”
The study is yet to be completed. “During the first phase of the research project, some 400 next of kin completed a comprehensive questionnaire, through a hospital in Rotterdam. We are now conducting another survey - in Groningen this time - involving some 300 respondents. There are a lot of stories that really give me the chills. These stores often revolve around wards being understaffed or staff who are too busy, as a result of which all manner of things go wrong. Or they are about family members who are made to deal with changing staff or who are poorly informed about the situation.”

> THE TABOO ON DEATH AND DYING IS GRADUALLY BEING BROKEN

## Breaking the taboo

Talking to terminal patients directly as a researcher is complicated. “But the idea is very much for us to go out and speak to patients. This year, I’m hoping to spend time working at a hospice as a volunteer to conduct interviews myself. A lot of people are referred to hospices via hospitals. They can see the difference and know what needs to be improved at hospitals. In due course, I’m also planning to run a pilot in a hospital setting to take a closer look at the things that work in terms of care and design.”
What Martens is ultimately hoping for is to see changes in the hospitals. “Obviously, hospitals are sluggish organisations, but I like to think I’ve got time on my side. My impression is that the taboo on death and dying is gradually being broken, and it is given a place within healthcare, society and the way people think about life.”