

Dying at home

Experiences and options



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More time at home and more home deaths – what needs to be done?

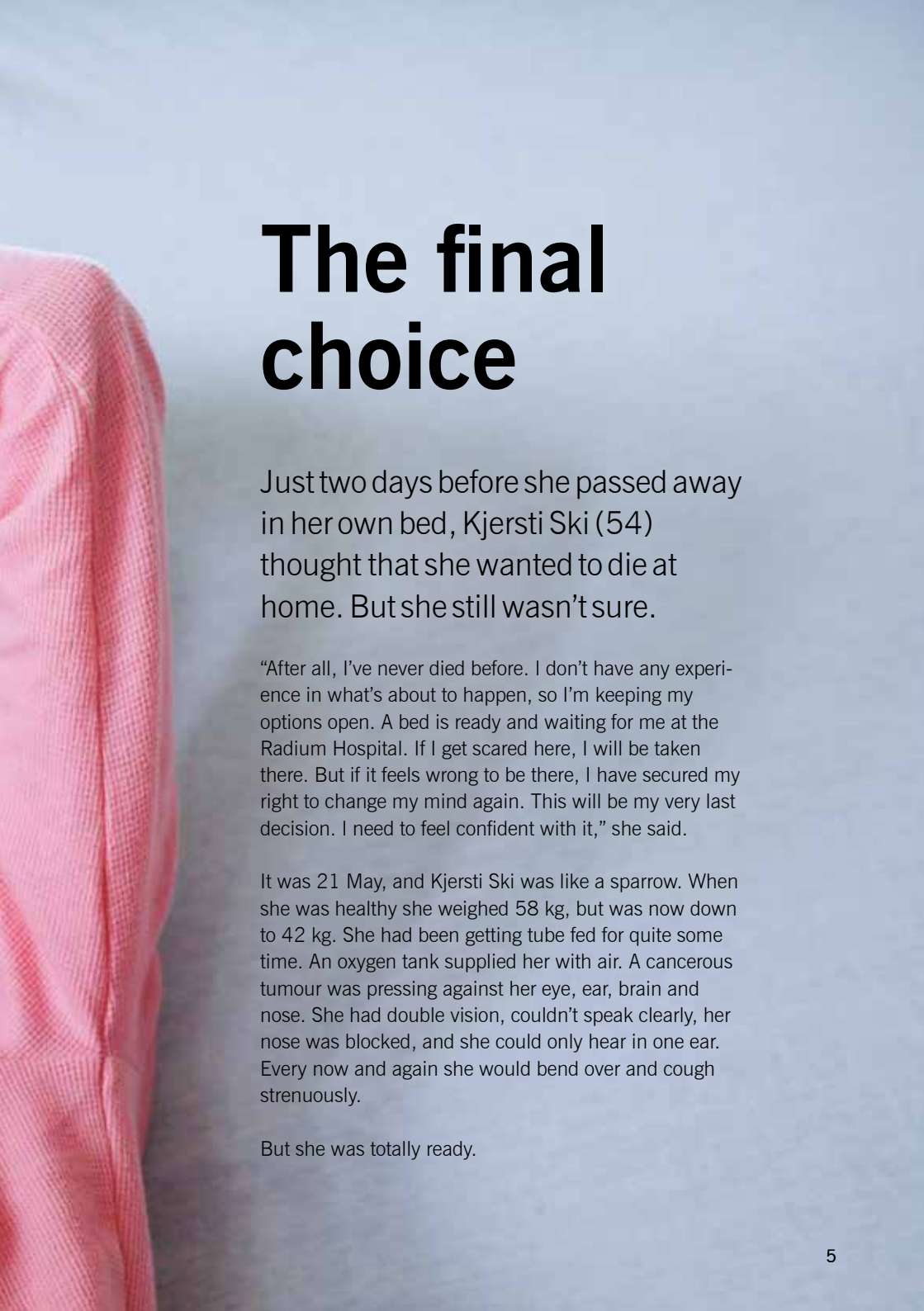
In Norway, most people die in nursing homes and hospitals. Only 15 per cent die at home, but many more express a wish to die at home. What needs to be done to ensure that more people are able to die at home? And just as important: what needs to be done to enable people to spend more time at home during the last phase of their life?

The Norwegian Cancer Society is committed to spreading the word about the option of dying at home. We can provide information on the various aspects that people should consider, and who can help when death is approaching. We are also keen to make people aware that a home death does not have to be a blueprint for how life ends. Dying at home is not right for everyone.

What is a dignified death is something that everyone must decide for themselves based on their own needs, possibilities and wishes. As in life, dignity in death is about respect, trust and reassurance. Our goal with this booklet is to enable greater openness about death – so that more people talk about the end and about their wishes for their own death.

We would like to thank everyone who has helped to make this booklet possible.





The final choice

Just two days before she passed away in her own bed, Kjersti Ski (54) thought that she wanted to die at home. But she still wasn't sure.

"After all, I've never died before. I don't have any experience in what's about to happen, so I'm keeping my options open. A bed is ready and waiting for me at the Radium Hospital. If I get scared here, I will be taken there. But if it feels wrong to be there, I have secured my right to change my mind again. This will be my very last decision. I need to feel confident with it," she said.

It was 21 May, and Kjersti Ski was like a sparrow. When she was healthy she weighed 58 kg, but was now down to 42 kg. She had been getting tube fed for quite some time. An oxygen tank supplied her with air. A cancerous tumour was pressing against her eye, ear, brain and nose. She had double vision, couldn't speak clearly, her nose was blocked, and she could only hear in one ear. Every now and again she would bend over and cough strenuously.

But she was totally ready.

“I’ve been through more than 30 operations. Now the cancer has spread to my gallbladder and pancreas. The doctors have said there is nothing more they can do for me. I accept what they are saying. I have full confidence in them. Since January, I have just been waiting to die. Hopefully it will happen soon. Peacefully and pain free.”

Ski was sitting up in bed in her pyjamas. The bed was in her living room in Nordstrand, with the back tilted up. She had a view of the silvery Oslofjord, shimmering and twinkling under a cloudless sky. Every now and then she managed to glean some pleasure from the light and the warm spring breeze that reached her.

“But I’m so weak. I can barely move my legs, I get tired out just bending them. It’s quite a strange feeling. I can manage a maximum of two trips to the toilet a day. I hope the end is soon,” she said.

Secrecy

In 1997, the married mother of two had a pain in her gums. When she studied the inside of her mouth in the mirror, she discovered a black spot on her uvula. A biopsy revealed malignant melanoma. The surgeons at the national hospital in Norway, Rikshospitalet, hoped that an operation would be enough to remove it.

Unfortunately, that wasn’t the case. Her daughter and son were 13 and 10 years old. All of the doctors insisted that openness was the best way to deal with it and that she should tell her children everything as soon as possible. But Kjersti Ski refused. She feared that if Christine and Fredrik learned about her illness their world would fall apart.

Not to mention her own.

“It was really pure selfishness. I wouldn’t have been able to cope with seeing them so upset. I knew that life would be much easier if we all continued to believe that nothing had changed. I have an amazing ability to suppress things. Any time I have come out of the hospital after an operation, I have imagined that I am 31 years old and healthy. If I hadn’t managed to think like that, I would have gone mad.”

In the years following the cancer diagnosis, the experienced driving instructor underwent a new operation at least every six months. But the sham of normality continued. The procedures were done during working hours. The day after, Kjersti Ski was always back at work.

Sometimes it was hard keeping the illness hidden from the children. While she was getting radiation treatment, she was constantly thirsty and drank huge amounts of

water. But as luck would have it, the benefits of drinking large amounts of water were being heavily promoted in the media at the time. The children just thought their mum was looking after her health. They did not suspect the truth.

Incomprehensible

In 2002, her husband suddenly fell ill with leukaemia. A bone marrow transplant gave them hope that he would recover from the illness. But just one year after the diagnosis, he died.

For Kjersti Ski, it was incomprehensible and unacceptable. He wasn't supposed to die! It was she who was in danger of dying, and then her husband was to be the one who would keep the family going.

The children still had no idea that their mum was sick. In 2005, when a major operation destroyed her voice, it became impossible for Kjersti Ski to keep it secret any longer.

"I've had cancer for eight years," she said to Christine and Fredrik. The children don't remember how they reacted.

"There were so many shocks at the time. Everything had fallen apart when dad died, and mum was still working full time. We thought everything would be okay," said Christine.



"After all, I've never died before."





Home is best

When Kjersti Ski's mother died in 1987, it was at Ullevål Hospital, with her family by her side. Her father, on the other hand, refused to die in hospital. He sat at home, with friends and their dogs, until he passed away in 1995.

Ski thought that her father's death was better. He didn't have the sterile surroundings. That was one of the reasons she checked out her options for dying at home. Another was the memories from when her husband died at the hospital.

"I think he would have wanted to die at home as well. But it all happened so fast."

I don't know if I would have dared to choose a home death if I had suddenly been told that I had 14 days left to live. Death is a strange and dangerous thing, but it's been in my life for the past 15 years. I can relate to it in a completely different way to my husband. For me, a home death is a sense of freedom, where I am in charge. I decide who is allowed to be present."

"We have the lowest share of home deaths in Europe. Why do you think that is?"

"It's because neither the person who is dying nor their relatives know that the possibility exists, or how well it can actually be facilitated. Dying at home doesn't seem comforting to

most people. But I have been followed up by the same doctors throughout the entire period of my illness. If I am worried, I send an email and receive an answer straight away. I also receive visits from the community nurses from the charitable organisation Franskushjelpen. And not least, I have my son and my daughter here. I'm very spoiled," answered Ski.

Her daughter Christine is a doctor. But she was not her mother's doctor. Both Kjersti and Christine were very much aware of that demarcation line.

"Here she is my daughter, my child. However, it is of course reassuring that she has a professional understanding of what is happening to me."

60 days

When we visited Kjersti Ski, Christine had just started to take the 60 care days that a loved one is entitled to.

Very few people know about this arrangement.

"If I hadn't been working in the medical profession I doubt that our family would have known about this option. A special form has to be completed together with the doctor, and it varies from one case to another how much the relatives have to do with the doctor treating the patient," explained Christine.

For the children, it meant a lot that one of them could be there for their mother even during the daytime. Not just for the sake of emotional closeness, but also for purely practical reasons: a whole host of medications sat on the kitchen table. Some had stoppers that were difficult for Kjersti to open. The children had to crush some of the pills in the mortar and administer them by injection as their mother could no longer swallow them.

But even as sick as Kjersti Ski was towards the end, she still had to remember to get her doctor's certificate renewed so that the payments from NAV didn't stop.

Dying is not supposed to be easy.

TV

A phone, a bell to ring when she needed help, and the remote control for the TV sat on the nightstand. Kjersti and the children spent a lot of time watching DVD box sets together.

"On the TV, it's all food, food, food. "Come Dine With Me" and "The Great British Bake Off." Food constantly. I can't eat, so it's better to watch a doctor series," she laughed.

She had more or less stopped accepting visitors.

"A few here and there. But it happens on my terms. I can't bear to see their pity. All their tears."

Self-pity was not for Kjersti Ski.

"I've lived a full life, done lots, never slowed down. Of course I would have liked to live longer; there's a lot left undone. But I don't think about how I will no longer be able to do this, that and the other. The children have grown up and will manage just fine. Now I can die.

Sound of Music

When Kjersti Ski died, it happened fast. When Fredrik was eating breakfast with her, she was just the same as usual. But her condition deteriorated suddenly. Christine called an ambulance. By the time it arrived, it was already too late.

The funeral at Bækkelaget church ten days later was something Kjersti Ski had both set money aside for and planned in detail. It was, as she had wished, a celebration of her life, with lots of nice music, including from her favourite film "Sound of Music".

"We are almost 100 per cent certain that it was right for mum to die at home, and I think she was relieved when the end came. Thanks to the support unit and the Fransiskushjelpen organisation she felt she was in good hands throughout. If she'd stayed in hospital we wouldn't have been able to continue everyday life with her. My mum, Fredrik and I would all probably choose the same again," summed up Christine.



A close-up portrait of a man with short dark hair and a slight smile, wearing a black hoodie. In the background, a black trampoline is visible on a green lawn. The man's hoodie has white text on the right side: "Finn Larsen", "oppmåling", and "93 22 23 53".

Help was always at hand

Finn Larsen gives cancer coordinator Aud B. Ødegaard much of the credit for his wife Gro being able to die peacefully in her own bed, at home with him and their children.



“Aud ensured that we got exactly the help we needed, when we needed it, and where we needed it,” he says, and sends a grateful glance towards Aud B. Ødegaard.

The cancer coordinator in Lunner in Hadeland is quick to return the praise.

“I just laid out the local authority’s offer on the table. Friends and family also offered to help. So then it was up to you to help yourself to what you needed. You formed the four table legs. Without you the table would have collapsed,” she affirms when we meet them at home with Finn and his two children, Mathilde and Trym.

Honesty

The merciless verdict fell on Friday 23 June 2012: Gro’s breast cancer had spread to her bones. Chances of survival? In the long term zero, admitted the oncologist at the Radium Hospital.

“So what do we do now?” asked Finn and Gro.

“Now you go home and open a good bottle of red wine,” answered the oncologist.

In the car on the way back to Lunner, they discussed when and how they should tell Mathilde aged eight and six year-old Trym. But when they came in the door and saw the



children's reaction to their parents' ashen faces, they decided to tell them there and then.

"The doctor said that mum will die. But not when. It may not be for a long time. And until it happens, we are going to enjoy life," said Gro.

Mathilde cried, Trym asked and probed, but both fell asleep quickly when they went to bed. Then Finn and Gro brought out the wine. The next day they went on a camping trip with family friends just as they'd planned. Summer was spent on a car holiday in Norway. Gro wanted to visit their friends around the country and tell them. It was a nice trip, with some great conversations. Gro was still in good shape.

What now?

During the autumn, her condition worsened. At Christmas she had terrible headaches. In January 2013, they found out the cancer had spread to her brain.

So what do I do now, thought Finn. One thing is the overwhelming emotional side of it, but how should I deal with the practical aspects, with two active children, a house and a job as a self-employed surveyor?

Fortunately, Lunner is one of the 215 Norwegian municipalities that has a cancer coordinator supported by the Norwegian Cancer Society.

And Aud B. Ødegaard took personal responsibility for ensuring good support around the Larsen family.

"A GP, cancer nurse, home help, occupational therapist, physiotherapist, health visitor, pastoral carer, local supplier of medical aids, teachers: everything and everyone was made available. My job was to coordinate the support with Finn and Gro," she says.

The family's needs quickly became more extensive and precarious when Gro became acutely ill at the start of March 2013. When she was taken to Gjøvik hospital as an emergency admission, the doctors feared that she would not survive the night. But over the days that followed, she slowly began to feel better.

The weekend after was Trym's 7th birthday, and he really wanted his mum to be part of the celebrations.

"We'll take care of it," said the hospital, and brought her home to Lunner in an ambulance, together with a bag full of painkillers that Finn had been taught to dispense.

"As my sister, who is a doctor, said: 'You have enough drugs here to keep a dozen drug users doped up for six months'," recalls Finn.

At home

The whole family enjoyed the birthday celebrations, but there was no longer any doubt that Gro was in the final phase of her life. The question was, where should she spend her last weeks and months. A care centre? A nursing home? Hospice?

“I’d rather be at home,” said Gro.

It was exactly what Finn had hoped to hear, even although he knew how much work it would entail.

“What do you need?,” asked Aud when she was told of their decision.

She listed their options and Finn answered yes or no. Hospital bed? Yes please. Walker or wheelchair? Not yet. Commode? Ok, just to be on the safe side. Alarm? Yes please.

A home help to clean the house was arranged. The community nurse was there within a few minutes when Gro had one of her frequent epileptic seizures. Her GP was available by phone around the clock. Respite was provided so that Finn could take the children training. A friend of the family received a 60-day attendance allowance to be with Gro.

“The only thing that the local authority didn’t do for us was cut the grass. Towards the end, I think the house was cleaned four times a week. I got the feeling that econo-

mic and practical limitations simply disappeared,” says Finn.

“They were not taken into account, no. Everyone involved was touched by the plight of your family. If someone had an hour to spare one day, they popped in,” said Aud.

Friends and family also provided support willingly. When the hospital bed was being moved into the ground floor, an electrician friend of Finn worked through the night to install an electricity supply.

“I’ve never received any invoices, either from him or anyone else,” adds Finn.

At school, the health visitor had held information meetings for the pupils in Trym and Mathilde’s respective years. In the meetings, they were told about cancer and it was explained to them why Trym and Mathilde would sometimes be sad.

After a while, Trym and Mathilde had weekly appointments with the health visitor. Aud had at least as many meetings with Finn, where she was careful just to give an outline of what the local authority could provide by way of support – she let him make the decisions himself.

But one day at the end of April, she couldn’t restrain herself.



The albums

“It’s possible I’m overstepping the mark here, Finn, but you have so many pictures on the walls and on the computer. What about making a memory album for each child? Gro could write a few lines about what’s in the pictures and how much she loves Mathilde and Trym. Maybe you could drive to Gran and buy two photo albums?” she suggested.

Off he went, and when he came back, Gro got stuck into the task in hand. She worked on it all weekend even though her sight was so impaired that Finn had to tell her when to take a new line.

When she was finished, Trym and Mathilde both slept with their album under their duvet. And when Finn left for work, he no longer saw his wife’s sick face; he saw his school sweetheart, the girl he’d met on Lekter’n at Aker Brygge when he was 21 and she was 20 and he baked the pizzas that she served to the guests.

“And then he felt relief. That her death was so easy and comfortable. That she wasn’t in pain.”

In-house brass band

The local community formed a ring around the grieving family. Trym had been dreading the 17 May celebrations and the brass band

playing at the school without mum playing the cornet. But the band decided to forego the traditional school concert and instead go to the Larsen family home and play for Gro, Finn, Mathilde and Trym.

By that time, it was obvious to everyone that the end was not far off. Gro and Finn therefore had meetings with the local authority’s pastoral carer and the brass band leader to plan the funeral.

But Gro still had the occasional good day. Sunday 2 June was one such day. In the evening, she was sitting on the terrace with Finn, enjoying the spring sounds and smells, the sunset over the hill. But as Finn was helping her to bed, she had an epileptic seizure and developed breathing problems.

This is only going to go one way, he thought, and called the night watch at the home care service.

She came quickly and sat with Gro while Finn tried to take a nap. But after half an hour she came running:

“Finn, Finn, I think it’s the end!”

Finn rushed in. Gro had stopped breathing. He held her hand and could not feel her pulse; her heart had stopped beating.

And then he felt relief. That her death was so easy and comfortable. That she wasn't in pain.

In the morning, Aud came round to help Finn with practical matters, and the health visitor came to talk to the children.

"These first few days, the funeral and afterwards have all gone well. In a way, the children were already finished grieving when she passed away," sums up Finn.

Continue the efforts!

Aud believes that the investment in cancer coordinators enables the local authorities to provide the kind of reassuring end that Gro and her family experienced.

"With its 9,000 inhabitants, Lunner has the added benefit of being large enough to have the support system but small enough for the coordinator to retain an overview," she says.

The Norwegian Cancer Society would like all local authorities to have a cancer coordinator and experience the benefits of the scheme. Finn hopes they take up the challenge in order to help other affected families.

Finn has been to Lunner's local council to tell his story and extend his thanks for all the help his family received.

"I told them that Aud probably saves the local authority a lot of money. As I mentioned, we got exactly what we needed, when we needed it, where we needed it. For example, when Gro needed a wheelchair with a neck support in order to be able to sleep in it, it took an hour for the local services to bring it. That's how it was with everything. It was perfectly timed and designed."



No blueprint for a dignified death

“Perhaps the most important thing is not a home death, but facilitating the best possible home *time*,” ponders Tove Nyenget, adviser in the Norwegian Cancer Society.

The Norwegian Cancer Society is receiving growing numbers of requests for information about dying at home. Patients who dream of being able to stay at home for as long as possible and spend their last days in their own bed want to know whether it is really feasible in practice. Unsure relatives call us after hearing their dying relative's wish: "Can we, will we manage, dare we?" they wonder.

"The answer is that, for many people, dying at home is a good and realistic alternative, under close professional supervision by health care personnel. And we are keen to emphasise that if something unforeseen should occur it is certainly not defeatist to change the plan and for the patient to spend their final days in an institution, whether it's a hospital, nursing home or hospice.

Having that reassuring back-up is absolutely vital, both for the patient and their relatives," emphasises Tove Nyenget.

No blueprint

Norway has the world's lowest proportion of home deaths. But the indications are that far more than 15 per cent of us actually want to be home with our nearest and dearest during our last days. In a Danish survey, 81 per cent of terminally ill cancer patients said they would rather die in their own home.

The Norwegian Cancer Society therefore wants to bring the subject into the spotlight and throw light on what options are available. It also aims to show that most local authorities are able to provide support with both dying at home and spending time at home as the end approaches.

At the same time, Nyenget is absolutely clear that a home death must never be the only right way to die.

"There is no blueprint for dying at home. I have followed very many people who have had a positive experience dying in hospitals and nursing homes. The patients and their relatives have all experienced that everything happened on their terms. But we also want to show that we don't automatically have to end our life in an institution," she says.



What should be prioritised?

In order to get the message across, the Norwegian Cancer Society needs to work in close collaboration with the National Health Service.

“Health professionals should raise the subject either at or before the point when they know that the patient will not get better and goes from curative to palliative care. The patient may still have several years left, but the question that must be asked is what he or she wants to prioritise in the time remaining.”

For some, the answer will be to have treatment that prolongs their life as much as possible.

“And we respect that. But many would rather prioritise spending as much time as possible at home, with good pain and symptom relief, and their journey must then be based on that objective,” says Nyenget.

A number of patients and their families will, however, be afraid that the emotional strain of dying at home will be too much for those involved, especially if there are children in the

“Ideally, we should all talk about death with our loved ones long before we get sick.”

house. However, in Nyenget’s experience, a home death is normally perceived to be less gloomy.

“Death is a natural thing for those who have been closely involved in a patient’s final journey.”

That also applies to children. While the patient can go through major changes between each hospital visit, the changes seem more gradual when the patient is at home. Children can ask questions along the way, and they generally feel more reassured.

Talk!

But, as is the case in life in general, everything is easier if people talk about it.

“Ideally, we should all talk about death with our loved ones long before we get sick. Talking about it makes it easier to address this still taboo subject when it becomes a reality,” concludes Nyenget.

A blurred photograph of a hospital room. In the foreground, a bed with white and blue linens is visible. In the background, there is a medical cart with various equipment, including a red and black bag. The overall scene is out of focus, emphasizing the text overlay.

More people should die at home

“We in the health service must start promoting home deaths,” says Dr Siri Tau Ursin. She believes that far too many people die in the hospital.



It's a natural reflex for a doctor: Save lives! Prolong lives! But according to Dr Tau Ursin, this priority is often wrong.

"We in the health service think about life *quantity* instead of life *quality*. We have such a strong focus on keeping people alive for as long as possible. All too often this mindset is transferred to terminally ill patients who should instead be receiving care and pain relief, preferably at home with their family. When a patient actually takes the time to think about it, it is not generally more days they want, but for the days that remain to be meaningful," says the head of the intensive care unit (ICU) at the University Hospital in Stavanger.

A total of 11,000 Norwegians are treated every year in ICUs. Fifteen per cent of the population die here. We also have the lowest share of home deaths in the world.

"A sign that something is wrong," says Dr Tau Ursin.

"Many will of course still be treated and die in ICUs, but lying in a hospital bed and having to breathe with the aid of a respirator is often high-tech and alienating. A number of patients would have made a different choice if they had known there are effective, mobile palliative care units in many parts of the country, and that many places are well prepared for home deaths. We in the

health service must help to spread the word and create a demand. Our support services will then improve even more.

Talk to each other!

Everyone needs to start talking to each other. Before it is too late.

"An early dialogue with the patient is crucial. We will all only die once, which means we in the health service have a tremendous responsibility to ensure that the patient, the relatives and the health care personnel are aware of the options available to them, and are comfortable with the choices made."

Dr Tau Ursin believes we don't talk about death enough in general.

"It's become like a stranger to us, we all beat around the bush. But in the same way that we have to make our wishes clear in relation to organ donations before we die, we also need to communicate how we wish to die as early as possible. Other-



wise, it is often those we leave behind who have to make the difficult choices for us.”

Dr Tau Ursin says that in many hospitals in the USA the patients’ thoughts on death are recorded upon admission. How much treatment do they want if their heart stops? Some respond “As much as possible,” while others say “Stop before there is a risk I end up needing constant care.”

“That scenario would be ideal for us. And it must be an open, ongoing conversation, with the opportunity to change your mind. But we are too cowardly, we don’t talk about death. The consequence is that we often go too far in the treatment of the terminally ill.”

There is also pressure from the relatives to continue life-prolonging treatment for as long as possible. After all, the relatives want to hang on to their loved one and expect health care personnel to do everything in their power to prevent their death.

“This creates dilemmas. I remember an old female patient who said that enough is enough, and that all she wanted now was care and pain relief. But then she and I both talked to her relatives. They insisted that we should keep trying. The patient wasn’t able to object to their wishes so we continued with the treatment, and it was just painful for everyone involved.”

Some die

Dr Tau Ursin thinks that the cancer care service in particular should think about these issues more consciously.

“When it comes to cancer, we are very fixated on survival, talking about the effective medication and treatments that are available, explaining that the patient will undergo radiation and chemotherapy but that so and so many survive, so and so many recover completely. But it is still the case that many will die of cancer. These people should also be treated, plans should also be drawn up for them. They should be informed about the arsenal of symptom and pain relief available, the option to stay at home, how even their final days can have meaning and that they can have a dignified death.”

Fortunately, attitudes are changing.

“There must be an open, ongoing conversation, with the opportunity to change your mind.”

“Our aims are achievable, but responsibility for a dignified home death cannot be placed solely at the doorstep of the local authorities. We in the specialist health care service also need to be involved. We must, among other things, be able to visit people at home. It is not certain that this will be cheaper than the current provision, but it will be better,” concludes Dr Tau Ursin.

A photograph of a person in a white long-sleeved shirt standing in a dark room. The person is seen from the side, with their hand on their hip. In the background, there is a dark door with a window consisting of four small panes. A bright light source is visible through the window, and a small red square is on the door. The overall mood is somber and contemplative.

It's your death

“I want to die at home. The stage is already set,” says Per Fugelli. He hopes that many more of us will have this option.





A few years ago, when he was very ill with cancer, frightened and convinced that his last days were approaching, he raised the subject of dying at home with his wife and adult children. They all promised to help him as best they could.

The professor in community medicine then made a trip from his flat in Grønland in Oslo to Lovisenberg Hospice a few kilometres west. There he was assured that they can provide him with palliative care at home, and that their door remains open if he decides to be at the hospice towards the end. He then

spoke to Nina Borge, a doctor who specialises in supporting people in their last days and months. She also promised to support him.

But in Per Fugelli's last dance, it is he, not they, who will take the lead. On his final journey, he insists on being the skipper.

As the late great Sinatra once said: I did it my way! That is the ultimate premise for a good death. Relatives, priests, imams, doctors, carers and cancer coordinators must respect that they are only the crew.

There is no gold standard for how we should die.

“This country is made up of five million mysteries. Each and every one of us know how we as individuals are best served at the end of our life. We must be allowed to feel, experience and act in our own way, with dignity and freedom, when we are faced with the news: You are going to die.”

Not ideal

A couple of years ago, Fugelli wrote an article on the quality of death in the Aftenposten newspaper, where he called for home deaths to be better facilitated.

“Norway has the lowest home death rate in the world. I don’t think it’s because people want to die in an institution,” he commented.

The response was quick: “Per Fugelli wants to introduce a monopoly in home deaths,” cried his critics.

“It was a useful reminder. In my eagerness, I had helped create an image of home death as the ideal model. That was completely wrong,” he says now.

Most of us will still die in hospital or in a nursing home. Many of us would not wish for anything else. And that is entirely legitimate.

“But we also need to humanise death in the hospital factory setting, give the right of ownership back to the people. We must also rid ourselves of the medical tradition that the experts always know best. That is completely wrong!”

“There is no gold standard for how we should die.”

Impossible?

Fugelli believes that dying at home must be made much more accessible than currently. He is in no doubt that far more than 15 per cent of us would rather die at home, in familiar surroundings, surrounded by our loved ones.

“This is based on my many personal, powerful experiences with fellow patients at the hospital. Too often have I heard this touching exclamation, “Oh, I so wish I could die at home – if only it had been an option!”

This conviction that dying at home is not an option is obviously unfounded in many cases. But in order for the offer to be regarded as widely available and realistic, the following changes are required, according to Fugelli:

- More information and debate. We need to put an end to the notion that death is all about hospitals,





nursing homes and medicine. We must present good arguments to show that it does not have to be like this.

- Practical, financial support. The family must have more opportunities to be part of the team. At the moment, a relative can receive an attendance allowance for up to 60 days, but a terminally ill patient may need care at home for six months or more. The welfare benefits need to be improved.
- Medical support. The health service needs to coordinate its powers and improve its efforts in facilitating home deaths with a high standard of medical care. Among other things, GPs need to learn more about palliative care.

Embarrassing

Fugelli was diagnosed with cancer in summer 2009. Since then he has written and talked about death extensively. In autumn 2012, he notified the VG newspaper that the end was approaching, that he had barely more than two years left. But, fortunately, he is still here – apparently as fit as a fiddle.

What happened?

“Ah, well, that’s a bit embarrassing. I’ve been exposed as a phoney! It’s actually really puzzling. I was diagnosed with cancer in the colon, and

after that tumours were spreading to my lungs every year, which the surgeons were removing as they appeared. I had the fourth operation on my lungs in March. So I still believe in the dream in Olav H. Hauge's poems that "something wonderful will happen."

"I am so grateful that I can turn something so awful into something useful and meaningful."

"You have written several books on death and given hundreds of talks. What has "dying in front of the nation" been like?"

"It's been great fun. When you are as ill as I have been, the best thing that can happen is having something to get up for in the morning – to be fired up! I am so grateful that I can turn something so awful into something useful and meaningful. It has been an empowering experience," says Fugelli.

He says that in ancient Persia there were three types of doctors: the knife doctor (surgeon), herbal doctor (specialist in internal medicine) and the word doctor.

"For the last five years I've felt like a word doctor, and the massive amount of feedback I've received tells me that I have helped many people. It's been amazing! Fantastic!"

Open

Although Fugelli is fully committed to a home death at the moment, he is also open to meeting his end in a hospice or hospital.

"I'm no fundamentalist. I have a pragmatic approach to this. Yes please, a home death if possible. But if it gets too difficult for me or my loved ones, it's very reassuring to know I have the option of changing my mind. Everyone should have that option," he states.

What should you consider when thinking about dying at home?

Talk to each other about what you want

Perhaps the most important thing for you is to be home for as long as possible when the end is approaching? Perhaps it is your greatest wish to die at home? Or perhaps the most important thing is to avoid hospitalisation as far as possible? Talk to each other and with the health care personnel about this. Perhaps you make the decision to die at home, but then things don't go as planned? The situation could change for any

number of reasons, and it may no longer be possible for you to be home at the end. This could be due to your need for extensive pain and symptom relief, or because it is a far greater strain on the patient or relatives than envisaged. In such a scenario, you can talk to health care personnel and arrange to go to a nursing home, hospital or hospice instead of staying at home.

Home deaths need to be planned

- The earlier you raise the subject, the easier it is to plan. In order to plan spending time at home and dying at home there are a number of people you can talk to. Your GP, cancer coordinator, cancer nurse or the community nurse can all help you. You can also talk to your doctor at the hospital, the palliative care team or the hospital's social worker.
- Some others you may have a need to talk to during this period include a physiotherapist, occupational therapist, priest/minister or equivalent for other faiths, psychologist or a local authority social worker. Perhaps you also need to talk to someone at NAV in connection

with, for example, your entitlements, practical help in the home or necessary aids.

- Create a list of key contacts and telephone numbers of those who can help you, both during the day and at night if necessary.
- For many, a tailored care plan is a useful aid that provides an overview of who can help you when you need coordinated assistance from several agencies over a longer period of time. Many patients have the right to such a plan which they and their families help to devise, so talk to your doctor or to other health care personnel about this.

Relatives

- Dying at home requires the patient's loved ones to be present for a large part of the time.
- It is essential that the relatives have enough information and follow-up to feel confident that this is something they can be involved in and manage.
- It is particularly important that children are taken care of. The health visitor and school health service, for example, can play a key role here.
- As a relative, you may be entitled to attendance allowance. In order for someone to be entitled to attendance allowance, they must either have their own earned income or be in receipt of unemployment benefit. Relatives are also entitled to attendance allowance if they are on sick leave for their own illness prior to acting as a caregiver. Attendance allowance is granted under the

same criteria as for sickness benefit for personal illness. If the relative has not accrued an entitlement to sickness benefit, care benefit and/or supplementary benefit may be other options. The attendance allowance is limited to the final phase of a person's life and can only be paid for a maximum of 60 days for each patient. The attendance allowance is flexible in so far as the 60 days can be shared between two or more relatives. The days can be taken on single days over a number of weeks, and the care must take place in the home, but this can be either in the patient's home or in the relative's home. The caregiver is usually a close family member but can also be someone who is not related, such as a close friend or neighbour. Terminally ill cancer patients can apply for the attendance allowance from their doctor. An electronic application form is available at NAV's website, nav.no.

What if hospitalisation becomes necessary?

- If the situation changes and staying at home is becoming difficult, immediate hospitalisation may be necessary.
- As far as possible, there should be an advance agreement with the hospital that immediate admission or an "open return" may be necessary. The patient/relative or community nurse can then contact the hospital directly, without going through a GP or the emergency clinic.
- If possible, moving the dying patient should be avoided during their last few days.

Further information about death

Information in Norwegian about home deaths, how to talk to children about death and answers to various questions are available at the Norwegian Cancer Society's website - kreftforeningen.no/doden. We also have a number of brochures on this topic:



Mum or dad is seriously ill

Brochure about a child's reactions when a parent becomes seriously ill.



When parents die

Brochure about children's grief and other reactions when a parent dies.



Questions about death

Brochure containing various questions and answers about death. (This brochure is also available in English.)



Rights of patients and relatives

The brochure is a guide to the help available – such as welfare entitlements, patients' rights and other support.



Guide for teachers – children's grief

A guide for teachers for use in school if a pupil experiences serious illness or death of a loved one.

These brochures are available at kreftforeningen.no/brosjyrer

Do you have questions about cancer?

Call 800 57 338 or chat with us at kreftforeningen.no in Norwegian, English, Somali and Polish

The Norwegian Cancer Society is a national voluntary organisation working on cancer-related issues. We have 113,000 members and around 20,000 volunteers*.

The Norwegian Cancer Society takes an active part in society, contributing to targeted efforts within research, care, prevention, information, political influence and international efforts. Our activities are financed through funds raised, bequests and national lottery funds.

Do you have questions about cancer? Visit kreftforeningen.no

At kreftforeningen.no you can find up-to-date information on types of cancer, treatment, support and rights, as well as prevention and research.

Can we help you?

The Norwegian Cancer Society offers various services to cancer patients and their families throughout the country. If you want to talk directly to a health professional, you can contact the Cancer Line on 800 57 338 or chat via kreftforeningen.no, where specialist nurses, legal professionals and social workers can help you to understand your options. From our website, you can also order brochures and factsheets or apply for financial support.

The Norwegian Cancer Society works closely with several patient and peer support organisations that represent people with cancer and their families. A wide range of services are available, including professional and social get-togethers, courses and conferences. The organisations also have well organised peer support groups aimed at providing hope and enabling patients and relatives to talk to someone who has had cancer or is a relative of someone with cancer.

Varde centres

In cooperation with a number of university hospitals, the Norwegian Cancer Society founded the Varde centres which provide cancer patients and their families with an offer of holistic cancer care. A number of Varde centres are now scattered throughout Norway. For more details, see vardesenteret.no

Around the country

We have offices in several towns, with various types of help: Tromsø, Trondheim, Bergen, Stavanger, Kristiansand, Hamar, Tønsberg and Oslo. For addresses, see kreftforeningen.no.

Do you want to contribute?

Become a member or make use of our various donor opportunities. Send a text with the word MEDLEM to 2277 (NOK 305), or visit kreftforeningen.no.

* Figures as of June 2014.



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