

Hospice Care

- Handbook for family members and close friends



Different farewells

It's been expected by many.

Can't I leave, please?

For how long still suffer and wait?

Until the time has come to leave.

Sometimes it surprises one.

I'm not ready yet.

My suitcase still unpacked.

It is there, but still.

Some depart against their will.

I do not want to leave you, not yet.

Let me stay.

So many things are still undone.

Yet, there always are some

who prepare their journey themselves.

I can't stay here.

Have to get away.

We have, as known, all kinds of leavers to see off.

We need to have sensitive

but also sensible antennae,

to find out

how best support

those who are seeing off and those who are leaving.

(Eila Karjalainen)

Hospice Care

Hospice care means taking care of a terminally ill person in situations, where curative treatment has been laid off and the advance of the disease can no longer be affected.

Hospice care is safe and continuous symptom management, where the dignity of the patient and the importance of the loved ones are respected.

The aim of hospice care is to provide the patient with a death as symptomless and safe as possible and provide support to the family members and close friends to cope with the bereavement. When curative treatment can no longer be found, the main focus is to concentrate on curing the tiresome and harmful symptoms of the patient as well as possible and to ease his or hers wellbeing.

Hospice care includes taking into consideration the wishes the patient may have, treating the symptoms as well as possible, preparing the patient for the approaching death and providing support for the patient's family, caregivers and close friends. In hospice care the individual is treated in the best possible way at the final stage of the persons life.

On the threshold
you have to stop for a while
breathe deep
look back - once more.
To gather from the past
things that will carry
and give up the things
that hold back
that weigh too much
and hinder your wings to rise
You have to set off
it cannot be cancelled, not any more
The threshold has to be crossed
It's time to let go...
(Hanna Ekola)

Hospice care decision

Once the decision to begin hospice care has been taken the end of life care starts.

The doctor makes a legal written document on starting a hospice care together, in mutual understanding, with the patient and his family members or caregivers.

The patient in hospice care is being prepared for the end of life and resuscitation is withheld.



Photo: Emmi Vuola

Hospice care place

After the hospice care decision has been made, the patient's hospice care place will be discussed. The choice of the place depends on the place of residence of the patient and the patient's own wishes.

Own home

Following the wishes of the patient and his or her family, hospice care can be given in a person's own home with the help of a good support network. The care given at home is supported by home hospital, home nursing and assistive devices installed in the patient's home, and the permission to be moved the health care center if needed.

Health centre ward

The normal treatment place is the patient's own health centre ward.

Hospice care unit or a hospice nursing home

Hospice care can be realized in the hospice care unit or in a hospice if services are available for the residents.

University hospital, central hospital, or local hospital

Hospice care is given in hospital in case the patient's deteriorating health prevents the transfer or there is no place free for continuing care in the health center of the municipality, hospice care unit or in a nursing home.



Photo: Satu Uotila

Symptom management

- **Pain**

One of the main aims of the treatment is to manage and relieve the pain and suffering. Pain is always a personal experience. Every individual has the right to die without pain. With pain management the quality of life of the patient is remarkably enhanced.

In addition to pain medication, it can also be alleviated by position treatment, massage, presence and nearness.

- **Nausea**

Feeling nauseous can have many causes. The cause can be the illness itself or a medication side effect. Medication treatment is used to prevent these side effects.

- **Fatigue**

When the general state of health of the patient deteriorates, her or his vitality also goes down. Many medicines also cause fatigue. To treat these symptoms the patient should rest and eat if she or he wishes to do and needs.

- **Breathlessness**

Shortness of breath can have many causes. Factors which mostly cause it may be due to fluid accumulating in the lungs and abdomen, distress, blockage in respiratory system, mucus and heart failure. Breathlessness can be treated with medication, position treatment, giving the patient extra oxygen, lung or abdomen puncture, and by being present makes the patient feel safe.

- **Swelling**

Swelling can appear on the face, in the body and limbs. It can be reduced and alleviated by medication, compression bandaging and position treatment.

- **Constipation and diarrhea**

Strong pain medication is the most common cause for constipation. Other causes consist of the changes caused by the illness, scarce nutrition, dehydration, and little exercise.

Constipation causes pain and restricts daily life. To treat constipation there are medicines that soften the contents of the large intestine and enhance the colon to function more efficiently.

Diarrhea can be caused by excessive use of constipation medicines, antibiotics, and infection in the intestine or malabsorption.

Sedation

Extremely difficult symptoms can be treated with sedation. In sedation the patient is given medication to calm her or him down in continuous infusion in which case the level of consciousness is lowered.

Nutrition and hydration

In approaching death appetite and feeling thirsty reduce. It is normal, because body is no longer able to digest food as before. Loss of appetite and feeling thirsty with decreased physical strength are symptoms of advancing illness and they cannot be helped.

Intravenous hydration does not take away the feeling of thirst. Giving the patient more liquid may even increase the symptoms. The accumulation of fluid in the abdomen or elsewhere in the body causes swelling, mucus and shortness of breath.

We have learned to show affection to our loved ones by food. This is why the patient's loss of appetite and refusing to eat shocks us. You can always serve your family member his or hers favorite food and drinks whenever they wants and is capable of taking them.



Photo: Satu Uotila

Good basic care

Good basic care and cleanliness reduce the symptoms of the illness and enhance pleasure. Good basic care done with empathy will open possibilities to nearness and touch.

- **Skin care**

Various factors such as immobility and dryness make the skin more sensible to imprints on skin, skin damages and pain. Cleaning, spreading moisturizer to the skin and changing position are very important factors in skin care.

- **Mouth care**

When drinking decreases the importance of mouth care increases. The production of saliva is reduced and dry mouth is prone to skin damage in the mucosal surfaces. If the patient is able to swallow, the mouth is moisturized with water and ice cubes. Lemon sticks, gels and mouth sprays are also used for this purpose. Brushing teeth and greasing lips is taken care of.



Photo: Paula Einiö

Spiritual care

Taking spiritual needs into consideration is one part of hospice care. The concept of spirituality and the amount of spiritual needs is individual.

When the end of life approaches the meaning of dear people, the life behind, its meaning and the life that remains unlive are of great importance. Something that burdens the mind is perhaps a thing that has been unsettled during life time.

At its best, spiritual things can become the patient's source of strength. Confidence and feeling safe replace the fear and distress.

Pastoral care can be either speaking with the hospital pastor of the patient's religious needs regardless of his or her religious conviction or speaking with the priest or member of their own religious community. For some it's enough to be alone in silence and being present, while others are comforted by music opening their emotions.

Reading the Bible or texts on one's conviction, reading poetry and praying, being silent, meditating together with family and friends can be of great significance in the last moments of a person's life.

Ward staff will arrange a meeting with a hospital pastor, if needed, or possibly with a member of the patient's own community in case he or she is unable to do so.

Once the death has occurred, a devotion can be held in the patient room with the support of the hospital pastor.

Hospice care room

With the approaching death, the patient is moved to a single room where it is possible for the family members and close friends to stay around the clock until the patient dies. The hospital also provides for family rooms, where family members and close friends can stay overnight for a limited period of time.

The atmosphere in the care room is softened by music, led candles, illumination and the color of bed cloths to create peace and safety at the time of the approaching death. Music calms and supports also the loved ones of the patient.

Close people can also bring photos, flowers and music or anything that is important for the patient. The patient's own blanket or a pair of warm woolen socks bring feeling of safety.



When I die,
I want autumn leaves,
a ray of the sun
to gently touch
those I loved.

(Anna-Mari Kaskinen)



Photo: Iina Vuola

Symptoms of the approaching death

The symptoms of the approaching death are a normal part of the final stage of life.

- Breathing becomes more shallow or jerky. It can also become noisy. The mucus in the respiratory system causes this stertorous respiration. This seldom does any harm to the patient even if those near him or her take it hard.
- Skin gets cool and as circulation weakens this happens especially in hands and feet. The color of the skin is pale and there may be seen bluish spots on it. The body can be kept warm with a blanket and woolen socks.
- Disorders in the thermoregulation cause fever. Fever is natural and there is no need to treat it with antibiotics. Medication to get the temperature down may be used. The patient is covered lightly.
- The patient may be disoriented and confused. He or she does not recognize the people around them. The patient may also have hallucinations or they may move restlessly.

The best way to help is being present comforting and staying calm. The patient's well-being can also be alleviated by medicines.

- The level of consciousness lowers and reaction to the environment decreases.

Giving support in approaching death

When your loved one approaches death you can support him or her by touching gently or talking to them. The senses of touch and hearing are the two last remaining senses before a person dies. Tell him or her who are present in the room and who is touching their hand or shoulder.

Tell your loved one what is being done and who does it, if it is simply to turn the pillow or change position.

Don't address your loved one in the past tense. They might become upset, especially when they can't participate in the conversation.

At the time of death it's important that the spouse, a close relative, a companion, the family and friends can touch and hug their loved one and give their last final goodbyes in peace.



If still in the days of yesterday I could wander,

if still begin from the start

and something I could change,

would I do something otherwise.

If the door still remained open,
one new opportunity,
offered by surprise
Would I seize it?
Would I, after all, be able
to let loose the secrets of the past?
Live a bit more to the full
every moment, every second.
Would I still be able to hear
the call without words?
Would I be able to look
into your eyes for long?
(Anna-Mari Kaskinen)

Your own well being

The ward staff is responsible for the patient's needs and well-being also at the approaching death. It is important to give time to yourself, too. Identify your personal needs.

Protect your own health and well-being:

Eat and rest sufficiently according to your possibilities.

Go outside even for a short time.

Discuss the things that burden your heart, your possible worries and fears with the ward staff.



Photo: Iina Vuola

After the death

The death of the patient is announced to the doctor in charge, the nearest emergency unit, home hospital or the home hospice care team according to the practices agreed on in advance.

The nursing staff will announce the death to the next of kin according to their wishes agreed on before, in case they are not present at the time of death.

The deceased person is prepared according to wishes of the close relatives or the practices used in the nursing unit. If they wish to participate in the caring for the deceased person, they can do so, or even care for their loved one themselves.

The close relatives are given a possibility to leave their goodbyes to the deceased person before the transfer.

The close relatives contact a funeral office of their choice, which will help them in the arrangements, and give them an opportunity to view the deceased person later. The death certificate is sent to the next of kin. The funeral office will take care of the death certificate if the next of kin wish them to do so.

Further information is available on the website of Palliatiivinen talo. See the contact information at the end of this booklet.



Photo: Emmi Vuola

Grief

Grief is a natural feeling. It can't be escaped or postponed to another time more suitable for me.

Grief is an internal experience. Every person experiences grief in a different way. Nobody can tell how long it takes to grieve. Experiencing grief and processing it, is something personal. Some of us deal with grief quietly in their interior while others want to open up by telling about it to other people. Presence and touching serve as comfort to some whereas others find it a relief to scream away their grief.

Crying is a natural reaction to grief. With tears you get into contact with your emotions and gradually it is easier to talk about them. Give your grief time. By grieving your loss, you can turn it into memories. The memories will always follow you. Nobody can take them away from you. It is vital that you accept your emotions and process them in the best possible way.

Be gentle to yourself. Treat yourself with care.

In the hospital the ward staff will support you along with the hospital pastor.

Get help in your grief also in grief groups. Grief group counselling is arranged by parishes and cancer organizations.

The nursing staff is there for you at all times of the day and night. Do not hesitate to ask for more information that you can't find in this booklet or if you need to talk to somebody about things occupying your mind.



I'm recovering, in the forest
a nightingale to keep me company
a spruce to protect me
wind to comfort me
moss under my heart.
(Anna-Mari Kaskinen)



Grief is love that hurts.
On the bottom of it I see hope
a gentle brightness.
Goodbye my dear
Goodbye.
(Saraleena Aarnitaival)

Contact information

- Hospital chaplain, parish priest or a corresponding person
- Parish or the grief recovery support group of the parish
- Cancer Associations/Cancer association/Grief recovery support groups
- [Cancersociety](#)
- Evangelical Lutheran Church of Finland. Phone hours Sun - Thu 18-01, Fri and Sat 18-03, phone number 010190071
- You can also leave a message to our website: evl.fi/palvelevanetti
- [Website discussion forums of Cancer Associations](#). In the forum you can discuss hospice care and the loss of your loved ones.
- [Palliative House](#) (only in Finnish) is meant to support the patient suffering from an incurable disease and their family members.

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