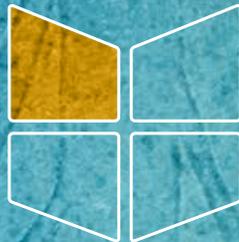


English
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*To you
as a close
relative*



Foreword

This information booklet is intended for close relatives of those receiving palliative care as they approach the end of life. The booklet briefly describes what happens to the body as life comes to an end, as well as the support you can receive and are entitled to as a close relative.

Palliative care is given to a patient who can no longer be cured of a disease or illness that will sooner or later lead to death. The word palliative is often associated with the term alleviation and comes from the Latin word for cloak. This association can be interpreted in two ways; in the case of an incurable disease, it is no longer possible to eliminate the cause of the disease, but the symptoms can be alleviated, “covering them up” as if putting a cloak or coat over them. Another association is the image of a warming coat in which the patient can be wrapped. Both of these associations fit well with the measures involved in and the purpose of palliative care.

Although a cure is not possible, based on my experience as a physician in the field of palliative care, much can still be done both for the patient and for you as a close relative to make the best of the situation, given the circumstances. Palliative care involves creating a “space” in which the patient can live with dignity, alleviated from any symptoms, until it is time to leave this world.

Uppsala, January 2017

Johan Sundelöf, Physician
Head of Programme, Betaniastiftelsen



What happens to the body as life comes to an end?

In the vast majority of cases, dying is a calm and non-dramatic event. As a close relative, you may worry about what the final moments will be like – but the knowledge that, in most cases, death is calm and non-dramatic for the person dying can provide some comfort. It is not the case, as you would perhaps imagine when someone is dying, that it is only possible to keep the symptoms in check until a certain point in time, at which point everything collapses. Difficult symptoms that are hard to control may indeed sometimes occur. However, in most cases, the staff can subdue these symptoms so that the patient is not in pain, or troubled by other symptoms, and instead experiences a sense of inner peace.

Tiredness

As death approaches, the patient's lack of energy means they become increasingly uninterested in their surroundings. They sleep more and become ever more withdrawn. Moments of confusion may occasionally come and go.

Early signs of imminent death:

- Declining interest in/diminishing awareness of surroundings or what is happening, becoming increasingly withdrawn.
- Tiredness that cannot be alleviated by resting.
- Lack of hunger and thirst.

Late signs of imminent death:

- Production of urine decreases or stops.
- The patient has reduced consciousness or becomes unconscious.
- Shallow, irregular breathing, sometimes breathing interruptions.
- Wheezy breathing.
- Cold, blue hands and feet.
- Possible motor disturbances and restlessness.

Lack of hunger and thirst

Hunger and thirst are also affected in the final stages of life. It is not uncommon to think that the deterioration in the patient's condition is because they are starving to death. In fact, it is the opposite. The patient does not die because they do not eat or drink; they stop eating and drinking because they are about to die.

Everyone who has an incurable, progressive disease eventually reaches a state in which the body can no longer absorb or consume the nutrition that is provided. If the patient is given more nutrition in such a situation, this just leads to nausea and vomiting. In a similar way, the provision of more fluid, such as via a drip, to the patient most often leads to an accumulation of fluid in, for example, the lungs, which can give rise to breathlessness.

In other words, it does not help to give a dying person a nutrient drip or fluid drip. On the contrary, this is likely to aggravate the situation. The process cannot be reversed, no matter how much nutrient or fluid is provided. The deterioration is not due to a lack of nutrition or fluid; it is the condition of the disease that is causing the patient to die. On the other hand, what can be

done – which is helpful to the patient – is to alleviate dryness in the mouth by moistening the oral mucosa. In fact, dryness in the mouth will probably be a greater problem for the patient than a lack of fluid. Staff will be happy to show you how to provide oral care if you so desire.

Urine production and intestinal function

When bodily functions deteriorate and cease to work, kidney function and urine production are also affected. Urine becomes dark (concentrated) before it stops being produced completely. Similarly, the amount of faeces decreases towards the end and often ceases completely.

Anxiety and confusion in the death phase

Confusion is a common condition as life draws to a close. This confusion is the result of the patient not having enough energy to “keep a grip on things” and they therefore become confused.

This kind of confusion is usually not helped by medication. Instead of providing medicine, other measures can be taken to calm the patient. For example, a dimmed night light or a clear clock on the wall may help. >>



A human presence brings calmness

Having someone sitting next to the patient, holding their hands or giving them a relaxing massage can be very calming for them. Calming music is also often appreciated and effective.

Reduced awareness – hearing and touch senses remain

The normal progression when someone is dying is that their level of consciousness decreases until they eventually become unconscious. Despite their decreasing capabilities, however, their senses of hearing, touch and perhaps even smell often remain for some time.

This means that, as a close relative, you could consider talking to – rather than about – the person who is dying. Many very sick people are calmed by a touch or a tactile massage even though they are not awake.

Breathing

A sign that the patient is coming to the end of their life is when their breathing becomes weaker, shallower and possibly also irregular. It can stop altogether and then start up again. Sitting with the patient without knowing whether or not they will breathe again can be difficult for a close relative. Another sign that the end of life is approaching is when the nostrils widen with nasal flaring, which can also give the impression that the nose has become more pointed, narrower and sometimes whiter.

Provision of oxygen towards the end of life

It is not uncommon for close relatives to feel stressed when the patient's condition deteriorates and their breathing is affected. It is common and natural to think that the patient could be helped by oxygen provided via, for example, a nasal cannula. However, the provision of oxygen in the final stages of life is usually not crucial because the patient is not conscious and cannot perceive the reduced oxygenation. If the patient is conscious and experiencing breathlessness, low doses of morphine can in most cases be given

instead of oxygen. In practice, it is therefore rarely a problem if there is no supplementary oxygen available for end of life care. However, what is important is what the patient feels. So, if the person has been on oxygen for a long period, this does not have to be discontinued if it provides a feeling of safety in the last part of life, regardless of the arguments for or against. When the patient is no longer conscious, the usage can then be reassessed in terms of the possible perceived effect.

Wheeziness

In some cases, wheeziness can occur in the final stages of life. This is caused by mucous moving up and down the windpipe. This wheeziness may make a close relative feel stressed. However, if the patient is unconscious, they are unlikely to be troubled by this. In other words, the mucous/wheeziness does not necessarily need be eliminated. Sucking away the mucous should be avoided, as it irritates the throat and does not reduce the wheeziness. Raising the head and changing the patient's position are non-pharmacological measures that can help in this regard.

Skin and body

A sign that blood circulation is affected when death is imminent is that the person's hands and feet become cold or dark. Another sign is that their skin becomes pale or yellowish, as the body has to prioritize the blood supply to the vital organs. The legs and sides (around the waist) may become somewhat blue and spotted.

Fever

When a person is dying, they may sometimes become feverish and get sweaty, warm and a little rosy, while their feet remain cold. If the patient is not troubled by the fever, no fever-reducing medication is required. Here too, the benefits should be weighed against the discomfort that is being experienced.



Support for close relatives

All relatives, regardless of whether adults or children, have a statutory right to receive information, advice and support. You also have the right to receive information about how the sick person can get the best possible support.

A municipality's assistance counsellor assesses and decides on support measures outside the hospital. The assistance counsellor also assesses the need for the provision of, for example, home care, an assistant, home respite, special accommodation, short-term accommodation or regular short-term care placements. The assistance counsellor can provide information about the support available in your specific municipality. Some county councils also have patient advisors who can provide further information. The eligibility and sums regarding economic assistance, as well as the processing routines, vary between municipalities. You can contact the assistance counsellor via the municipality's switchboard to obtain information about the situation in your particular municipality.

More information is available at
www.anhoriga.se

Benefit for care of close relatives

In order for you to be able to be with a sick person without having to use up your holiday allowance, it is possible to receive a benefit for care of closely related persons, which is called "Närståendepening".

Benefits for care of closely related persons are approved and paid out by Försäkringskassan (Swedish Social Insurance Agency). A doctor's certificate has to be submitted to Försäkringskassan in order to be granted the benefit for care of closely related persons. The certificate is issued in the name of the sick person and is sent to Försäkringskassan, which then approves payment of the benefit. Close relatives can then make reference to that certificate. To be paid the benefit, you have to register yourself whether you wish to receive the allowance for whole days or parts of days. The maximum benefit that can be paid to the relatives of a sick person is 100 days.

The benefit can be received by different relatives, one at a time and on different occasions. Check with the responsible doctor or nurse if you are interested in the possibility of receiving the benefit for care of closely related persons.

More information is available at
www.forsakringskassan.se

Statutory right to a permanent care contact

As a close relative of someone who is approaching the end of their life, you are entitled to have a permanent care contact, who is responsible for coordinating and planning the patient's care. The planning should be designed to make it easy for everyone involved in the care to provide it, even when the permanent care contact is not available. If the need for this arises, the manager of each of the units with which the patient has contact is responsible for appointing a permanent care contact. Ask a member of staff, such as a nurse or doctor, if you would like to have a permanent care contact.

Aid and assistance

Many close relatives find that the most important support consists of concrete solutions to concrete problems. These may include various aids that facilitate personal hygiene, getting dressed and undressed, meals, transporting the patient, incontinence problems or the prevention/treatment of bedsores. Occupational therapists, physiotherapists and nursing staff can help you review and test various aids that can hopefully make your life a little easier. The cost of such aid varies in different municipalities.

More information about education and support for close relatives is available at

www.anhoriga.se



Coping for an indefinite length of time

Bear in mind that you have to have the energy to cope right through to the end. Nobody knows exactly how an illness will progress. For some people it takes days or weeks, whereas for others it may take months. It may therefore be taxing for you if you try to do too much right from the very start. The level of commitment has to be reasonable and realistic.

You are welcome to discuss with staff how you wish to receive information about various matters. For example, it is important that you feel confident that the staff will contact you if changes occur that mean you have to get there quickly – or that they will tell you if they think you should not leave the patient.

At the same time, it is important to be aware that unforeseen things can happen. As a close relative, you can never guarantee that you will be able to be there at the actual moment of death. It can often be the case that the patient “takes the opportunity” when nobody is in the room. It is therefore not a failure on your behalf if you

do not manage to be there at the exact moment when a person you love dies. You should therefore not be too hard on yourself. Do not be afraid to tell the staff if you would like to stay or sleep in the room or in the vicinity of the ward. Such requests can usually be fulfilled.

How long is there left?

– an unanswerable question

A common question that is basically impossible to answer is “how long does the patient have left?” Staff should avoid specifying a particular time because there is a considerable risk that the patient or close relative will become fixated on the period of time that is stated, which may well not be correct anyway. The truth is that no one knows for sure.

Instead, it is better to focus on making every day as good as possible based on the circumstances.

Can I travel?

It may be the case that you have planned a trip or another event and you feel unsure if you can or dare to travel away from the patient. In these circumstances, it is best for you to decide yourself what you should do. You should not have to risk feeling that you travelled away based on someone else's advice and then regret it.

If you are unsure about travelling, one piece of advice is to consider what you think the patient would have liked you to do. Or, better still, discuss the matter with the patient, if that is possible. They will often answer: "Of course you should go". It is easy to forget the possibility of actually discussing such matters with the patient. This also applies when sitting next to the patient in silence and wondering what they are thinking. Why not ask them? It could turn into a very pleasant conversation.

In the end, the most important thing to consider is how you would feel if the patient died while you were away. Would you regret it? Because you cannot turn back time.

Also bear in mind that close relatives can make different choices, and not everyone has to have the same approach. Coming to an agreement with the patient is one way of helping you stand firmly by your decision. Then it does not matter what other people around you may say or think.

How to avoid feeling responsible or guilty

As a close relative, you can help the medical staff understand how the patient would want things to be if they could communicate, in terms of planning the care that is given. You can also state how you perceive the situation yourself, and whether the plans being proposed or considered feel reasonable.

However, it is always the doctor's responsibility to decide whether to withdraw or not use measures that could prolong the patient's life. It is important that you know that such issues are ultimately never your responsibility, even though your views are, of course, important.



Finding a different type of hope

Even in a situation in which a cure is no longer possible, a lot can be done to ensure the patient is alleviated from symptoms and instead experiences a sense of peace. A key aspect is to identify what provides hope for the patient. Such hope may not immediately be obvious, but hope can gradually grow even in a seemingly hopeless situation.

Remember not to wait too long to do things that are important to you. Even if you feel there is plenty of time, you should do such things sooner rather than later, as nobody knows how the situation will develop further down the line.

A patient or close relative should never feel they have been deserted. The members of staff are there, at your side, to provide the necessary support, including in the final stages of life.



Betaniastiftelsen

BETANIASTIFTELSEN

Postal address:
Högbergsgatan 13
116 20 Stockholm
info@betaniastiftelsen.nu
www.betaniastiftelsen.nu

PRODUCTION

Author, editor
Johan Sundelöf, MD, PhD,
Head of Programme,
Betaniastiftelsen
Translation
Nick Butler
Reviewed
Ian Nicholson

Design
Ohlsson Stridbeck
Layout
Moa Roos Svensson,
Communicator, Betaniastiftelsen
Illustration "Life links"
Rebecka Sundelöf
Printer
Wessmans Musikförlag AB,
Visby





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