

# Information for people involved in a death

This watch bag is offered to you by the care institution where your loved one is staying. Hopefully, this Watch bag will offer relief in a period you are facing in which watchfulness is central. Because watchfulness often comes unexpectedly, this bag is filled with products you may use during this period. Think of a candle to create an atmosphere of trust, skin oil to massage your loved one's hands, a notebook to write down important matters and a colouring book with coloured pencils as a distraction. A comb, toothbrush, handkerchiefs and lip balm for your own care should watchfulness be suddenly necessary. For after the death of your loved one, the bag also contains an aluminium screw box that you can use as a lock of hair box or storage box for smaller jewellery. A death brings with it a lot that no one is fully prepared for. Moreover, practical matters often cut across all feelings. This folder provides information about the dying phase and waking. If you have any questions after reading this leaflet, do not hesitate to ask the nurse, GP or other staff. We wish you a lot of strength and fortitude. At the end of life, physical and mental changes take place that indicate approaching death. This is sometimes after a short, sometimes after a long illness. We do not see all the changes mentioned in this leaflet in every dying person and not to the same extent. The order in which they appear also differs from person to person: every person and every deathbed is unique. The information addresses potential questions you may have and hopefully encourages you to ask new ones. If you have any questions, you can ask the nurse, GP or other employees.

#### Letting go of life

Dying means letting go of life. Leave everything you love behind. This is a difficult task for both the dying person and their loved ones. Every deathbed has its own time and its own pace. Sometimes the mind seems ready, but the body isn't ready yet, sometimes it's the other way around. As death approaches, the dying person can experience a kind of relief and this can be felt by the environment: as if the dying person then lets go and surrenders. You will notice that a dying process brings both difficult and beautiful moments: moments of sadness, fear, powerlessness, anger, but also of gratitude, resignation, love, humour and hope. Often, a loved one is the appropriate person to assist the dying person. That is not an easy task. Talking to people you trust, such as family and friends, provides support.

#### What if children are involved?

When a child is confronted with a situation in which a loved one is going to die, it is important to involve the child as much as possible, depending on age and level. This prevents a child from creating its own fantasy world that is unrealistic in relation to reality, as a result of which the child may have to deal with more trauma than necessary. Being honest, listening to the child and involvement in every phase appropriate to the age of the child is therefore of great importance.

## Watching

When death is near, you can agree to start watching. This means being quietly present day and night with the dying person, taking turns or together. Waiting always takes more time than you think. Death can take a long time. To turn waiting into real watching, time and inner space are needed. Adjust your agenda, cancel appointments. Make sure there is sufficient childcare for other obligations, such as your work, caring for children or pets. Those who watch and wait do not have to talk all the time. Just being together 4 can offer a lot of peace and comfort. Create an atmosphere of trust, for example by burning (electric) candles, placing pictures or a

beautiful flower, dimming the light, praying, listening to music or reading something. Music, which can be turned on and off gently, can make the silence more peaceful and encourage conversation. Watching can be a time for a farewell rite, such as the blessing of the sick or a custom ritual. Often, this is also a time for reminiscing and telling anecdotes from better times. Don't be disappointed if you don't get a response. People are usually too weak to react, but they certainly appreciate your effort. If possible, take care of yourself a little too. For example, by alternating with each other, by continuing to eat well and by taking sufficient rest. Variety gives you room to relax and do something different. In this way, waking can be a very valuable period in which one can support each other as family and friends.

#### What can you do as a loved one?

It can be nice to take part in the care in small ways: placing the pillow properly, oral care, combing the hair gently, a nice scent and helping with bathing. Feel free to discuss your wishes with the nurse. You may like to collect memories, for example, by cutting a lock of hair or photographing the hands, possibly with other hands. An attitude of calm and confidence is important. It helps the dying person if he has the feeling that life can be let go of. If you notice that there are still matters that occupy the dying person in such a way that they complicate the dying process, check together whether you can discuss this. You can also think of calling in a chaplain or someone else with experience and expertise in the psychosocial field.

#### What can help

It can be music, poems, stories, or nature, but also your philosophy of life or belief. Everyone has their own way of dealing with this, and all ways are good. It can be in small things, short moments or a sense of togetherness.

## The dying phase

#### Less need for food and drink

People who die often have little or no need for food and fluids. They can lose weight quickly. The body changes: the cheeks sink in, the nose becomes pointed and the eyes sink deeper into their sockets. 5 Fluid deficiency normally leads to thirst, but in the dying phase, this feeling of thirst hardly occurs, if at all. Because the lips and mouth are often dry, it can be nice if they are moistened occasionally. This can be done in various ways. The nurse or doctor can tell you more about this. The less a person drinks, the less he urinates. The sphincter muscles of the bladder often work less effectively and there may be urine leakage. In that case, measures can be taken to limit the discomfort – using incontinence material or a bladder catheter.

#### Changes in breathing

In people who are about to die, halting and irregular breathing is usually a sign that death is fast approaching. Breathing then regularly stops and then starts again with a deep sigh. The time between breaths becomes longer and longer, sometimes up to half a minute. This is not experienced by the dying person as shortness of breath. The face often looks very calm, even with this faltering breathing. Only when there are signs of severe discomfort do doctors decide to administer additional sedative drugs. Because the normal coughing and swallowing stimuli disappear, mucus can accumulate in the pharynx or trachea. This can lead to a rattling sound when breathing. Bystanders sometimes think that the dying person is then seriously short of breath or even in danger of suffocating, but it is something that does not bother the person himself. The phase of irregular breathing and rattles is followed by longer and longer pauses in breathing, shallower breathing and finally the last breath, in many cases no more than a gasp after a (very) long silence.

#### **Blood circulation decreases**

The body maintains blood flow to the heart and lungs for as long as possible. The blood withdraws more and more to the chest and abdominal cavities. This can make hands, arms, feet, legs and nose feel cold. Purple-blue spots may appear on the legs. The complexion becomes grey and with the last breath, the colour completely disappears from the face ('death pale'). This often recovers a few hours after death. As a result, someone looks more like themselves again.

#### Less contact – change in consciousness

In the dying phase, the periods of wakefulness are shorter and shorter. The dying person seems to withdraw more and more and is increasingly difficult to reach. Often, the dying person no longer understands everything that is being said. Yet, he or she probably hears everything and remains sensitive to sound to the end. Rest around the dying is important. Make sure there are not too many people around the bed at the same time and avoid loud voices or noises. Talking softly often has a calming effect. Touch can be soothing, but this differs per person and per moment. In the period before death, consciousness continues to decline. In the last hours, this usually causes a person to slip into a deep sleep or coma.

#### **Restlessness and confusion**

It is possible that a person's behaviour changes due to a lowered level of consciousness. The dying person then looks differently out of his eyes and may appear restless and confused. This is called delirium. It seems as if someone

experiences or sees all sorts of things, but what exactly, is not clear. This is quite common in the last days of life and especially in the last hours. The dying person often makes small (hand) movements, as if to pick or point at something. You can offer support by being calmly present and by not contradicting any delusions or hallucinations, but also by not going along with them. If there are signs of serious discomfort, such as shortness of breath, restlessness or pain, the doctor may decide to prescribe sedative medicines. We call this palliative sedation. You will receive more information about this from the doctor and nurse if applicable.

## After the death

If your loved one has passed away, you can take the time to say goodbye in a way that is right for you. You can then contact the funeral director. If you want to help with the final care, you can. The nurse or carer can guide you in this. Remember that even in this sad period of saying goodbye and mourning, there are people who want to assist you.

#### **Bereavement counselling**

The general practitioner must be informed of the death the next day or after the weekend. You can contact us yourself or a hospital or healthcare institution where you are located can do this for you. In the initial care at home, but also at a later stage, the GP can play a role in guiding you as a surviving relative.

#### Warn the funeral director

Once you, as a surviving relative, have completed the formalities in the care institution yourself, you can warn a funeral director. The funeral director can arrange a lot for you. Which funeral director you choose depends on what has or has not been arranged. Initially, an insurance policy may be present in the personal papers of the deceased. If a policy is available, you can contact the relevant funeral insurer or entrepreneur mentioned in it. It is also possible that the deceased has discussed wishes about the funeral with you as the next of kin during his or her lifetime. You will then know which funeral director to contact. In all other cases, you are free to make a choice.

#### **Personal wishes**

If you have any personal wishes with regard to make-up, clothing, jewellery and the like, you can make these known to the funeral director. Ritual washing can take place in consultation with the funeral director.

#### Making available to science

If the deceased wishes to make themselves available to science, he or she had to register with a university during his or her life. A deceased person can only be made available to science if the next of kin are in possession of proof in which a university has given permission for a later availability. Consultations on this will take place with the relevant university.

#### **Unnatural death**

An unnatural death means that someone has died from an unnatural cause. This includes a traffic accident or a crime. In the event of an unnatural death, the police and the judiciary will investigate the cause of death. As a result, a funeral visit can only take place when the deceased has been released by the public prosecutor.

We wish you much strength. Remember that even in this sad period of saying goodbye and mourning, there are people who want to assist you. If you have any questions or would like to talk to someone, feel free to contact the doctor or other health care professional.

For more information or if you want to read this leaflet in another language, go to www.waaktas.nl

Sources: www.iknl. nl and www.etz.nl.waaktas. nl www.waaktas.nl

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