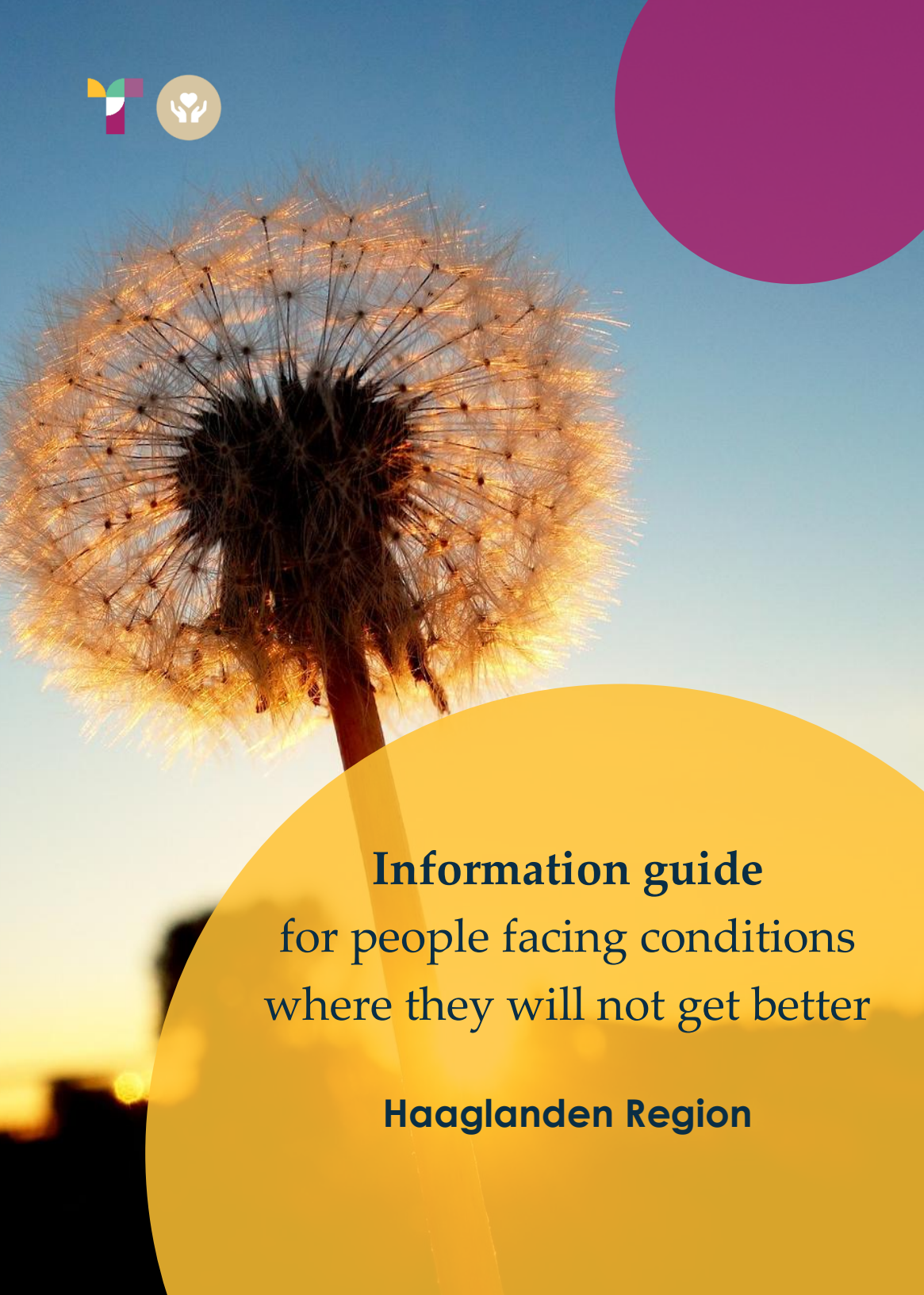


Information guide

for people facing conditions where they will not get better

Haaglanden Region

At the end of your life
my big world becomes small.
Everything is suddenly incomprehensible
and hurts me inside.
What we thought was so important together,
loses its lustre, loses its meaning.
But behind your closed eyes,
there is a new beginning for you.

Information guide for people with life-limiting conditions/ with incurable conditions

What is in this guide?

In this guide we have tried to include everything you need during the last part of your life or that of your friend or relative.

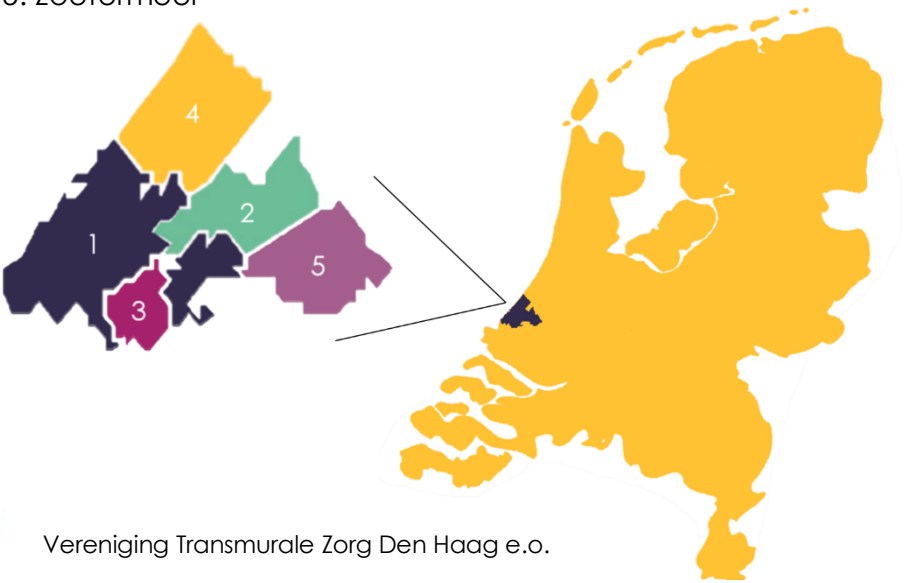
This information guide was put together by the Palliative Care Network Haaglanden.

If you think something is missing or information has changed, please let us know at info@transmuralezorg.nl.
This information guide can also be ordered free of charge using the email address provided above.

Please note that all the referral links are in Dutch.

We collaborate with organisations from these municipalities:

1. The Hague
2. Leidschendam - Voorburg
3. Rijswijk
4. Wassenaar
5. Zoetermeer



Contents

1. What is palliative care?

People with fragile health or those who will not get better can receive palliative care.
Palliative care is not focused on getting better, but rather on your well-being and quality of life.
Despite the fact that you are ill, palliative care focuses on making your life as pleasant and enjoyable as possible for you (by preventing and reducing your symptoms).
What matters first and foremost is what you, your family and friends value and need.

Who can provide palliative care?

Various caregivers can still do a great deal for you, your family and friends, for example:

- doctors;
- nurses;
- carers;
- spiritual caregivers;
- psychologists.

What can caregivers help you with?

They can help you with your questions, symptoms and problems. This could include:

- physical complaints, such as pain or nausea;
- emotional problems, such as anxiety or sadness;
- making important decisions;
- questions about options in the hospital, at home or another care facility;
- questions about the final stage of life.

Who is palliative care for?

Palliative care is not just for people in the final phase of life.
It can also be of great help to people who are not getting better, but still have time to live.
Palliative care can help keep your life as pleasant and enjoyable as possible, despite your illness.

Care in the final phase of life

The final phase of life is called the terminal phase.
This phase can last several weeks or months.
The most important thing at this stage is to make sure you are comfortable and to help minimise your symptoms.
You can also talk to someone about how you feel and about saying goodbye.
Your family and friends can also get help, for example with saying goodbye.

Why is palliative care important?

Research shows that people who receive good palliative care feel better in the final phase of their lives:

- They are often less gloomy and anxious.
- They suffer less from other symptoms and problems.
- They experience a better quality of life.
- They need fewer (unexpected) hospital visits.
- They are much more likely to pass away in familiar surroundings.
- Family and friends are able to cope with the loss better.

2. Advance care planning

It is important to state your wishes and limits for treatment.
These wishes and boundaries can be written down in a care plan.
We call this advance care planning or proactive care planning.
Creating a care plan can help provide you with peace of mind.

To create the care plan, you must discuss with your care provider what is important to you.
Your loved one can be with you for this, of course.
In the conversation, a discussion will take place on what to expect in the final phase of your life.
Consider, for example, symptoms that are common for your medical condition.

Your wishes and boundaries can of course change over the course of the palliative phase, there's nothing wrong with that.
The care plan then simply changes accordingly.
You can request a conversation about this yourself, for example with your general practitioner (GP) or district nurse.
We strive to ensure that your care plan goes with you if you are admitted to hospital, a nursing home or hospice.

3. Informal care

Caring for family and/or friends is natural for many people and is done out of love for each other.
Informal care is caring for someone close to you without it being your profession.
Often, this care is provided by a partner, parents, children or friends.

When caring for a sick loved one, you might overlook your own needs.
It is important to take good care of yourself as well.
You can only look after someone else if you feel good yourself.

If you, as an informal carer, need help, you can sometimes turn to family, friends or neighbours.
You can also use informal care support.
Informal care support can be used to help you with:

- laws and regulations;
- money matters, such as allowances, co-payments, etc.;
- help and advice on, for example, handing over care or work and informal care;
- applications for household help.

Information and advise for caregivers is provided for by the municipality through the Social Support Act (Wmo).
Welfare organisations and/or social neighbourhood teams offer support or courses.

More information

You can find more information for anyone caring for another person in the brochure 'Looking out for Carers' from the LUMC.
W www.oogvoornaasten.nl

4. Palliative care at home

Many people who know they will not get better prefer to stay at home in their own environment.
In this case you can get care from, for example:

- your GP;
- a district nurse;
- a psychologist;
- a spiritual caregiver;
- a social worker;
- a volunteer.

4.1 Assistance from the GP

Feel free to contact your GP.
The GP is the central point of contact for care, advice and information.
You can discuss difficult issues with the GP, for example:

- the pros and cons of treatment;
- whether you want to be hospitalised or not;
- your wishes for the end of your life, dying with the help of a doctor and palliative sedation;
- care options at home, in hospice or in a nursing home during the last phase of your life.

Tips for discussing these topics

Beforehand, write down questions, doubts and other points you don't want to forget.
The e-book '*Praten over je levenseinde*' can help. This e-book contains information on talking to the doctor about boundaries, wishes and expectations around the end of life.
The book can be found via:
www.patientenfederatie.nl/extra/levenseinde

The role of the GP during and after hospitalisation

When you are in hospital, the GP does not automatically visit you.
If you do however want to talk to the GP, you can call the doctor's office .
When you return home from hospital, you can contact your GP yourself.
The GP assistant might contact you to ask how you are doing and whether you would like a visit from the GP.
Your GP can always contact the hospital for consultation.

The GP and partner and/or children

It is nice to have one fixed point of contact with whom the GP can interact, such as your partner.

4.2 Assistance from home care

The district home care nurse can do a great deal for you. He or she provides support and guidance at home.
This is more than just help with personal care, such as showering and dressing, wound care or pain management.

Home visits in the palliative phase

If you do not yet need to receive home care, you can use home visits in the palliative phase.
You can request an orientation meeting for this via your GP.
A nurse will then help you with any questions and problems, until district home nursing care is started.

What can you discuss with the district nurse?

It is also possible to talk about being ill and treatment.
You can discuss questions such as:

- How to proceed?
- How can I best prepare for what is to come?
- Where, when, for what and from whom can I get care and help?
- What can I do about my symptoms, such as nausea, pain or a dry mouth?

Applying for home care

If you are in hospital:
Discuss this with the ward nurse.

If you are at home:
Please contact your GP and the home care organisation of your choice.

What happens after your registration?

After you register, the district nurse will contact you by phone to make an appointment.
The district nurse can tell you more about the cost of the care. This is usually covered by your health insurance.

Home care organisations in the Haaglanden region

In the Haaglanden region, the following home care organisations are members of the Palliative Care Network Haaglanden:

Amarosa
T 070 512 32 00
E info@amarosa.nl

Cardia
T 070 - 800 88 88
E klantenbureau@cardia.nl

Evita Zorg
T 070 - 314 16 00
E info@evitazorg.nl

Florence
T 070 - 413 10 00
E info@florence.nl

Haagse Wijk- en Woonzorg
T 070 - 379 50 00
E info@hwwzorg.nl

Stichting Thuiszorg Nescare
T 070 – 200 23 60
E info@nescare.nl

Respect
T 070 - 306 91 70
E info@respectzorg.nl

Liefs Thuis
T 085 – 8000 930
E info@liefsthuis.nl

Saffier
T 0800 – 7233 437
E info@saffiergroep.nl

Stichting Eykenburg
T 070 - 750 70 00
E info@eykenburg.nl

Stichting Johannahuis
T 070 – 512 45 00
E info@vanommerenpark.nl

WoonZorgcentra Haaglanden
T 070 - 756 16 00

4.3 Psychosocial counselling and spiritual care

When you are seriously ill, you, your family and friends have a lot to deal with.
Illness or approaching death can make you feel scared, sad, angry and/or powerless.
Talking to someone can help you deal with questions and emotions.

There are several care providers who can help you, these include:

- a social worker;
- general practice-based nurse specialist;
- a psychologist;
- a spiritual caregiver.

You can be helped by several care providers at the same time.

Professional secrecy

All psychosocial care providers have professional confidentiality, which means they are not allowed to tell anyone else the content of your discussions with them.
Only if you give your consent can the care provider share information from your discussions with another care provider helping you.

What do the different care providers do?

Social worker

A social worker helps and advises on issues surrounding the disease and treatment.
Among other things, the social worker can help with:

- changes in the day-to-day lives of you, your family and friends;
- your concerns about being ill and the consequences of the illness;
- the impact of the illness on you, your family and friends;

- involving other care providers if necessary.

You can contact a social worker through the municipality.
Getting help from a social worker costs you nothing.

Primary care nurse specialist

Many GPs employ a primary care nurse specialist for mental health.
Many people are not happy about being referred to a psychologist (immediately).
Among other things, the primary care nurse specialist can help with:

- anxiety;
- sadness;
- problems in the relationship;
- recurring memories of an unpleasant event;
- symptoms you already had which get worse or recur due to the illness.

The GP can refer you to the mental health nurse specialist and make an appointment.
The costs are covered by the basic health insurance.
If the mental health nurse specialist assesses that the complaints are more severe, he/she may recommend referral to the psychologist.
The costs of a psychologist are usually reimbursed through your health insurance policy.

Psychologist

A psychologist helps with mental health symptoms caused by your illness.
A psychologist treats by:

- talking about symptoms and problems;
- by doing exercises or assignments with you.

The costs are usually reimbursed through your health insurance.
You can be referred to a psychologist via your GP.

Spiritual caregiver

A spiritual caregiver provides guidance, help and advice in reflecting on what is happening in life.

This is does not necessarily have to be based on your faith or church, but it is possible to receive that kind of guidance. There are spiritual carers who work from a specific religious background.
This spiritual caregiver can fit in well with your religion and/or cultural background.

Questions with which the spiritual caregiver can help you include:

- Why is this happening to me?
- What is important to me now?
- Who am I? Who do I want to be?
- How do I handle this situation?
- What do I need?
- What is the point of my life?

Counselling is free for people aged 50 and above, people with life-threatening illnesses and their families and friends.
Spiritual care is also free for adults and children in the palliative phase of a life-threatening illness.

You can get in touch with a spiritual caregiver via Haagsche Zin or the Centrum voor Levensvragen Den Haag.

Haagsche Zin/ Centrum voor Levensvragen Den Haag
T 06 – 82 38 85 20
E info@haagsche-zin.nl
W www.haagsche-zin.nl

4.4 Household help

Keeping the house clean and tidy can take a lot of energy.
It is nice to have help with this, so that you have energy for other things.
If you can get household help, you will pay a co-payment.
This is determined according to your income.
This help falls under the Social Support Act (Wmo) and you can apply via the municipalities.

Municipality of The Hague
T 14 070
W www.denhaag.nl

Municipality of Leidschendam - Voorburg
T 14 070
W www.lv.nl/huishoudelijke-ondersteuning

Municipality of Rijswijk
T 14 070
W www.rijswijk.nl/inwoners/leven/zorg/wmo

Municipality of Wassenaar
T 14 070
W www.wassenaar.nl/wet-maatschappelijke-ondersteuning-wmo

Municipality of Zoetermeer
T 14 079
W www.zoetermeer.nl/wet-maatschappelijke-ondersteuning-wmo

4.5 Welfare and volunteer organisations

Welfare organisations

Wijkz and Incluzio Haags Welzijn are welfare organisations based in the Hague that is happy to help you with any questions about informal care, getting older, living safe and independent, and everything that comes with it.
The senior care consultants can discuss your situation with you and work together to find solutions that fit your needs.

Among other things, they can help you with questions about:

- Information, advice and solutions to live independently for as long as possible
- Making social contacts
- Activities and facilities in the neighbourhood that meet your needs
- Help with administration and finances
- Contributing ideas on arranging (home) care, so you get the care you need
- Meal and shopping services
- Transport (and assistance) to take you to appointments or for other necessary trips
- Volunteer work

Wijkz
T 070 205 22 22
W www.wijkz.nl
W www.haagsesenioren.nl

Incluzio Haags Welzijn
T 088 298 65 20
W www.incluziohaagswelzijn.nl

Other welfare organisations in the Haaglanden region

Stichting Maatschappelijke Ondersteuning Wassenaar
T 070 511 22 26
W www.smowassenaar.nl

Welzijn Rijswijk
T 070 757 92 00
W www.welzijn-rijswijk.nl

Welzijn Scheveningen
T 070 416 20 20
W **www.welzijnscheveningen.nl**

Woej Leidschendam-Voorburg
T 070 205 47 50
W www.woej.nl

Volunteers for Terminal Care

Often, your family and friends want to continue caring for you themselves.
However, if it becomes difficult for your family and friends to keep up the care, there are also volunteers who can help.
Or if you cannot be alone.
They come to your home or a care facility.
Volunteers do not do medical, nursing or heavy household tasks.
They often do whatever family and friends do, such as:

- offer a listening ear;
- help with eating and drinking;
- help bringing someone to the toilet;
- be on hand for a little while when a loved one goes away for an errand or something else;
- look out for you.

Help from others, such as GPs and district nurses, continues as usual.
The help of a volunteer can be requested if a person is expected to have less than three months to live.
You can request help from a volunteer by phone or email.
A referral is not necessary.
There is no waiting list and it is free.

Volunteers for Terminal Care
The Hague, Leidschendam, Voorburg, Rijswijk, Wassenaar, Zoetermeer
T 070 754 13 30
W www.terminalezorg.nl

4.6 Palliative advisory team in the hospital

The Palliative Advisory Team (PAT)/ Team Support and Palliative Care (TOPZ) at the hospital can help you discuss your wishes and needs and those of your family and friends.
The PAT/TOPZ will work with you to see how they can best help you, your family and friends.
Topics you can discuss include:

- your symptoms, such as pain and nausea;
- the impact of your illness on your work or family and friends;
- information about the last phase of your life;
- the help you, your family and friends can get.

Palliative Care consultation teams in the Haaglanden region

You are eligible for the PAT or TOPZ if you are hospitalised or receiving treatment at the hospital.
The nurse can refer you to the PAT or TOPZ if you want this.
In the Haaglanden region, the following Palliative Care Consultation Teams are affiliated with the Palliative Care Network Haaglanden:

Haaglanden Medical Centre (HMC)
Support and Palliative Care Team (TOPZ)
T 088 - 979 30 40
E palliatie@haaglandenmc.nl
W www.haaglandenmc.nl (search term: Palliative Care Department)

HagaZiekenhuis The Hague and/or Zoetermeer
Palliative Advisory Team (PAT)
T 070 - 210 26 05 (The Hague)
T 079 - 346 28 80 (Zoetermeer)
W https://www.hagaziekenhuis.nl/specialismen/palliatieve-zorg/

4.7 Devices and appliances

Many people would prefer to live independently at home for as long as possible, despite disability, old age or illness.
Sometimes daily activities such as walking, showering or going to the toilet become more difficult.
A wheelchair, shower chair or commode can help someone remain independent for as long as possible.
At the home care shop, you can borrow, rent or buy devices and appliances. Your health insurance will know what rules there are for devices and can inform you about them.
They will also know where you can get a device.
Sometimes you pay a co-payment for devices.

When problems suddenly arise, it is useful to already have some devices for this on hand.
Things like hygienic gloves or an incontinence pad, for instance.
You can buy this from a chemist or drug store.

Occupational therapy

An occupational therapist can help you perform daily activities yourself as much as possible.
Treatment from an occupational therapist could consist of:

- practising;
- learning to do your daily activities in a certain way;
- using devices or appliances;
- educating your family and friends.

You can request an occupational therapist via your GP.
Usually, this help is covered by your health insurance.

The ‘cuddle bed’

A special device for the last weeks of life is the ‘cuddle bed’.
The cuddle bed is a guest bed for people who would like to be physically close to their loved one.
It consists of a frame with a special mattress that can be widened.
As such, it can attach easily to an adjustable hospital bed.
This makes it possible for people to enjoy physical closeness.

Home care organisations (see page 15) can help you apply for a cuddle bed. The use of the cuddle bed costs about 20 euros.

Contact details Haaglanden region

For enquiries, you can also contact customer service at:

Vegro
T 0900 288 77 66

Medipoint
T 088 102 01 00

4.8 Personal alarms

Sometimes it can be an anxious thought that there is no help nearby. Your family or friends may also find it difficult to leave you alone for fear of something happening.
Personal alarms can be helpful in such cases.

A personal alarm is a system, which allows you to contact a monitoring centre 24 hours a day through a transmitter on your neck or wrist.
The control room calls relatives, friends or neighbours who have signed up as key addresses.
If necessary, home care can also be called.

Requesting a personal alarm

Many healthcare organisations provide personal alarm systems. You can ask your GP, district nurse or other care provider about the possibilities.
You can also contact the municipality for more information.

5. When living at home is no longer possible

Many people want to die at home.
Sometimes this is not possible, for example because the care becomes too intensive to provide at home.

5.1 Hospices

You can go to a hospice if you are expected to have no more than 3 months to live.
A hospice provides a homely environment for people in the final phase of their lives.
There is someone there 24 hours a day to help you.
A hospice employs specially trained volunteers in addition to nurses.
Care and attention focuses on making life in this final phase as bearable and comfortable as possible.

What does a hospice look like?

A hospice is often small, with about 4 to 8 rooms.
You have your own room, and a lot of attention is paid to you.
In a hospice, a homely environment is provided, while sufficient nursing assistance is still available.
It is important that you feel at home.
It may be nice to visit beforehand to have a look.

How can you register?

A (GP) doctor, district nurse or transfer nurse can help you register with a hospice.
You can also register yourself, or with the assistance of your family or friends.

Costs

Your health insurer pays for nursing and care at the hospice.
This is done through the mandatory basic health insurance.

Hospices charge a co-payment for hospice stays .
This co-payment is sometimes partly paid by the supplementary health insurance.
Call your insurer to ask what they reimburse.

Hospices in the Haaglanden region

In the Haaglanden region, the following hospices are affiliated with the Palliative Care Network Haaglanden:

Jacobshospice
T 070 308 10 81
W www.jacobshospice.nl

Hospice Het Vliethuys
T 070 340 13 15
W www.hetvliethuys.nl

Hospice Wassenaar
T 070 779 61 50
W www.hospicewassenaar.nl

Hospice de Witte Roos
T 070 204 00 47
W www.hospicedewitteroos.nl

Xenia
For young adults, 16-40 years old
T 071 513 54 54
W www.xenialeiden.nl

Hospice Zoetermeer
T 079 - 347 89 27
W www.hospicezoetermeer.nl

5.2 Staying in a nursing home

If you are temporarily unable to live at home in the last phase of life, you can stay in a nursing home.
We call this first-line palliative stay or a palliative unit.
Your GP can tell you more about the possibilities and conditions.
First-line palliative stay is reimbursed from the basic insurance or from the Long-Term Care Act.
An excess pay does apply.

Palliative Units in the Haaglanden region

A palliative unit is a ward in a nursing home for palliative patients.

Hospice Claude Monet
T 070 750 7000
W www.eykenburg.nl

Hospice WZH Waterhof
T 070 – 756 15 00
W www.wzh.nl

Hospice Saffier Nolenshaghe
T 070 – 447 01 00
W www.saffiergroep.nl

WelThuis Vivaldi – De Irishof
T 088 – 929 30 40
W www.welthuis.nl

6. Physical symptoms in the final phase of life

Many people suffer from the same kind of symptoms in the final phase of their lives.
It is important to talk to your doctor about this.
Your doctor can then seek appropriate treatment for you.
It can be useful to have some medications in the house for emergencies.
Contact your GP about this.

6.1 Common symptoms

Exhaustion and fatigue

Exhaustion and fatigue are the most common and difficult symptoms to treat.
A good night's sleep, a fixed resting time during the day and properly spreading your energy out throughout the day can help.
Save your energy for important things.
Sometimes your doctor may give medication that gives you a boost, or medication to help you sleep better.

Pain

Pain can manifest itself in different ways.
It is important to know what you can do if you experience pain.
Discuss this with your GP.
Your doctor can then work with you to create a plan.

Shortness of breath

Shortness of breath can have several causes, for example:

- anxiety;
- breathing incorrectly;
- fluid behind your lungs;
- anaemia.

If you suffer from shortness of breath, you should report this to your doctor.
Your doctor will need to investigate what is going on and what can be done about it.
Sometimes it helps to sit up straight or do breathing exercises.

Confusion and delirium

If you are very ill, your illness or your medication may cause you to feel confused.
This is called delirium.

You may pluck at things in the air, have very vivid dreams, or hallucinate.
You may also become very drowsy and sleepy.
To recover from delirium, it may help, for example:

- to be in familiar surroundings;
- to have peace and regularity;
- to drink regularly;
- to administer or reduce medication if necessary;
- to refrain from contradicting the confused person.

People may not recover from delirium in the last phase of life.

Constipation

Constipation is a common problem.
There is constipation if:

- bowel movements are difficult;
- your poo is very hard;
- if you are not experiencing bowel movements at all.

Constipation is sometimes difficult to treat.
Your doctor can prescribe various medications; these medications are called laxatives.

Eating, drinking and oral care

When you are ill, your sense of taste and appetite may change. This is a normal signal from your body and does not cause you to die faster.
You may also experience problems with swallowing, making it difficult to eat properly.
Sometimes a speech therapist can be called in to help you with these problems.

It is also important to keep drinking fluids.
This prevents dehydration and constipation.
It may help, for example:

- to only eat what you have an appetite for;

- eat small portions more often;
- eat fresh, acidic meals without too much spice.

Medications can give you a dry mouth.
You may not be able to speak and taste as well.
Wounds and fungal infections in the mouth can develop more frequently as a result.
It is important to keep taking care of your mouth and lips.
Keeping your lips moist, continuing to brush your teeth and keeping your mouth clean can help.
You can always ask your GP for advice.

Nausea and vomiting

There are many causes that can make you feel nauseous, such as:

- eating too much;
- constipation;
- medications;
- your illness.

Your doctor can work with you to find treatment.

6.2 Treatments for pain

Morphine

If you are in a lot of pain or are very short of breath, your doctor may give you morphine to relieve these symptoms.
If you are given a lot of morphine, it can sometimes make you drowsy for a while.
There is an increased risk of confusion in the elderly and people with poor kidney function.

There are different types and ways of administering morphine.
It can be given as:

- tablet;
- drink;
- via a patch;
- via injection;
- via a pump through the skin.

All types of morphine work somewhat the same and have the same side effects.

There are many misunderstandings about morphine.
It is important to know:

- Morphine is not the drug a doctor uses for palliative sedation or euthanasia.
  However, you may also be given morphine during palliative sedation.
  This is done to combat symptoms like pain or tightness in the chest.
- Morphine does not shorten your life, even if you receive it in high doses.

There is no risk of addiction to morphine if you receive morphine in the last phase of life.

Palliative sedation

In palliative sedation, a doctor gives you medication to reduce your consciousness.
With the aim of alleviating suffering.
Your doctor will do this if, for example, you are in a lot of pain or are very short of breath.
Palliative sedation can only be done when other drugs are no longer effective.

There are two forms of palliative sedation:

- In intermittent sedation, the doctor puts you to sleep temporarily.
  Afterwards, you will wake up again.
  This could be used, for example, if you cannot sleep because of pain.
- Continuous sedation is administered until the person passes away.
  This is possible if your doctor thinks you have no more than a maximum of two weeks to live.
  Sometimes this needs to be done on short notice because you suddenly experience severe symptoms, such as severe pain, tightness in the chest or confusion.

With palliative sedation, you do not die from sedation or from lack of fluids.
You die as a result of your illness(es).
It is a natural death, but one in which you no longer suffer from pain or tightness of chest.

Starting palliative sedation is a medical decision.
The doctor will discuss this with you first.
If this is not possible, your doctor will consult with your family and/or friends.

7. Death

Most people die naturally.
You can discuss your options with a doctor if you want to choose to hasten the end of life or end your life (or have it ended).

What can you do before your death?

Even before your death, you can think about your wishes around saying goodbye.
Above all, discuss this with your family and friends around you.
You can also get in touch with the funeral director for a preliminary conversation.
You can discuss in this conversation:

- your wishes and the possibilities for the farewell;
- what your funeral should look like;
- your choice of burial or cremation;
- your choice of flowers, music and coffin.

7.1 Hastening the end of life

There are several ways to hasten the end of life, end your life or have your life ended, such as:

- consciously stopping eating and drinking;
- euthanasia;
- or assisted suicide.

Consciously stopping eating and drinking

In elderly and seriously ill people, at some point the body can no longer absorb food and liquids.
This is because the organs are no longer functioning properly.
Not eating and drinking is then a consequence of old age or illness. This is part of the natural dying process.

You can also choose to hasten the end of life yourself by deliberately not eating and drinking any more.
People sometimes do this because it is not possible for them to get euthanasia or because they do not want to depend on others.
If you have fragile health, stopping eating and drinking can help hasten the dying process.
However, it is important to discuss this with your family, friends and doctor before you stop eating and drinking.

You always have the right to stop eating and drinking.
The doctor should help you reduce any symptoms.
You usually die within 1 to 2 weeks of stopping eating and drinking.
This is not euthanasia.

Euthanasia and assisted suicide

You can ask your doctor for euthanasia or assisted suicide.
You make your own request for euthanasia in a conversation with your doctor.
Your doctor can then help you in the dying process by giving you medication that helps to bring about your death.

A doctor is never obliged to comply with a euthanasia request: a person does not have the right to euthanasia.
Some doctors do not perform euthanasia; in that case you will be referred to another doctor or to the Euthanasia Expertise Centre.

Also, the legal requirements of due care for euthanasia always apply.

What requirements of due care must the doctor adhere to?

The doctor must follow a number of due care requirements under the euthanasia law.
Such as checking that no pressure was put on you by others during the request for euthanasia.
Your doctor needs to be sure that you have thought carefully about the euthanasia request and other options.
Also, a second doctor (an SCEN physician) must always assess whether the due care requirements have been met.
These conditions also apply to doctor-assisted suicide.

What is the difference between euthanasia and assisted suicide?

Euthanasia is usually performed by the doctor with an infusion or injection.
In assisted suicide, the doctor hands you a drink containing a lethal agent.
You take that drink yourself.

How do you make a request for euthanasia or assisted suicide?

You can only make a euthanasia request yourself.
So your family or friends cannot make a euthanasia request for you.
If you are thinking about euthanasia or assisted suicide, it is important to talk to your doctor about it in time.
You can prepare a written euthanasia request in case you can no longer ask for euthanasia yourself.

Your family and friends can bring your previously drafted written euthanasia request to your doctor's attention at a time when you can no longer do it yourself.
It is important in that case that you have already discussed this with your GP yourself, so that your GP is aware of the wish you might have in this regard.

7.2 The final hours

It can be difficult to recognise when those final hours are coming.
You can tell that the end of life is approaching by the following things:

- you eat and drink less and less;
- you become increasingly drowsy and less responsive;
- your breathing becomes irregular and stops occasionally;
- your skin becomes cold and pale.

Dying can be quick (in hours) or very gradual (in days or weeks).

Less need to eat and drink

When you die, you usually have little or no desire to eat and drink.
You may lose weight quickly.
Your cheeks become sunken, your nose appears more angular and your eyes settle deeper into their sockets.
This is natural and is part of dying.
There are things family members or friends can do:

- You can give small sips to drink or wet the mouth with a wet gauze.
  They can also give some ice chips.
  Be careful if swallowing is difficult, the dying person may choke.
- You can apply a thin layer of petroleum jelly on the lips to make them less dry.
- Don't try to feed the person if they have no interest.
  This can cause choking, nausea, feeling full, lots of mucus in the throat and difficulty breathing.
- If your loved one drinks very little, he or she also urinates little.
  Bladder function often deteriorates.
  It sometimes fails to hold in urine.
  Incontinence pants (diapers), pads or a catheter (a tube to the bladder) can help collect urine in that case.
  This is done via home care or GP.

Breathing changes

When dying, you start breathing irregularly.
Breathing sometimes stops and then resumes with a deep sigh.
The time between breaths gets longer and longer, sometimes up to half a minute.
You will not feel short of breath in the process.
The face also looks calm.

More mucus may remain in your throat.
This is because the coughing and swallowing reflex stops working as well.
The mucus causes noises when breathing.
To your family and friends, you may appear to be short of breath or almost suffocating.
But you yourself are not affected.

You take fewer and fewer deep breaths.
Finally, there is the last breath, in many cases a small sigh after a (very) long silence.

Blood flows differently

The body makes sure that blood keeps flowing to your heart and lungs for as long as possible.
As a result, your hands, arms, feet, legs and nose get less blood.
They may feel cold to the touch.
Purple-blue spots may appear on your legs.
The face becomes paler, and at the last breath becomes completely pale (deathly pale).
After death, this becomes more normal again.
This makes a person look more like themselves a few hours after they die.

Less and less awake

When dying, you will become awake less often and for shorter periods of time.
You seem to be increasingly withdrawing from life.
Your family or friends may notice that you no longer understand everything they say.
You will probably hear them until the very end.
There are things family members or friends can do:

- Talking softly to the dying person often has a calming effect.
  Preferably no loud voices or noises.
- Touch can also give peace of mind.
  But this varies from person to person and moment to moment.
- Keeping everything calm is important.
- Make sure there are not too many people around the bed.

In the final hours, a dying person slips into a deep sleep or coma.

7.3 What should your family and/or friends do?

If your relative or friend has died at home, you can take your time to say goodbye.
Afterwards, call the GP.
The GP will come to examine the deceased.
This means that the GP examines the body to officially determine death.
The GP then completes the death papers.
Once the GP has done this, you can call the funeral director.

If you want to help with the final care, you can discuss this with the home care or the person providing the funeral.
They can help you with this.

Information from the central government on what to arrange in case of death
W www.rijksoverheid.nl/onderwerpen/overlijden

8. Help and advice on grief and loss

When you lose a loved one, the world stands still.
What often remains is the feeling that nothing matters anymore.
Grieving is important to go on with life.
Everyone grieves in their own way and at their own pace. Sometimes that takes more energy than you have.
Sometimes you have doubts, and need help.

More information

You can find more information for anyone caring for another person in the brochure 'Oog voor naasten' from the LUMC.

W www.oogvoornaasten.nl

9. Other information

9.1 Specific target groups

KesslerPerspektief

KesslerPerspektief offers help to vulnerable people who are homeless or temporarily unable to live independently, for example due to:

- psychiatric problems;
- addiction;
- social challenges;
- experience with domestic violence.

The organisation provides care, safety and prospects to people in socially or medically vulnerable situations.
For people in the final phase of their lives, KesslerPerspektief also offers appropriate care in the nursing ward, so that both they and their loved ones get the help they deserve.

KesslerPerspektief
T 088 530 00 00
W www.kesslerperspektief.nl

Parnassia

People with severe psychiatric disorders often cannot access mainstream care.
People who need palliative care and also have a serious psychiatric condition can turn to Parnassia for palliative care.

Parnassia
T 088 357 57 57
W www.parnassia.nl

9.2 Living will

A living will allows you to state your wishes around the care you receive.
You can prepare this living will yourself, but your GP can help.
A living will states:

- a clear explanation of your wishes;
- your full first names and surname;
- the date and your signature;
- details of your authorised representative.

There are different types of living wills:

- non-resuscitation statement, in which you state whether or not you want to be resuscitated;
- advance directive, in which you indicate which treatments you do or do not want;
- euthanasia declaration, in which you make a request for euthanasia.

Sample living will

You can find a sample living will at the website below.
You can also scan the QR code.
W www.juridischedocumenten.nl/leven-en-samenleven/wilsverklaring

9.3 Taking care of practical matters

You can take care of some practical matters before you die. This can give you, your family and friends peace of mind. Practical matters can include things like:

- money matters;
- preparing a will or codicil;
- telling or writing down your wishes for your funeral;
- taking your data on the internet offline or giving your login details to a family member or friend.

You can discuss this with your family and friends, your GP or social worker.

Useful links for arranging practical matters

Wijzeringeldzaken.nl

Website with information, advice and tips on money matters and death.

W www.wijzeringeldzaken.nl/overlijden

Notaris.nl

Website with information on drafting a will.

W www.notaris.nl/testament

Website with information about your data on the internet.

W www.notaris.nl/testament/digitale-nalatenschap

Erfwijzer.nl

Website with information on preparing a codicil.

W www.erfwijzer.nl/codicil

9.4 Useful links

Overpalliatievezorg.nl
Website for anyone seeking information on palliative care.
W www.overpalliatievezorg.nl

Thuisarts.nl
Website with information on illness and health created by doctors.
W www.thuisarts.nl/levenseinde

Stichting Ambulance Wens
Stichting Ambulance Wens is a group of medically trained volunteers who grant last wishes on a daily basis.
They do this every day for people who depend on ambulance transport.
For example, they go along to the zoo, a graduation ceremony or a last visit to a person's own home.
They do this for free.
E info@ambulancewens.nl
W www.ambulancewens.nl

Pal voor U
Information on palliative care.
Pal voor U also has a magazine.
W www.palvooru.nl

Knowledge centre for paediatric palliative care
This website provides information on palliative care for children and their families and friends.
W www.kinderpalliatief.nl

10. Definitions

Civil-law Notary	A person who legally records agreements between people
Consultation teams	A team of nurses and specialists who can give you advice in the palliative phase
Euthanasia	With euthanasia, a doctor ends the patient's life; this is done at the patient's request
Hospice	A place designed for people who cannot or do not want to stay at home or in hospital for their last weeks or months of life
Incontinence	A condition where you can no longer hold in your poo or urine.
Informal care	Unpaid and usually long-term care for a sick family member or friend
Living will	In this you describe which medical treatment you do or do not want
Morphine	A strong painkiller, which does not cause your death
Palliative care	Care aimed at ensuring you have the most comfortable time possible when you will not get better
Palliative phase	This phase begins when recovery is no longer possible
Palliative sedation	You are given medication that causes you to sleep, with the aim of alleviating suffering. This does not cause your death

Respite care	Care in which someone takes over the care from the informal carer
Terminal phase	The final stage of your life, where life expectancy is a few weeks to a few months

You can help us improve this information guide by completing a short survey via the QR code.

This is a publication of
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This information guide can be ordered free of charge at info@transmuralezorg.nl.

Vereniging Transmurale Zorg sterk in verbinden

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