



# What is Legionnaires' Disease?

*Information for  
patients and relatives*

## INTRODUCTION

This information brochure from the Stichting Veteranenziekte (Legionnaires' Disease Foundation) is intended for patients infected with Legionnaires' Disease and their relatives.

In it you will find information about the legionella bacteria, the course of the disease and the recovery period. It also includes an overview of organisations dealing with legionella which can provide further information.

This brochure gives only general information. If you have specific questions regarding your personal situation, please contact your doctor. For further advice you can contact the Stichting Veteranenziekte.

We hope this brochure will help provide you with answers to your questions about Legionnaires' Disease.

### ***The Board of Stichting Veteranenziekte***

*Legionnaires' disease acquired its name in 1976 when a large number of people attending a convention for war veterans of the American Legion in Philadelphia (USA) became seriously ill. Some of them died as a result of severe pneumonia, caused by a bacteria called legionella (or legionella pneumophila). The name Legionnaires' Disease refers to the victims of the first known epidemic.*



### **Monument 'De Bomentuin'**

Spoorsingel opposite number 72  
in Bovenkarspel.

*Stichting Veteranenziekte (Legionnaires' Disease Foundation) was set up in 1999 in the Netherlands after a major outbreak of Legionnaires' disease at a flower festival. To date, as a result of this serious outbreak 32 people have died and more than 200 people have become seriously ill. The foundation looks after the interests of patients and provides information. In addition, it concentrates on the prevention of legionella, both in the Netherlands and in Europe.*

[www.stichtingveteranenziekte.nl](http://www.stichtingveteranenziekte.nl)

## WHAT IS LEGIONNAIRES' DISEASE?

Legionella is the name of the bacteria that can cause legionellosis (Legionnaires' Disease). The bacteria is mostly found in places where water comes into contact with a solid material, such as in a water pipe. Normally the legionella bacteria is present in small quantities which are harmless. However, warm water with a temperature between 20 and 50 degrees Celsius could allow the bacteria to grow, especially where water is stagnant.

### **How do you become infected?**

Infection occurs after inhaling the legionella bacteria. This could, for instance, happen in areas where water is vaporized, such as showers, whirlpool baths or cooling towers. You will not get infected by drinking water which contains the legionella bacteria.

### **Who is at risk?**

People with lowered resistance are especially prone to Legionnaires' Disease, such as older people, immunocompromised patients, transplant patients or heavy smokers. Most healthy people will not become ill after being infected with the legionella bacteria.

### **What are the symptoms?**

People who become ill with the legionella bacteria will often get the first symptoms five to six days after being infected; those symptoms are a slight fever, headache, muscle aches and feeling generally unwell. A few days later the patient will get legionella pneumonia with a high fever (over 39 degrees) and chills. People may also develop a persistent cough and experience shortness of breath. Often hospitalization is needed.

### **Can the disease be treated?**

Yes. Although Legionnaires' Diseases can have serious consequences, in most cases the disease can be treated effectively with the right antibiotics. Laboratory tests will diagnose the legionella infection.

However, once the legionella pneumonia is cured it can take a while before someone is completely recovered. Sometimes people will have lingering symptoms such as getting tired more quickly, shortness of breath or trouble remembering things.

### **Legionella and the social environment**

Being infected with legionella has serious consequences for both the person infected and those around him or her. The course of the disease is intense, and the patient's confusion and shortness of breath may be difficult for others to witness.

After recovery some patients will be over anxious about being infected again, which may cause them to avoid saunas or swimming pools out of fear.

Partners and relatives do sometimes notice changes in a recovered patient's character or behaviour, which can be quite stressful for them.



## IN HOSPITAL

If you are admitted to hospital with legionella pneumonia you will be treated with antibiotics to fight the legionella bacteria.

### **Notifying the GGD**

If the doctor in the hospital suspects you have been infected with the legionella bacteria, he is obliged to notify the infectious diseases control department of the GGD (Area Health Authority).

The GGD will contact you and/or your family as soon as possible to find out when and where you contracted the infection as it is important to identify the source of the infection and prevent more people becoming ill. A doctor from the GGD will ask you some questions and will, for example, collect water samples from places you have visited recently. This could pinpoint the source of the infection.

### **Being infected abroad**

If it turns out that you were infected abroad, this will be notified to the European Legionnaires' Disease Surveillance Network (ELDSNet). In turn they will contact the health authorities in the country you visited. ELDSNet will ask them to investigate the likely source of your infection ([eldsnet@ecds.europa.eu](mailto:eldsnet@ecds.europa.eu)).

### **Recovery period**

If the antibiotics are effective, you will gradually start to feel better and you can start preparing for the rehabilitation process. This may take a long time.

Your personal situation will determine where rehabilitation takes place; sometimes this can be done at home and/or the rehabilitation ward of a nursing home, at other times a rehabilitation centre will be the best place to work on your recovery.



## REHABILITATION AND PHYSIOTHERAPY

Infection with the legionella bacteria may lead to severe limitations, both at home and at work. You may experience difficulty coughing up mucus, walking and going up and down stairs, and may suffer from shortness of breath, both when resting or during exertion.

During the rehabilitation period you will meet with various practitioners, such as the rehabilitation specialist, the psychologist, the occupational therapist and the physiotherapist, who will help you get your strength back.

### **What will the physiotherapist do?**

Through exertion training and muscle exercises the physiotherapist will help you to get back in shape. You will, for example, exercise the muscles in your legs or the muscles involved with breathing. An example of exertion training is practising walking or going up and down stairs.

The physiotherapist will set up a personalised training programme for you and he will also explain what you should or should not do.

It could be that you find it hard to exert yourself, or are afraid to do so, because you get short of breath easily. The physiotherapist will be able to help you with this. He will also teach you an effective way of coughing if you experience difficulty with coughing up mucus.

If you are experiencing shortness of breath the physiotherapist will teach you to adjust your breathing technique and pace to your capabilities, so that you get breathless less easily.

Relaxation exercises will also help you to accomplish this.

### **What can you do yourself?**

Everyone benefits from exercise. This also goes for people who are short of breath or get tired more easily than others. Exercising will help you get back in shape, which in turn will help you to feel less tired and breathless after exertion.



By making exercise a part of your daily routine you will improve your condition; if possible you could consider taking up a sport. This can be done individually or in a team, sometimes under the guidance of a physiotherapist.

Try to go for a (long) walk or a bike ride every day, or go swimming. The exercise will train your muscles, causing them to need less oxygen so that you get short of breath less easily. If you practise a sport already, continue to do so.

**Keep on exercising**

It is very important you keep on exercising, regardless of your condition. If you have any doubts about whether you are able to exercise or practise a sport, consult your doctor or specialist. He will test your lung function. If necessary he can refer you to the physiotherapist, who will give professional guidance and advice about exercising.

Try to continue the exercise, even when you are no longer treated by a physiotherapist.

## ADDITIONAL INFORMATION

If you are looking for information or have specific questions, there are several authorities, government bodies and other organisations dealing with legionella which can help.

### What does the government do?

- The Ministry of Infrastructure and the Environment deals with drafting and supervising legislation on preventing legionella infection. The VROM-inspectie (Inspectorate of the Ministry of Housing, Spatial Planning and the Environment) is responsible for the supervisory element, for example in swimming pools and showers at sports clubs. More information can be found at <http://www.vrominspectie.nl/onderwerpen/milieu/legionella> (in Dutch only)

- The Ministry of Health, Welfare and Sport deals with the health aspects of legionella.

More information can be found in the Legionella file at <http://www.rijksoverheid.nl/onderwerpen/legionella> (in Dutch only)

- The GGD concentrates on research into the source of legionella infection. They do this by collecting information from the patient and those around them about their whereabouts and by taking water samples. If someone was infected abroad, this research is carried out in correlation with the European Legionnaires' Disease Surveillance Network (ELDSNet).

For more information on this research please contact your regional GGD. You can find the nearest GGD on the national website [www.ggd.nl](http://www.ggd.nl) (in Dutch only).

- The RIVM (Dutch National Institute for Public Health and Environmental Protection) deals with, amongst other things, the prevention and control of infection diseases. The RIVM advises the VROM-inspectie and the GGDs on the prevention of and approach to legionella in the Netherlands. For more information please go to <http://www.rivm.nl/milieuportaal/dossier/legionella> (in Dutch only).

## **What does Stichting Veteranenziekte do?**

The Stichting Veteranenziekte is a patients' association for people who have been affected by legionella infection.

The main activities of the Stichting are:

- supporting patients and their relatives;
- organising contact with fellow-sufferers;
- providing an information helpline for patients and their relatives;
- writing informational material;
- sending out newsletters;
- maintaining a website;
- preventing legionella in the Netherlands and Europe;
- promoting scientific research into legionella.

## **Further research**

Stichting Veteranenziekte feels that further research is needed into the consequences, both temporary and permanent, of the legionella infection on body and mind. Stories from patients and relatives have shown us that even patients who have fully recovered experience lingering symptoms such as difficulty concentrating, problems with remembering everyday information, confusion, mood changes and a permanent poor health.

## **Questions? Please contact us!**

If you have any questions about legionella and you are unsure about who best to ask, please feel free to contact us. Stichting Veteranenziekte is here for you!

If we are unable to answer your question ourselves, we will refer you to the right organisation or person.

**You can reach us via [www.stichtingveteranenziekte.nl](http://www.stichtingveteranenziekte.nl)**

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