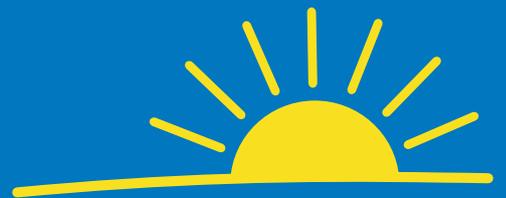


Information & Advice

Helping you to help yourself

Shingles



Help the Aged



Endorsed by

Pain Relief Foundation

This leaflet was written in association with the Pain Relief Foundation, a medical research charity. The information in this leaflet is correct at the time of printing in June 2003.

If you would like this leaflet in another format, such as large print or audio tape, please contact the Information Resources Team on 020 7278 1114.

Contents

What is shingles?	page 4
Is shingles infectious?	page 4
Who is at risk from shingles?	page 5
Recognising shingles	page 5
Treating shingles	page 7
Complications	page 8
Long term pain	page 9
What causes PHN?	page 9
What can be done about PHN pain?	page 9
Other ways of managing PHN	page 12
Support groups	page 13

What is shingles?

Shingles is a common disease that causes a painful rash, usually in a band across one side of your body or face. It is caused by the same virus as chickenpox and you can only get shingles if you have already had chickenpox. The chickenpox virus stays in your nervous system and you develop shingles if it becomes active again and attacks the nerves.

Shingles can affect people of any age, but it occurs much more often in older people. It can be very painful but you may be able to lessen the severity of an attack if you visit your doctor as soon as the symptoms appear.

This leaflet explains more about shingles, so that if it ever happens to you, you will be able to recognise it and get help from your doctor as soon as possible. It also gives information on the treatment and management of shingles pain.

Is shingles infectious?

Shingles isn't spread through the air and, as far as we know, you can't 'catch' shingles from someone else. No amount of contact, not even touching the rash, will make you catch it. However, if you have never had chickenpox, it is possible to catch chickenpox from someone with shingles, but you can **never** catch shingles from somebody with chickenpox. This means that if you have shingles you should avoid contact with the following people:

- Babies and young children who haven't had chickenpox
- Pregnant women who haven't had chickenpox

- People with weakened immune systems, such as people who have cancer or HIV and AIDS

Who is at risk from shingles?

There is often no obvious reason why the chickenpox virus becomes active again and causes shingles. However, it is more likely to happen when your immune system becomes weaker, which is something that happens with age. Certain diseases may also make you more susceptible, such as some forms of cancer and HIV and AIDS. Some treatments and drugs can make you more vulnerable, such as radiation, chemotherapy, and high doses of steroids. Infections, injuries and surgery may also weaken your immune system, as well as physical and emotional stress.

Recognising shingles

Most cases of shingles occur in people over 60, so it is particularly important for older people to recognise the symptoms as early as possible, when treatment is likely to be most effective. Unfortunately, the early symptoms of shingles are often vague and can easily be mistaken for other illnesses. These are some of the signs of an attack:

- The first sign is often a tingling or prickling sensation
- Pain or numbness on **one** side of the body
- The pain may be an 'ache', or it could be a 'shooting' or 'stabbing' pain
- You may feel like you have flu and have a high temperature

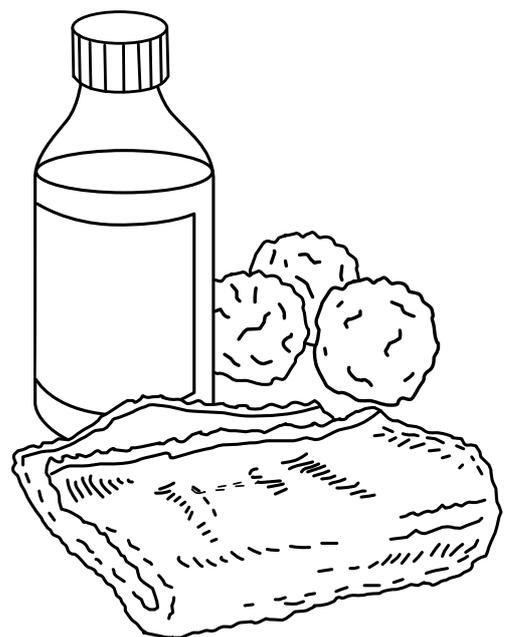
During these early stages, you may not have developed a rash. The rash will appear some time within the first few days of the illness. It will be made up of blisters containing fluid, and appears in groups or bands on one side of the body or face.

It is very important to see your doctor as soon as possible and report all your symptoms.

Once the rash has appeared, the blisters will usually form scabs and then heal over the next two to three weeks. Some people will continue to feel pain for up to a month or even longer after the blisters have healed. You might also notice that your skin is a bit discoloured or scarred.

The pain caused by shingles varies from person to person. For some people, it is very like chickenpox; the rash may sting and then itch as it heals. Sometimes these symptoms can be helped with cool water compresses or by wrapping ice cubes or a bag of frozen peas in a towel and pressing it on the rash. Calamine or menthol lotions and ordinary painkillers, like paracetamol, can also help. Try and keep your rash clean, but don't use scented oils or soap on it.

For other people, shingles may be much more painful, with the pain lasting weeks or months after the blisters have healed (see the section on **long term pain** on page 9). This pain can be difficult to treat, but the earlier you see your doctor and get treatment, the more effective it could be.



Treating shingles

There are some steps you can take which may reduce the severity of an attack. The most important thing is to see a doctor as soon as you feel any of the signs and symptoms (see section on **Recognising shingles** on page 5).

There are treatments for shingles, but many of them depend on you reporting the illness early enough. The choice of treatment depends on where the rash is and on how badly you are affected.

Some antiviral drugs such as acyclovir, famciclovir (Famvir) or valaciclovir (Valtrex) can shorten the attack of shingles, and will usually relieve the pain of the attack. However, for these drugs to work, they should be started **within two to three days of the rash appearing**. In addition to shortening the attack and relieving pain, these drugs, if taken in time, ensure that no permanent scars will be left by the shingles - important if the shingles is on your face or neck. Don't worry if you are still in pain after finishing the one-week or ten-day course of antiviral drugs; your doctor will treat your pain separately (provided you tell him or her about it).

You might find that your doctor will prescribe antibiotics for you if you develop a secondary infection, or painkillers for your pain.

If you're not sure about what you are being prescribed, or how long you should take it for, don't be afraid to ask your doctor.

Although they were originally developed to treat depression, many doctors prescribe a low dose of antidepressant drugs (such as amitriptyline or nortriptyline) every night, starting as

soon as shingles is diagnosed. This can help to **prevent** long term pain. Higher doses of antidepressant drugs can also **relieve** nerve pain, but it may take a few weeks before they have any effect. If you are still in pain six weeks after you began taking the drugs, your doctor may increase the dose. Once your pain has stopped, your doctor might want you to carry on taking the drugs for another month or so.

Your doctor may be interested to know that the **Pain Relief Foundation** (address on page 14) produces information for doctors and patients on the treatment of long term pain.

It's important to try and keep eating a healthy diet while you're unwell with shingles as it may help you to get over your illness more quickly and reduce the risk of suffering from long term pain. For more advice, see our free advice leaflet, 'Healthy Eating'.

Complications

Shingles does have some complications, including problems with your sight or hearing. This is not very common but it may happen if shingles affects your face. If your immune system is weakened, infections can spread to internal organs, such as the lungs and the central nervous system, but this is **extremely** rare.

Shingles can come back, particularly if you are under any physical or emotional stress.

You should see your doctor immediately if you experience any signs of the above.

Long term pain

The most common complication of shingles is pain that continues or returns three months after the shingles rash started. The medical term for this condition is **post-herpetic neuralgia** or **PHN**. Many thousands of people suffer from PHN each year and older people are more likely to be affected.

Unfortunately, PHN is sometimes not properly treated. People with PHN often suffer from intense pain that makes their life miserable. It is usually described as a tender, burning pain but some people say that it is 'aching', 'throbbing' or 'stabbing'. Clothes rubbing against the body or the effect of wind on the face can make the pain unbearable. People suffering from PHN can also suffer from depression, weight loss and difficulty in sleeping.

What causes PHN?

When the chickenpox virus becomes active again and causes shingles, the nerves it attacks either recover completely or become permanently damaged. PHN pain happens when the nerves are damaged. The nerves send confused messages to the brain that register as pain. Unfortunately, taking the antiviral drugs early on doesn't guarantee that PHN will not develop later on, but it does mean that it will be easier to treat.

What can be done about PHN pain?

If PHN is diagnosed and treated early, there is often a good chance of a cure. If treatment is delayed, the chance of a cure becomes considerably less

It is important to tell your doctor if you have had shingles and you are still in pain, or if the pain returns, three months after the rash first appeared. Don't 'wait and see' what happens - you may risk making your illness worse.

The best way to deal with PHN is to treat it early on and this means going to your doctor straight away.

Unfortunately ordinary painkillers have little effect on PHN but there are some drugs available through your doctor:

- Many cases respond well to certain drugs originally developed for the treatment of depression (such as nortriptyline or amitriptyline) but which have also have an effect on nerve pains. Note that low doses of these drugs may also be used for the prevention of PHN, if started during the acute shingles phase
- If the pain disappears, you should continue to take the antidepressants for the next three months before the dose is gradually reduced. Ask your doctor for advice. If the pain starts again, you should go and see your doctor **immediately** - you may need to start taking the drugs again
- Nortriptyline and amitriptyline may cause dry mouth and drowsiness. A more recent and equally effective drug with fewer side effects is gabapentin (*Neurontin*). Ask your doctor for advice about these drugs



- There are some creams and lotions that can be put directly on the rash to provide immediate relief, but they're not a cure. There is a cream made with capsaicin that can be helpful but might sting or burn when you first put it on

One way of monitoring the effectiveness of the medicine you are taking is to keep a record of your pain. You can do this by keeping a daily score of how much pain you have been in (using a scale of 0 to 10, with 0 = no pain and 10 = worst pain ever). It would be useful to record the number of hours a day you are in pain. You can use this record to help your doctor find the most effective way of treating your pain.

Clothing

Some people find that wearing clothes next to their rash can cause tenderness and a 'burning' sensation that is very painful. Try and keep clothes away from your rash but, if you can't, cotton clothing is less painful. The following advice may make you more comfortable:

- If your rash is around your waist, try and wear trousers and skirts without a waistband and don't tuck your clothes in. Wear loose or low cut underwear
- If your rash is on your back, try not to wear a bra. If you would rather wear one, choose an old one that's lost its elasticity
- If the rash is around your hips or thighs, wear french knickers or boxer shorts, and baggy trousers and skirts

Other ways of managing PHN

If you are not getting relief from your pain you should tell your doctor. He or she may refer you to a specialist **pain clinic**. These are often based in hospitals, although not every hospital has one. They are places where medical professionals will assess your pain and find ways to help you manage it. You or your doctor can contact the **Pain Society** (address on page 14) for details of clinics.

Other treatments that some people say relieve their pain include physiotherapy, transcutaneous electrical nerve stimulation (TENS), laser and ultrasonic therapy. Ask your doctor for more information.

Some people have also found that alternative medicine can offer relief. This includes treatments like acupuncture, aromatherapy, hypnotherapy and homeopathy. Your doctor can advise you on how to find a suitably qualified and experienced practitioner or you can contact the **Institute for Complementary Medicine** (address on page 13) who can give you details of practitioners in your area. It's likely that you will have to pay for these treatments privately unless your doctor can refer you through the NHS.

Pain can be made worse by stress and anxiety, so relaxation is a very important part of managing your pain. Try and find out what helps you to relax, whether it's listening to your favourite music, lying in a warm bath, or just watching television. Audiotapes that help you to relax are available from the **Pain Relief Foundation** (address on page 14).

Support groups

As we have seen, living with long term pain can cause a lot of misery and suffering. Pain can make you feel tired, sad and irritable, so it's important to explain to your family and friends why you feel the way that you do so that they realise they're not to blame for making you unhappy. Some people also become depressed and it's very important to talk to your doctor if you start to feel this way.

There are also some voluntary organisations who can give you advice and information, or offer you the chance to talk to someone who will listen and understand what you are going through. Some of these groups are listed here:

Institute of Complementary Medicine

PO Box 194

London SE16 1QZ

Tel: 020 7237 5165

Website: www.icmedicine.co.uk

Can supply a list of complementary practitioners in your area. Please send a sae as well as some loose stamps to help with the postage.

NHS Direct (England and Wales) - 0845 4647

NHS helpline for Scotland - 0800 22 44 88

Offers information and advice about illnesses, patient's rights, self-help and support groups.

Pain Association Scotland

Cramond House, Cramond Glebe Road

Edinburgh EH4 6NS

Tel: 0800 783 6059 (freephone)

Website: www.painassociation.com

Offers information and details of local support groups.

Pain Relief Foundation

Clinical Sciences Centre
University Hospital Aintree
Lower Lane
Liverpool L9 7AL
Tel: 0151 523 1486

Website: www.painrelieffoundation.org.uk

Produces an information pack of leaflets about shingles and other chronic pains. They also have a book and a range of audiotapes on pain management and relaxation. The leaflets and information about the book and tapes can be obtained by sending an A4 sae with 50p worth of stamps, together with a minimum £1 donation.

The Pain Society

21 Portland Place
London W1B 1PY
Tel: 020 7631 8870

Website: www.painsociety.org

Provide details of specialist pain clinics in your area. They also publish a leaflet called 'Information for Patients' on the various treatments offered by pain clinics.

SSS

41 North Road
London N7 9DP
Tel: 020 7609 9061

Website: www.herpex.org.uk/shingles.htm

If you send a sae and a donation requesting shingles information they will send a pack that contains various leaflets and details of different treatments available. They also run a helpline for people with shingles and long term pain.

Help the Aged produces a range of free advice leaflets for older people

Financial Leaflets

- Can You Claim It?
- Check Your Tax
- Claiming Disability Benefits
- Managing Your Savings
- Questions on Pensions
- Thinking About Money

Housing and Home Safety Leaflets

- Fire
- Housing Matters
- Help in Your Home
- Keep Out the Cold
- Living Alone Safely
- Residential Care
- Safety in Your Home
- Security in Your Home

Leaflets are free of charge and available in single copies for individuals or in large quantities for organisations. You can get leaflets in the following ways:

- by writing to the Information Resources Team
- by email on adviceleaflets@helptheaged.org.uk
- by faxing on 020 7239 1839

Health Leaflets

- Bereavement
- Better Hearing
- Better Sight
- Bladder and Bowel Weakness
- Fight the Flu
- Fitter Feet
- Healthy Bones
- Healthy Eating
- Keeping Mobile
- Managing Your Medicines
- Shingles

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