



A1 HIDDEN ISSUES – INFORMATION FOR FACILITATORS

# Revealing leprosy: information for facilitators

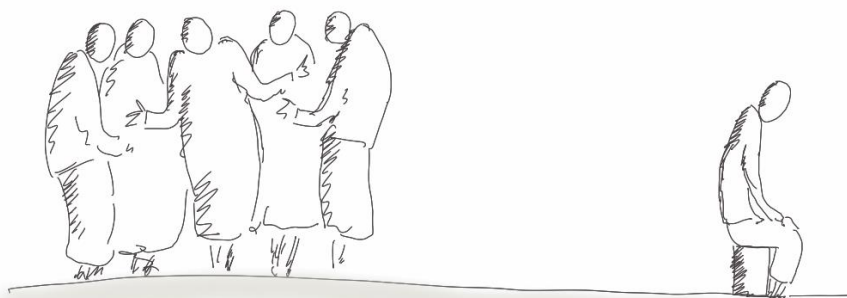
Tools in this section of *Reveal* provide background information on hidden issues for facilitators. Tools in other sections are designed to be used with communities.

### Questions to consider:

- How does the term ‘leprosy’ make you feel?
- Is leprosy spoken about freely in the community?
- Are you aware of people living with leprosy in your community?
- Are they included in community life and respected? Or are they treated with fear and stigma?
- How can we help people who have become disabled after having leprosy?

Worldwide, one person is diagnosed with leprosy every two minutes. Leprosy is present in all parts of the world, but especially in Asia, Africa and South America. Leprosy infection is curable, but unfortunately, misunderstanding and incorrect information leads to fear and stigma about leprosy, and some people do not seek diagnosis on time. Early diagnosis and treatment prevents most disability. Sadly, some people do develop disability as a result of leprosy – even though they take their medicines as directed. They may need help or special consideration for the rest of their lives.

Leprosy is not an issue which is openly discussed within communities or churches. There may be low awareness of leprosy, or myths and negative beliefs in the community. Sometimes, people with leprosy are isolated from their friends and families or sent away because of embarrassment and misunderstanding. Sometimes, it is hard for them to use general medical services, obtain help from organisations offering rehabilitation for the disabled, or attend educational institutions.



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## A1 HIDDEN ISSUES – REVEALING LEPROSY

Ignorance, fear, stigma and discrimination are the main reasons why people are not tested for leprosy. Undiagnosed and untreated leprosy can be spread to other people as well as cause disability.

It is very important that leprosy becomes revealed in communities so that people can speak to each other about leprosy, seek early diagnosis, receive timely and correct treatment and prevent disability. And to support those who are disabled.

**Note:** In some countries, the term 'Hansens Disease' is used instead of 'leprosy'.

### What does the Bible say?

The Bible teaches us about a God who loves us all, and who calls for us to love our neighbour as we love ourselves (Mark 12:30-31). In Mark 14:3 Jesus is having a meal at the home of Simon, a man affected by leprosy. Jesus' acceptance of Simon, and many other people affected by leprosy throughout his ministry, serves as an example for us all to treat people with compassion and respect.

For Bible studies on this issue, please see **Section B** of *Reveal*.

### Understanding leprosy

Leprosy is a mildly-infectious disease caused by a germ (a bacterium). Leprosy starts as a skin problem – **patches of skin appear that are a different colour to the rest of the skin.** Maybe only one patch, maybe many – small or large. The patches are not usually painful and do not itch. In fact, if you touch the patch, the person cannot feel that you are doing so.

**If left untreated**, nerve damage can occur leading to loss of sensation and muscle weakness in the hands, feet and eyes. As a result of nerve damage, people often get injuries (ulcers) on hands and feet. These injuries may become very infected and even result in shortening of fingers and toes, and loss of limbs. Damage to the eyes may lead to blindness. Leprosy is not passed down from parents to children and cannot be caught by touch, as many believe. It is most common in places of poverty where overcrowding and poor nutrition and housing make people more at risk of infection.

MDT (Multi-Drug Therapy) is a combination of drugs taken for 6 months or one year to cure leprosy. MDT should be available free of charge in health centres in countries where leprosy exists. The first day's treatment with MDT ends the risk of spreading the disease to anyone else, but people with leprosy still need to complete a full course of treatment to ensure they will get better. Early treatment of leprosy usually cures leprosy before any disabilities occur; this is why early testing, diagnosis and treatment are so important!

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## How is leprosy passed on?

Leprosy is not highly contagious; it is one of the least infectious of the infectious diseases. It passes from one person to the other through droplets from the nose and mouth similar to flu and tuberculosis (TB). People become infected through close and frequent contact with **untreated** leprosy patients.

You cannot become infected by:

- Sharing food, or drinking water (or wine at holy communion)
- Eating food grown, sold or cooked by a leprosy-affected person
- Sharing bedding or clothing
- Sharing toilets or latrines
- Using telephones
- Normal work or school contact
- Shaking or holding hands, touching or hugging
- Sexual intimacy with a person affected by leprosy
- Insect bites

## How does leprosy affect people?

A person can be infected with the leprosy germ for many years before symptoms such as the skin patches appear.

**Disability:** Nerve damage due to leprosy leads to a loss of feeling in hands and feet which means that people may hurt themselves without noticing. A person who has lost sensation in their hands, feet or eyes must take care to ensure that they do not damage their eyes, feet or hands while working, walking, cooking or doing any other daily activities. This is difficult to do for people working in the fields or a factory or kitchen without proper protection. Protective footwear may be used to protect feet that do not feel. Gloves can be used to protect hands when cooking and doing manual work. Tools can be made safer with padded handles.



**Stigma:** In some places, people living with leprosy face stigma and discrimination, even though they have taken MDT and are not infectious. Men, women and children are sometimes forced from their homes and sent away from their families and many end up living on the streets and begging. Some are not allowed to go with others to their preferred place of worship. This stigma against people with leprosy means that many people are afraid of being tested or diagnosed. This stops people from being cured and in turn leads to the following:

- Continued spread of leprosy, as people infect other people without knowing
- Increased disability as the leprosy spreads from skin to the nerves and eyes
- Loss of income and livelihood
- Loss of reputation
- Loss of hope and feelings of worthlessness
- Loss of marriage and childbearing options

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Some people who have had leprosy and become disabled feel guilty because they are unable to provide for their families or to fulfil their role in society, or because they fear they may be a burden to their loved ones.

Some people who have been badly treated by others because of having leprosy (or have seen their loved ones mistreated because of leprosy) continue to feel angry, and find it hard to forgive those who caused them suffering.

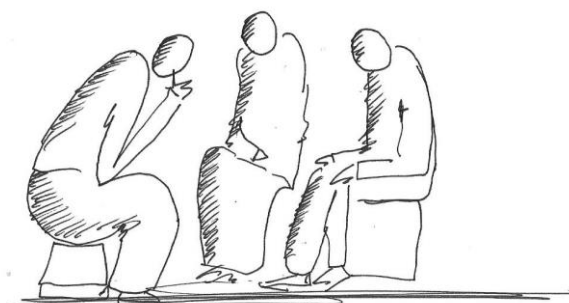
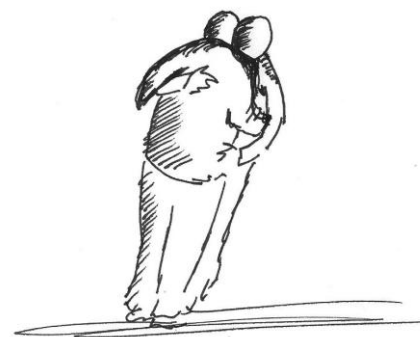
Some people living with leprosy might find it affects their trusting relationship with God, and need reassurance that the disease is not a sign of God's displeasure and that it need not hinder them from serving God.

## What can we do to understand more about leprosy and help people affected by leprosy in our communities?

Learn as much as you can about leprosy, and tell others about what you have learnt.

If there are people affected by leprosy in your community:

- pray for them (and with them if they wish!)
- visit them
- become their friend
- offer support, care and love to them
- share a meal with them introduce them to your friends
- join or start a leprosy support group
- encourage them to do their daily self-care tasks and exercises
- if you see someone with the early signs of leprosy (for example, lighter coloured skin patches), encourage them to visit a health clinic to get tested. You could offer to go with them
- If you find that someone disabled by leprosy is not being given a fair chance (to take a job or go to school or to attend church) then speak up for him/her and assist the person to obtain access to whatever public services are available.



## Using *Reveal*

There are activities in **Section A2** of *Reveal* which help to explore issues of vulnerability and disability, and Bible studies on this issue in **Section B**.



### Notes

This tool was written by Jannine Ebenso and Beth Crook of the Leprosy Mission.



### Finding out more

The Leprosy Mission International: <http://leprosymission.org/>

Contact [friends@leprosymission.org](mailto:friends@leprosymission.org)

International Federation of Anti-Leprosy Associations: <http://www.ilepfederation.org/about-leprosy/>

#### Related tools:

- A2 – Understanding vulnerability and disability [A2: *Discrimination & inclusion-1*]
- B – Attitudes towards disease and difference (Bible study) [B: *Discrimination & inclusion-1*]
- B – Disabilities – knowing our true value (Bible study) [B: *Discrimination & inclusion-4*]
- B – Healing from leprosy is at the heart of the Gospel (Bible study) [B: *Health & HIV-2*]
- B – Jesus and people affected by leprosy (Bible study) [B: *Health & HIV-3*]

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