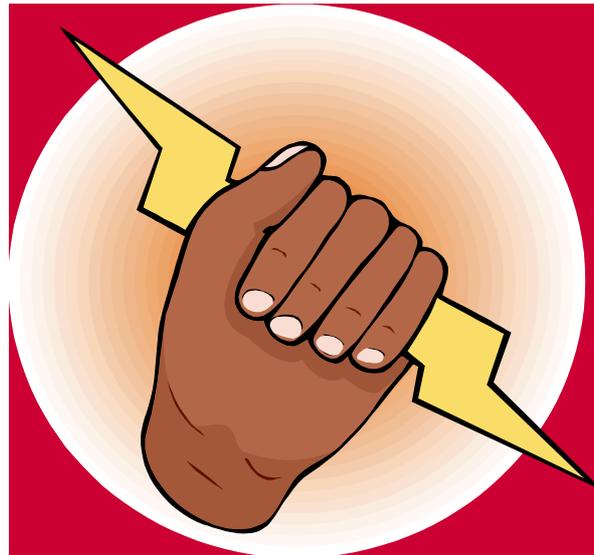


COPING WITH  
SICKLE CELL DISEASE  
AND PAIN



A SELF-HELP MANUAL

# Sickle Cell Disease

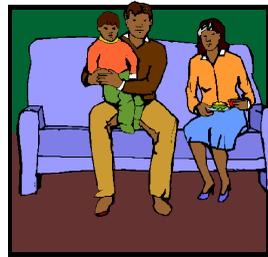
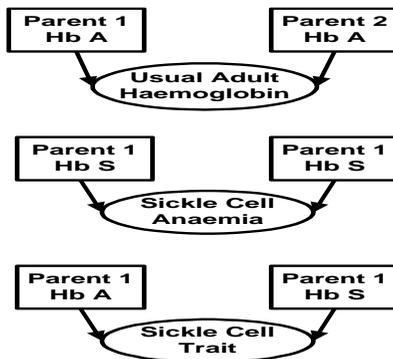
Sickle Cell Disease is a term used to describe a group of red blood cell disorders that people are born with (inherit). The inner part of the red blood cell is called Haemoglobin or 'Hb' for short, and most people have the usual and most common HbAA. There are many types of haemoglobin, such as sickle cell anaemia (HbSS), sickle haemoglobin C (HbSC) and sickle beta thalassaemia (HbS $\beta$ Thal).

Sickle cell disease occurs when:

- Haemoglobin S is inherited from both Parent 1 and Parent 2.
- Haemoglobin S is inherited from Parent 1 and another unusual haemoglobin is inherited from Parent 2 (eg. HbSC or HbS $\beta$ Thal).

Sickle cell trait occurs when:

Haemoglobin A is inherited from Parent 1 and haemoglobin S from Parent 2. People with sickle cell trait are said to be 'healthy carriers' because they do not usually have any symptoms.



Sickle Cell Disease is inherited from both parents

Sickle cell is common in people who come from countries where malaria is present. Sickle cell trait offers some protection to young children against malaria in these countries. Sickle cell disease is found in people from Africa, the Caribbean, the Mediterranean, Asia, Middle East, and some places in Europe such as Greece and Cyprus. It is found in countries where these people live.

# Sickle Blood Cells

Haemoglobin in red blood cells carry oxygen around the body. When most of the S haemoglobin gives up the oxygen to other parts of the body, the blood cells change shape from round to 'sickle'.



Usual Red Blood Cell



Sickle Red Blood Cell

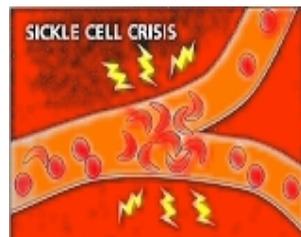
This can cause some problems:

1. Sickle blood cells live for less than 20 days. Usual blood cells live for about 120 days. The bone marrow where the blood cells are made cannot keep up with the rate at which the sickle cells die. This causes 'anaemia'.
2. Sickle blood cells are hard and rigid. This makes their movement through small blood vessels difficult. The cells get jammed and block the blood vessels.
3. Sickle blood cells may sometimes cause long-term damage to organs and other parts of the body such as the spleen, lungs, liver, kidneys, hip and spine.

**Sickle blood cells cannot move freely round the body**

## Sickle Cell Crisis

When the sickled cells block the blood vessels for example in the bones, joints and muscles, this causes attacks of pain called 'vaso-occlusive' or painful 'crisis'.



## Sickle Cell Pain

Sickle cell pain is described in different ways. Some of the terms used are 'stabbing', 'thorny', 'throbbing', and 'pulsating'. It is probably one of the worst types of pain that anybody can have in life.



Throbbing pain

This pain is so unique that it has been used to name the condition in some countries. For example, in Ghana some people call it 'ahotutuo'.

The pain experience is personal: – crises can start in any part of the body, and you cannot be sure how long or how bad it is going to be.

Sickle cell crises can last for 5 to 10 minutes or last from days to weeks. Some people have crises daily or weekly, others have a crisis once every few months or years.

Most painful crises come and go, but sometimes this is not the case. Pain from damaged parts of the body can stay for a long time, that is 'chronic' pain.

**Sickle Cell Pain  
is Unique**

## Treatment of Pain

One of the main treatments of sickle cell disease is to try and control the pain. Pain crisis is treated with pain killers and fluids, you have to drink a lot. There are different pain killers. For example:

1. Mild Pain— Paracetamol or Aspirin (in adults)
2. Moderate Pain — Ibuprofen or Diclofenac
3. Severe Pain— Dyhydrocodeine or Co-proxamol  
Morphine or Pethidine

## Other Medical Treatment

1. Blood transfusions may be required for severe anaemia or to treat and prevent a stroke.
2. Antibiotics such as Penicillin are used to prevent or treat infections.
3. A drug called Hydroxyurea is also effective in reducing sickle cell crises in some people.
4. Bone marrow transplantation is a possible cure. However, there are some

problems with this treatment, and only some children have benefited:

- i. It may be difficult to find a suitable donor.
- ii. It is a major procedure with risks.
- iii. There is an age limit beyond which it is less successful.



## Coping

Coping involves thoughts, feelings, and actions that people use to manage difficult situations.

Coping with pain means thoughts and actions that are used to manage or reduce pain and the distress caused by it.

## Ways of Coping

People can be active and do things to manage their pain such as massage and exercise, or they can be passive and wait for the pain to go in its own time.

There are different ways of coping with sickle cell pain. Coping can be in the form of taking medication and resting or praying.

Some people do a lot of social activities and work. Others may need some support to make their lives a bit easier.

**There are different types of treatment for sickle cell disease**



## Quality of Life

Certain aspects of your life are very important such as education, work, relationships with family and friends, shopping, and holidays. These determine the quality of your life and can be affected by sickle cell disease and pain.



Enjoying life

The way you cope is therefore important for your quality of life. Your ability to meet your daily needs result in satisfaction, well-being and better quality of life.

## Individual Differences

Sickle cell disease and painful crises affect individuals differently. Some people are limited in their day-to-day living. Others manage to get on with their daily lives, study or work, and do the things that they enjoy.

There are differences in people's quality of life.

**Sickle cell  
affects  
people  
differently**

## Taking Control

No matter how sickle cell disease affects you, there may be certain times when your symptoms and pain are too much. You may feel helpless or out of control.

You may or may not feel this way often, but when you do you may want to do something else apart from taking medication, or going to the hospital. What else can you do?

THIS MANUAL MAY HELP YOU.

## The Self-Help Approach

The self-help approach to managing sickle cell disease and pain concerns the way you see and explain your illness and pain. This is not the complete removal of pain.

You will gain a bit each time you practice. You will also benefit a lot when you combine this with the usual medical treatment.



This approach will enable you to learn and use specific skills quickly in order to gain some control over your illness and pain.

The key to the success of this approach is your promise to yourself to try out the suggestions in this manual.

## The Aims

The self-help approach is part of a therapy programme for sickle cell disease, and the aims of the programme are:

1. To help improve your understanding of the ways in which sickle cell disease affects you.
2. To help you take more control over sickle cell disease and decrease the pain by learning new and important skills for coping.
3. To help reduce stress and the effect of sickle cell and improve the quality of your life.
4. To identify issues that are important regarding sickle cell disease.

**Take control  
of illness and  
pain**



## Are You Ready?

You may have a lot of things on your mind at the moment. You may be asking yourself “Why this manual?” You may even want to throw it away – you have “seen it all.”



Unsure?

People have been talking about sickle cell disease for a long time but nothing much has been done to stop the suffering. You just want to be left alone to “get on with it.”

Remember This: YOU ARE NOT ALONE

## You are not sure?

*“I still think there’s a lot I need to know about sickle cell, anyway.....In a way I do want to know more about it....”*

*“I don’t really want to know more, cause there’s nothing more to know basically. Nothing more I would like to know. Like I said, except from knowing a cure. It’s too stressful! It’s stress!”*

Other people have the same feelings as you do. They also just want to get on with it. Ask yourself:

## Now or Later?

*“Is there anything I can do about all this suffering now?”* The answer is YES!

**This may not  
be the right  
time for you**

You must be ready. If you think this is not the right time for you, just put this manual away and come back to it later. That is OK.

## Understanding Pain Experience

Imagine you are walking about in the house and you knock your knee hard against a table. Your first reaction is likely to be a shout:- “*Aaarh*” because of the pain. This is what happens:



Pain messages from the brain

A message is sent from your knee through your nerves to the spine. These connect with other nerves and send the information to your brain to say that you have knocked your knee.

The brain deals with the information to say this hurts, so you then shout “*Aaarh*”. A pain message is sent back through your spine to your knee. This message can be changed.

Now imagine you are again walking about the house and the same thing happens. This time, just as you knock your knee against the table, the phone rings, you answer it, and get engaged in a long conversation.

You are distracted by the phone call, so you may not feel the pain as much. Perhaps you are not thinking about your knee.

**Pain experiences can be different**

### The ‘Gates’

The nerve connections in the spine and brain act like ‘gates’. When the ‘gates’ are full they block out pain messages.



Telephone conversation

## Controlling Pain

Remember this:

When you are only thinking about pain you tend to feel it more.  
When you are thinking about other things you are likely to feel less pain.



Therefore, other things such as your thoughts may change the way you experience pain.

Controlling your pain

## Blocking The 'Gates'

When you are in pain, one way to block the 'gates' is by taking pain killers. You can also block the 'gates' by filling them with other messages.

For example, massaging your knee after you knock it against the table fills the 'gates' with other messages so you feel less pain.

Also, when you are engaged in a telephone conversation you fill the gates with other thoughts, thus feeling less pain. It will be helpful if you can find other 'gate' fillers.

One simple method that helps to reduce pain and at the same time gives you control is relaxation. You can try this procedure now.

**Blocking the  
'gates' makes  
you feel less  
pain**



## Simple Relaxation

Find a comfortable chair in a quiet and warm place, you may also lie down on a bed or sofa. You do not want to be disturbed for a while. Take off your shoes and do not cross your legs. If you are sitting in an arm chair, rest your arms on the arms of the chair. If you are lying down, lie on your back with your arms to your side, use a pillow or a cushion to support your head.



Relaxing position

Read through the following a few times before you start:

1. *Close your eyes and be aware of your body.*
2. *Take a deep breath.*
3. *Hold your breath for a few seconds, then breathe out and empty your lungs completely.*
4. *Repeat this several times, and as you are breathing out each time, feel the tension from your body coming out with each breath.*
5. *Think of the word 'relax'.*
6. *Concentrate on your breathing in and out and start saying the words 'heavy', 'relax' to yourself as you feel your body becoming heavy and relaxed.*
7. *Carry on deep breathing in and out while saying the words 'warm', 'calm', 'peaceful', 'heavy' and 'relax' to yourself. Keep on doing this for about 5-10 minutes.*
8. *Enjoy the feeling of relaxation without falling asleep.*
9. *Carry on for a while and then gradually stop concentrating, and start breathing normally.*
10. *In your own time, come slowly out of that deep state of relaxation but keep enjoying the calm and peace a bit more.*
11. *Open your eyes.*

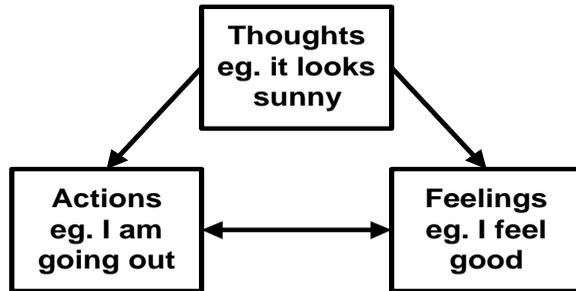
Practice this relaxation procedure often, the more you practice the easier it becomes. You can also play soft music to help you relax more (eg. jazz, easy listening, or moods).

## Thoughts and Feelings

Your thoughts and feelings give meaning to your life experiences, and this includes sickle cell disease and pain. Your thoughts also determine your feelings and actions.



Brain power



For example, on a sunny day you are likely to say to yourself *"it is a nice day today"* and this will make you feel good and want to go out. On the other hand, if you say to yourself *"it is cold today"*, you will not feel so good and perhaps want to stay indoors.

## Automatic Thoughts or Self-Statements

Usually you say things to yourself without thinking much about it. These thoughts are also called 'self-statements', they happen very quickly, are automatic, and very powerful.

Automatic thoughts or self-statements can lead to either negative or positive feelings so it is important to think about them. This may seem difficult at first but with a bit of practice you will be able to do it.

For a moment think about some of the things that pop up in your head or you say to yourself when you are having a crisis and write them down. Try and link these self-statements to your feelings and the things you do.

**Self-statements are powerful thoughts that determine feelings and behaviours**

## Strong Feelings

Here are some examples of real life thoughts regarding sickle cell that result in strong feelings:



Why me?

1. *"...I've got brothers and sisters and there is nothing wrong with them! How come it's just me?"... "Why?" "Why me?"....*
2. *....." it feels like a punishment."*

## Anger

The "Why" questions can also make you anxious and angry because you cannot answer them, and it is difficult to find any meaning to them. You have to accept that these are forms of negative thinking.

Also, think about whether you have been angry about having sickle cell for a while. What self-statements may have caused this? Write them down.

## Fear

1. *"The last time I had it (pain)...it was last month, after that pain it was like I had this fear in my head and I just kept remembering the pain I went through. And I think, to a degree, it was the same as going through it. Just the memory of it was the same as going through it...."*
2. *"There's the fear of having like further pain..."*

**There are a lot of feelings to do with sickle cell pain eg. Anger and Fear**



Fear

## Positive Self-Statements

Try saying more pleasant or positive words to yourself when you are having a crisis eg. "Relax", "Calm" or "It will get better soon", "This will all pass". After a while these words will become part of your thoughts and self-statements and help take away some fear.



Some pleasant things

Remember the number of times you have talked yourself into worse situations. You can also talk yourself into better situations.

## Catastrophising

Sometimes you say negative self-statements to yourself, this is not unusual, everybody does it. However, some people do this more often than others and in doing so they make certain situations seem real when they are not.

A lot of negative self-statements are not correct, and are unhelpful because they change the facts. The situation then seems worse than it really is and makes you feel helpless and out of control.

When you have a lot of negative thoughts the end result always seems like a disaster (catastrophe), so what you are doing is called 'catastrophising'. This process of negative thinking is not ideal for solving problems.

Again think of your self-statements when you last had a crisis and, and see how many of these are negative.

**Negative  
thoughts do not  
help, be more  
positive**



A dark alley

## Monitoring Thoughts and Feelings

Thinking about your automatic thoughts or self-statements when you have a crisis may seem difficult. Why not start thinking about your self-statements daily as they occur. These should not only be about sickle cell.



A thought diary

Refer to Thought Diary 1 included and write down your self-statements (positive and negative), feelings, and actions as they happen.

Also write down self-statements that are helpful for your general well-being and health in Thought Diary 2.

Having them written down would help you find out which positive self-statements make you feel better and do things that are helpful, or which negative self-statements make you feel worse and do things that are unhelpful.

This is very important because when you have a crisis you would be able to think about your self-statements.

### This is important

It is easier to practice monitoring your self-statements when you are well, to enable you to do something when you are ill.

Also, should the pain be so bad that you cannot think at all, you can always refer to your diary and see what positive self-statements can help you feel a bit better.

By having some control over you thoughts and feelings, you are also controlling the 'gates' in your body which allow or prevent the pain going through.

**Keeping your thoughts and feelings in check is very crucial**



Thinking about your thoughts

## Reframing Thoughts

Automatic thoughts or self-statements can affect the way you feel, therefore if you can change your negative self-statements you can change how you feel.



No way out?

When you have a crisis, it is true that the pain is there and you are probably miserable too, however your self-statements may not be accurate and could be changed.

Here are some examples of thoughts regarding sickle cell crisis:

### Some People's Thoughts

1. *"...It's the fact that I know nothing I can do will get rid of it..."*

You are not helpless because you have a crisis and are in pain, you can do something about it.

2. *"Like a slippery slope and you can't get off it."*

You do not really know whether your crisis is going to get worse. It may be short and you will become better.

3. *"Nobody cares."*

It may not have anything to do with other people caring about you.

**Some thoughts are not accurate, they need to be changed**



Some thoughts

## Distorted Thoughts

Thoughts come from a lot of different sources. Some may be due to your past experience, others from your cultural beliefs, or from external sources such as the media. Whatever the source, they can easily be distorted.

Here are some examples of the ways in which your thoughts can be distorted:

### Some People's Thoughts

1. *"...And because it happened while I was running for the bus, when I did come out of hospital and I was well again... I'd forget and go running for the bus and instantly it would be 'don't run for the bus!' would come back into my mind..."*

2. *Kofi just walked past me in the corridor without saying "Hello". He usually talks to me, he must be upset with me."*

3. *"I have been able to keep well and out of hospital for a few years, but knowing my bad luck I am sure I will soon be ill and be admitted into hospital."*

4. *"I have got sickle cell so I cannot do anything. I cannot pass my exams, I cannot work, I am useless."*

5. *"I shall never get over this sickle cell disease. I will never be able to do what I want."*



**Where do your thoughts come from? Are they reasonable?**

## Challenging Thoughts

You can reframe (change) your negative and unhelpful self-statements by challenging them. Challenge the truth about them by looking at different aspects of the situation. Consider the examples given on page 16.



1. and 2. How do they relate to the facts? -

eg. *"I was too late trying to catch the bus and running made me very tired. If I start off early I can just walk and that would not start a crisis."*

eg. *"Perhaps It is true that Kofi did not say hello, but I am sure that I have not upset him. We get on well – that is a fact. Maybe he just had something on his mind"*

3. What are the other ways of thinking about them? -

eg. *"I have been able to keep well and stay out of hospital, because I have been taking good care of myself. I eat well, drink a lot, and go for my check-ups regularly. I will continue to keep well and stay out of hospital."*

4. Are you blaming yourself without a good reason? - eg. *"I am usually not well during exams, and that is not my fault. But I can still try and get some training to learn new skills. This will help me to find work."*

5. What is the worst that could happen? -

eg. *"I shall go on getting more and more crises and doing less and less. However, it is more likely that if I work on it, I will learn to cope better, control my pain, and so be able to do the things I want to do."*

**Challenge your thoughts.**

**Try to justify them**

## This is Important

You do not have to change every negative thought to become positive, that is not the point. What is important is to change them to make sense or become more helpful to you.

## Activity

Being active and enjoying life is very important! Going out with friends, playing games or sports, shopping, travelling abroad, and work are some of the important things that keep the fun in your life.

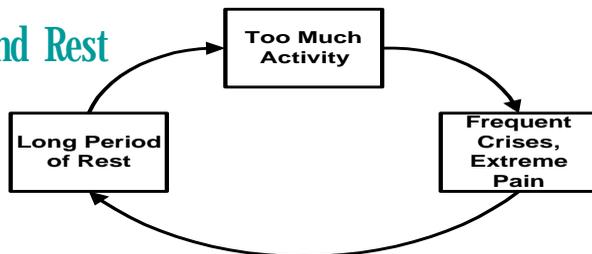
Activity is good, so if you are not active you should try doing a bit more. This would make you feel a lot better.



Out and about

However, too much physical activity may start a crisis, which means you cannot do anything for a while. You will need to have long periods of rest. When you are better, you want to catch up so you are physically overactive again and the cycle goes on.

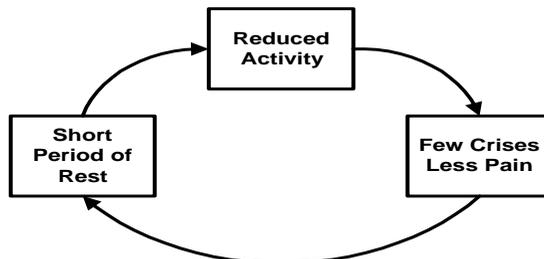
## Activity and Rest



Too tired?

This cycle may sometimes be difficult to stop. For example, you may not have any support at home and have to do everything yourself. You may also want to be with your peers and not be left out.

**Be active but  
also have  
adequate rest**

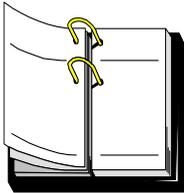


Try and reduce your physical activities a bit. You will have less frequent crises and will not need to rest for a long time. This will enable you to get on with things.



## Monitoring Activity

It is quite easy to make a note of your usual activities, and how much you can do without starting a crisis. Refer to the Activity Schedule included.



Activity Schedule

Think about your daily and weekly activities carefully and see how best to arrange them. For example, housework, social activities, college and work. Put them in order of priority as follows:

1. Essential – Need to do these immediately
2. Important – Have to do these as soon as I can
3. Less Important – These can wait a while

Do not stop doing anything that is important to you, but try not to push yourself too hard, just do as much as you can.

## Stress

Stress can be described as anything that makes you feel worried, tense, angry or unhappy.

**Stress causes  
pain**

There are a lot of things in life that can cause stress. For example, moving house, arguing with somebody, and preparing for exams.

## Effects of Stress

Although a bit of stress may help you to meet challenges in life, too much of it is bad for your health and well-being.

You may become very tense and unable to relax.  
You may not be able to eat or sleep properly.  
You may not enjoy the things you do.



**Stressful**

In addition, stress may also start a crisis or cause you more pain.

## Monitoring Stress

Stress may result from certain types of activity. It is therefore important to think about the things that you do and what may cause you stress.



Do not stop doing anything that is important to you, just make sure that it does not cause you too much stress.

## Causes of Stress

To help you find out the sources of stress, begin by writing down your activities over the next few weeks. Refer to the activity schedule.

Also, make a note of those things that cause you some stress. That is, things that make you feel worried, tense, angry or unhappy.

Knowing the causes of stress is important for your health. You can then try to prevent it.

**Do you know  
what causes you  
stress?**

## Dealing With Stress

Sometimes stress is caused by events or situations that are beyond your control. For example, being told some bad news. In such cases, you cannot prevent it rather try to deal with it.

When you are stressed, your muscles are tense and need to be relaxed.

Relaxation exercises can help you.

## Sleep Disturbance

Sickle cell crisis can interfere with your sleep. When you are in pain and unwell, you are not likely to sleep very well. You may find it difficult to fall asleep or may wake up often and not get enough rest.

Sleep disturbance (insomnia) may also be caused by other things. For example, you may have some thoughts on your mind, or perhaps you are feeling stressed.



Therefore, your lifestyle or what is going on around you may affect your sleep.

## Sleep Monitoring

If you have difficulty in sleeping, it is important to find out how much sleep you actually get at night. Using a diary may help you. Sometimes, you may have more sleep than you think.

Also, make a note of any thoughts and feelings of anxiety or worry, and your general health and mood. Refer to the Sleep Diary provided.

## Dealing With Insomnia

Spending a lot of time in bed, sleeping late in the morning, and having a nap during the day may help you cope with insomnia in the short-term. However, these may prolong your insomnia. Try these:

1. Eat a balanced diet and exercise regularly.
2. Monitor and challenge your self-statements in relation to sleep.
3. Do some relaxation.

**Eat well,  
exercise, and  
relax to help  
prevent  
insomnia**

## Progressive Muscle Relaxation

This type of relaxation involves making your muscles tense and relaxed in addition to breathing heavily and deeply. By tensing your muscles gently you force them to become relaxed.



Relaxation

Important: Do not to tense the muscles in the parts of your body where you have pain.

Before you start this procedure, you must make yourself comfortable as shown on page 10.

Go through the various muscle groups, as shown below, a few times. Get a feel of how you can tense your muscles. Relax them after each step.

This is important: Pay special attention to the difference between a tense and a relaxed muscle.

### Muscle Groups

1. Lower Arms and Hands – *Hold both arms out over your lap and clench your hands, and relax.*
2. Upper Arms – *Raise both arms to your shoulder, and apply pressure as if you were making 'muscles', and relax.*
3. Shoulders – *Draw your shoulders up toward your ears, and relax.*
4. Neck – *Try to almost touch your chest with your chin, but without actually doing so, and relax.*
5. Lips – *Press your lips together tightly, do not bite your teeth, and relax.*
6. Eyes – *Close your eyes tightly, and open them.*
7. Jaws – *Press your teeth together gently, do not bite on your tongue, and relax.*

**Know your  
muscles**

## Other Muscle Groups

8. Lower Forehead – *Frown and try to lower your eyebrows, and relax.*
9. Upper Forehead – *Try to wrinkle your forehead and raise your eyebrows, and lower them.*
10. Chest – *Take in a deep breath in and hold it, and breath out.*
11. Stomach – *Draw your stomach in tightly, and relax.*
12. Bottom – *Draw your buttocks in tightly, and relax.*
13. Thighs – *Press your thighs in tightly, and relax.*
14. Lower Legs – *Point your toes away from your knees, and relax.*
15. Calves – *Point your toes toward your knees, and relax.*



After you have done this a few times you will feel quite relaxed. However, you should continue deep breathing after you have tensed and relaxed the chest muscles.

Also talk yourself through further relaxation as on page 10. By now it should be a bit easier for you to do so.

## I Can't Do Relaxation

You may have found it difficult to practice relaxation. There could be a number of reasons for this. However, you have to remember your initial promise to yourself.

That is, you would at least try out the coping skills in this manual. Should you find that you have broken this promise, think about it for a while.

What have you been saying to yourself?  
What excuses do you make?

Think about how you can overcome these problems.

**Keep practising  
relaxation**



## Obstacles To Relaxation

### 1. *"I don't have time to relax."*

Have you given relaxation sufficient time in your busy schedule? Simple deep relaxation does not take very long to do. You can try it out for about 5-10 minutes every day to start.

### 2. *"I don't have any place to relax."*

Try and create one. Can you ask other family members or the kids to stay in another room and not disturb you for a short while? Otherwise, can you practice when others are out or the kids have gone to bed?



### 3. *"Relaxation seems too slow and boring."*

Are you too busy or too active? Perhaps it is time for you to examine your activities. You have to be able to slow down and take it easy, this is good for your body and your health.

### 4. *"I feel anxious when I try to relax."*

Relaxation may bring up some strong feelings, which could make you feel anxious. Practice for short periods of time until you get used to it. Open your eyes anytime you feel anxious until you feel better.

**Relaxation is  
good for your  
body and your  
health**

### 5. *"I just don't have the discipline."*

Is it like a new habit? Practising relaxation is like learning to change your behaviour. It may take some effort, but practice makes perfect.

## You can do it!

No matter your situation, just keep trying. Think about how relaxation can improve your health and well-being.



## Attention Diversion

Usually when you are in pain you would do certain things that take your mind off the pain. Try and think more carefully about these.

For example, you may watch television, listen to music or the radio, read a magazine or a book. In all of these situations you are distracting yourself, that is you are diverting your attention from the pain to something else.



Ghetto Blaster

It is important to find out which types of diversion are most effective ie. how long your attention is taken off the pain, and at what times or in what situations.

It may be useful to keep a diary for this purpose.

## Diversion Strategies

Remember thinking of other things fills the 'gates' in your body allowing fewer pain messages to go through, and thus making you feel less pain.

You can do more to divert your attention. Apart from distracting yourself from the pain, you can focus your attention on something other than pain.

## Mental Tasks

Some mental tasks can help divert your attention since your brain is actively involved in other things. A useful way is to count backwards slowly from 1000 or 100. When you are counting backwards it is also helpful to think the word "*Relax*" between the numbers.

This may seem a bit strange at first, however you are using extra effort to focus on the task rather than your pain. The result is that you are likely to feel less pain.

## Pleasant Imagery

You can use 'pleasant imagery' to help you relax and divert your attention. It may be easier if you close your eyes before you start.

Think of pleasant scenery in a place where you have been. Perhaps a nice place you have been on holiday, or an ideal place where you would like to go. For example, a warm sunny beach, a waterfall in a rain forest, a flower garden, or a lake.



Paradise

Try to involve all your senses in the imagery. Guide your imagery.

## Guided Imagery

You should see the sun, feel the heat, hear the water, listen to the birds chirp and toads croak, smell the flowers, and so on.

You can also talk through your images with somebody else if they are present in the room, that helps.

## Favourite Places

You can have other images in a scene, anything that makes it relaxing for you. Certain people or places like church or the mosque may bring you good thoughts.

Make a note of the most enjoyable places you go so you can re-visit them in pleasant imagery.

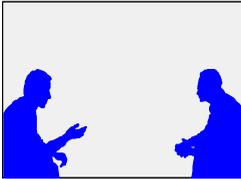
Sometimes it is more pleasant if you talk yourself through relaxation before using the imagery.

**Pleasant scenes  
lead to pleasant  
thoughts**



# Communication

Communication is a set of skills you learn so you can get a message across. This lets others know how you feel, enables you to listen to others, and get others to reply to you. These skills can be verbal or non-verbal.



Do they understand?

Sometimes it may be difficult for you to let others know about your sickle cell and what you are going through. Doctors, nurses, friends, family members, or even strangers need to be communicated to properly.

People make assumptions about others sometimes. This can be changed by effective communication.

## Effective Communication

You have sickle cell and you do have pain, so you want others to understand you when you communicate with them. You also want to understand them.

You have to be able to communicate properly with others in order to make things work out for your benefit.

A lot of problems can be avoided if people understand each other.

Effective communication is a two way process. The ways in which you get your message across to someone and receive a message from them is crucial.

**Effective  
communication  
is important to  
get your  
message across**

## Communication Skills

1. You have to make sure other people understand what you say to them, be clear about what you mean. Do not assume that they understand what you want to say.

2. You have to listen to other people carefully and try to understand what they also say to you. Do not assume that you know what the other person is trying to say.



Shouting at who?

3. Do not keep quiet about how you feel, however it is more effective to say how you feel to other people without becoming aggressive or angry.

## Ways of Communicating

Think of the different ways you can communicate with others. For example, you talk, write a letter, or listen to a conversation. You may also smile or wave your hand at somebody.

Write these down and try and group them into Verbal and Non-verbal communication. Also decide which types of communication are better for you.

**There are  
different ways of  
communicating**

## Assertiveness

Being 'assertive' is important in communication because it is a way of saying exactly what you feel while respecting the rights of others.

It gives you the opportunity to express your point of view without being aggressive or angry, and it also stops you from being quiet or passive.

## Role Play

Try and practice communicating with others by 'role play', or by writing things down. Do not only role play or write down what you want to say, also try and do the same for what you want others to say back to you.



Here is an example.

Imagine you are in hospital with a crisis and your pain seems to be getting worse, you feel a bit scared so you call the nurse to your bedside.

This is what may happen.

### Version One

You: *"My pain is worse."*

Nurse: *"It's nothing, what I have given you already is enough."*

**Role play a scenario**

This is certainly not the reply you wanted. Perhaps it is because of the way you said it. Now you may do one of two things.

You: *"OK." Keep quiet.*

OR

You: *Shout. "I want more pain medication now!!"*

Nurse: *"No! You have to wait a while."*



Does it help?

Now ask in a better way.

## Version Two

You: *"My pain is worse, I'm scared. Can you get the doctor to examine me to see if there is something else going on. I want to be sure."*

Nurse: *"OK. The doctor will be coming round soon. I will get her to have a good look at you. Is your pain medication alright?"*



Although this is just an example, it shows that by communicating properly and being more assertive, you are likely to get a better reply from others.

## Appropriate Assertiveness

Try to explain how you feel and what you want to be done about it without getting angry. You may also find it helpful to write down all the things you want to say to others.

In the above example, you may want to write down some questions for the doctor too. List the most important ones first. Your aim is to help others to help you, not make matters worse.

**Be assertive  
without making  
your situation  
worse**

## Practice

Think more about the way you communicate with others especially regarding sickle cell and pain just like you did earlier regarding your self-statements.

With practice it becomes easier.

## General Self Management

1. Drink a lot of fluids regularly throughout the day. At least 3 litres (8-10 teacups) per day.
2. Keep warm in the cold weather, and keep cool in hot weather.
3. Have enough rest, sleep and relaxation.
4. Avoid unnecessary stressful situations.
5. Take physical exercise at a pace your body can cope with, do not over do it.
6. Avoid infections. Seek prompt medical advice, and complete any course of antibiotics prescribed by your doctor.
7. Eat a well balanced diet. Do not take iron or iron supplements unless prescribed by your doctor.
8. Treat cuts, bruises and wounds quickly.
9. Live life to the full.



**Take good care  
of yourself**

## Prayer

Some people pray often because they find that it helps them to cope with their daily life and to feel better. Prayer can be seen as a means of using religion to help manage problems ie. Religious Coping.

You can use prayer as one of your coping skills for sickle cell disease and pain. Combine prayer with the other skills in this manual.



**A word of  
prayer**

## Complementary Therapies

Complementary therapies such as physiotherapy and acupuncture can be helpful for people with sickle cell disease. Therapists working closely with the medical team in particular are useful.

Remember This:



Natural Remedies

Complementary therapies are meant to be combined with your usual medical treatment. It is important to check with your doctor first to see if they are okay.

These types of therapy sometimes involve physical methods, therefore it is important that they are done by a qualified person.

### In the hospital

Physiotherapy— for muscle relaxation, and includes exercises.

Hydrotherapy— specialist exercises in a warm pool, and may be done with physiotherapy.

**Try some other  
therapies for  
pain control**

### In the community

Acupuncture— ancient Chinese therapy, aims to revitalise and heal by inserting and removing fine needles at specific points on the body.

Osteopathy— special manipulation and massage on bones, joints, muscles and tissues.

Aromatherapy— combines natural 'medicines' in essential oils with massage.



Acupuncture

## Maintaining Skills

A lot of different things have been covered in this manual, some may be more helpful to you than others. The important point is to find out what works for you. Keep practising these coping skills so that you can use them as and when you need to. You do not want to forget them.



Set of tools

Although you still have sickle cell disease you now have ways of reducing its effect. You also have a feeling of control. There is something you can do!

Just look back and see how much you have learnt in such a short time. Well done!

## Relapse Prevention

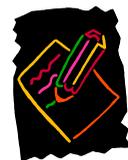
Now, you have to plan ahead. Sickle cell crisis can start at any time so you have to decide what to do.

You do not want to feel helpless and out of control again. This is called 'relapse prevention'.

**Practice makes  
perfect**

## Goal Setting

You have to set goals. Write down some of the things that can get in the way of your continuing with the skills that you have learnt, and what you can do to prevent this.



Set your goals

Also write down what skills you will use when you are in crisis. Put them in steps, this will be helpful.

## Keeping in Control

Make a list of options. This should include all the practical things you do. Here are some examples.

- Do you phone a family member?* – Keep their phone number in this manual.
- Do you remember your helpful self-statements?* – Keep a list with your options.
- Do you try relaxation?* – Do you remember how to do it?



Everything helpful to you is important. Do not leave anything out.

Keep this manual in a safe place where you can easily reach it.

## Always Remember

YOU DO NOT HAVE TO SUFFER SO MUCH FROM SICKLE CELL DISEASE OR PAIN.

**You can do more  
to help yourself**

## Final Word

It is important to see yourself change for the better, to overcome illness and pain, and to improve your quality of life. It is even more important to keep in control of your life. This is the best thing that can happen to you!



# Notes



# Notes

