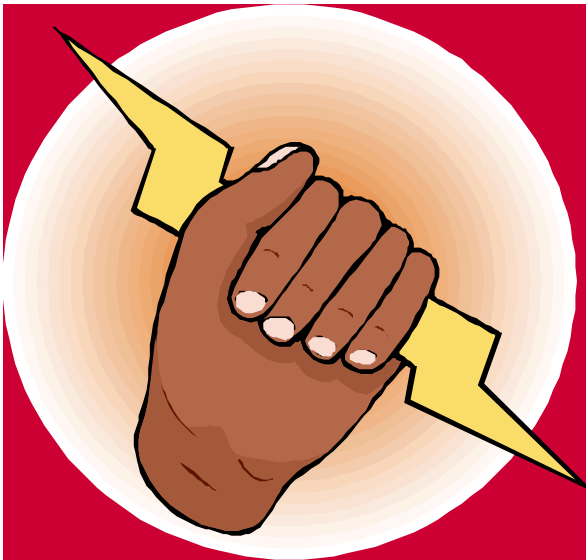


**COPING WITH
SICKLE CELL DISEASE
& PAIN**



**A SELF-HELP MANUAL
FOR CHILDREN**

Sickle Cell Disease

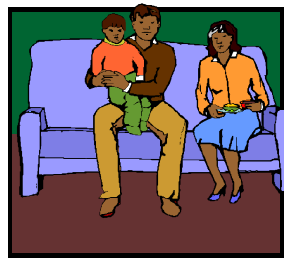
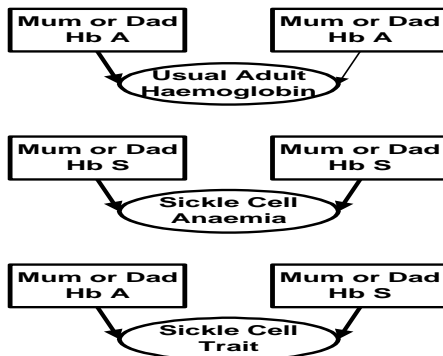
Sickle Cell Disease is what we call a red blood cell illness that some people are born with. Inside the red blood cell there is something called Haemoglobin or 'Hb'. There are many kinds of Hb, and every Hb has a letter or a name. For example, HbA, HbS, HbC, and Hb-thalassaemia. We are born with one Hb from Mum and one Hb from Dad, we have two. Most people have HbAA. HbA is the usual Hb.

If you have sickle cell disease, it means that you are born with:

- One HbS from Mum and one HbS from Dad (HbSS, also called sickle cell anaemia). OR
- One HbS from either Mum or Dad and another Hb from either Mum or Dad. (eg. HbSC or HbS-thalassaemia).

If you have sickle cell trait, it means that you are born with:

One HbA from either Mum or Dad and one HbS from either Mum or Dad (HbAS). People with sickle cell trait do not have an illness.



Sickle cell disease is from both Mum and Dad

In some countries there is another illness called malaria. People whose family come from these countries sometimes have sickle cell, because HbS does not make young children in these countries get serious malaria. That is why some people from the Caribbean, Africa, Asia, the Mediterranean, Middle East, and places in Europe (for example, Greece and Cyprus) have sickle cell.

Sickle Blood Cells

Hb (haemoglobin) in red blood cells carry oxygen from the lungs and gives it to other parts of the body. When HbS does this, the red blood cells change from their round shape to a 'sickle' shape.



Usual Red Blood Cell



Sickle Red Blood Cell

This can cause some problems:

1. Sickle blood cells only live for less than 20 days. Usual blood cells live for about 120 days. The sickle cells die so quickly the bone marrow where the blood cells are made cannot keep up. This makes you 'anaemic'.
2. Usual red blood cells are soft, spongy, and flow easily in the blood vessels. Sickle blood cells are hard and sticky. They cannot move through the small blood vessels easily. The cells get jammed and block the blood vessels.
3. Sickle blood cells sometimes harm other parts of the body. For example, the spleen, lungs, liver, kidneys, hip and spine. This harm can last for a very long time.

Sickle blood cells cannot move freely round the body

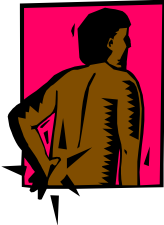
Sickle Cell Crisis

When the sickle cells block the blood vessels, for example in the bones, joints and muscles, this is what we call a 'crisis' because of the pain that you get.



Sickle Cell Pain

Children have many ways to say how sickle cell pain feels. Some say it is 'like needles', 'sharp', 'thorny', and 'prickly'. Some people believe that there is no other pain that can get as bad as sickle cell pain.



Thorny pain

This pain is different, so in some countries the name 'sickle cell disease' also tells other people how you feel the pain. For example, in Ghana some people call it 'ahotutuo', which means pinching.

Only you know how it feels: – sickle cell pain can start anywhere in your body, and you cannot be sure how long or how bad it is going to be. Every child is different.

Sickle cell pain can come for 5 to 10 minutes or for many days. Some people have pain a lot, sometimes every week, others have pain once every few months or years.

Sickle cell pain comes and goes, but sometimes when sickle cells have hurt your body for a long time you can get another kind of pain. This is called 'chronic' pain.

**Sickle
cell pain is
different**

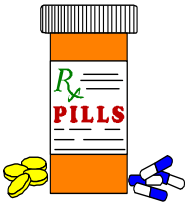
Pain Medicine

When you have sickle cell one of the important things is to make sure that you do not have too much pain. So when you are in pain, you have to take pain medicine and drink a lot of water. There are different kinds of pain medicine, these are also called 'pain killers'. For example:

1. Little Pain— Paracetamol (eg. Calpol)
2. A Bit Strong Pain — Ibuprofen (eg. Junifen)
3. Very Strong Pain— Morphine (You get this when you are in hospital)

Other Medicines and Treatment

1. Blood is sometimes given when you become anaemic. You may need it because, for example, you had a stroke or to stop you from having a stroke.
2. Antibiotics, for example Penicillin can help you not to get infections.
3. Hydroxyurea is another medicine that helps some people not to be ill, and to have less pain.
4. Bone Marrow Transplantation is special treatment, which stops your body from making sickle cells, and can cure the illness. It is not everybody who can have it because:



- a. It is not easy to find bone marrow from another child that will work.
- b. It is very hard to do, and there can be a lot of problems.
- c. If you are not very young it may not work for you.

To Cope

To 'cope' is to do with what we think, feel, and do about things that are not easy and bother us.

To cope with pain is to do with how you think and what you do about your pain and the things that it does to bother you.

What Children Do

Children do a lot of things to help them cope and make pain go away. For example, they play to try and forget. Sometimes they may do nothing, but this is not so good.

You can do some things to help when you have sickle cell pain, such as take your medicine, rest or use a hot water bottle.

Some children are able to do things and go to school when they are in pain. Other children may need some help to make them feel better.

There are different types of treatment for sickle cell disease



Feeling Good

There are some things that children like to do. For example, being with your family and friends, going shopping and on holidays. These, things make you feel good, but if you are ill or in pain it is sometimes hard for you to enjoy them.



Things we enjoy

The things that you do to help so that you can keep enjoying life are important.

If you are able to do the things that you like all the time, you feel good and you also feel well when you feel good.

Children Are Different

When it comes to sickle cell and pain, children are quite different. Some children are not able to do everything they want to do, because they fall ill a lot. Other children are able to do a lot of the things that they like.

Every child is different how they feel and what they like.

What You Can Do?

Sometimes, sickle cell and pain make you feel fed up. Sometimes, it also makes you feel that there is nothing you can do to feel better.

You may or may not feel like this a lot of the time, but when you do, you may want to do something to help yourself, not only take medicine or go to the hospital. What else can you do?

THIS MANUAL MAY HELP YOU.

Sickle cell disease is different in every child

Self-Help

Self-help is something you can do to help feel better about your sickle cell and pain. It is to do with how you feel, what you do and tell other people about your illness and pain.

You will learn some things called 'skills.' You need to try and learn them bit by bit. It helps a lot when you try some of these self-help skills, as well as take your medicine and do what your doctor tells you.



You can learn self-help skills quickly, and use these skills to help you feel better when you are ill and in pain.

Self-help will work only if you promise yourself to try to do the things said in this manual.

How It Helps

Self-help and other things can be used to help take care of children with sickle cell. This is called a 'programme.' There are a lot of things that the programme can do, these are:

1. To help you know more about sickle cell and pain.
2. To help you to learn new skills to use when you are not well, and help make you feel less pain or make the pain go away.
3. To help you so that things do not bother you too much, and so that you feel good.
4. To help you find out about other things to do with sickle cell.

You can do something to help when you are ill and in pain



Are You Ready?

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



People have been talking about sickle cell 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.”

Not sure?

Remember This: YOU ARE NOT ALONE

You are not sure?

Listen to what other people have said.

“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, but 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.

How You Feel Pain

Think as if you are walking around the house, and then you hit your knee hard against a table. The first thing you may do is 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 message to your brain to say that you have knocked your knee.

The brain takes the message and tells you that this hurts, so you then shout *"Aaarh"*. A pain message is sent back through your spine to your knee. You may be able to change this pain message.

Now think again as if you are 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 talk to your friend for a long time.

The phone call makes you think of something else, so you may not feel the pain so much. Maybe you do not think about your knee. The pain message has changed.

How you feel pain can be made to change

The 'Gates'

The things that connect the nerves in the spine and brain are like 'gates'. When the 'gates' are full they block out pain messages.



Talking on the phone

What You Can Do About Pain

Remember this:

When you are only thinking about pain you will feel it more.
When you are thinking about other things you will feel less pain.



This means that other things, for example what you think, may change how you feel pain.

Stopping pain

How To Block The 'Gates'

When you are in pain, one way to block the 'gates' is to take pain medicine. You can also block the 'gates' if you fill them with other messages.

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

Also, when you talk to your friend on the phone you fill the gates. This is because you think about what your friend is saying to you, so you feel less pain.

There are other things that can fill the 'gates.'

One 'skill' that can fill the gates and help make you feel less pain is called 'relaxation.' Try this now.

**If you block the
'gates' you feel
less pain**



Simple Relaxation

Find a nice chair in a quiet and warm place, you may also lie down on a bed or sofa. You want to be on your own 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, put a pillow or a cushion behind your head.



Relaxing

Read this a few times before you start to help you remember:

1. *Close your eyes and think about your body.*
2. *Take a deep breath.*
3. *Hold your breath for a few seconds, then breathe out all the air from your lungs.*
4. *Do this over and over again. When you breathe out each time, feel the tension from your body coming out with the air.*
5. *Think of the word 'relax'.*
6. *Think about your deep breath in and out. 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. Also say the words 'warm', 'calm', 'peaceful', 'heavy' and 'relax' to yourself. Keep on doing this for about 5 to 10 minutes.*
8. *Enjoy how relaxed you feel, but try not to fall asleep.*
9. *Carry on for a while and then slowly stop breathing too deep, and start breathing as you always do.*
10. *When you are ready, come slowly out of the deep relaxation. You can still enjoy the calm and peace a bit more.*
11. *Open your eyes.*

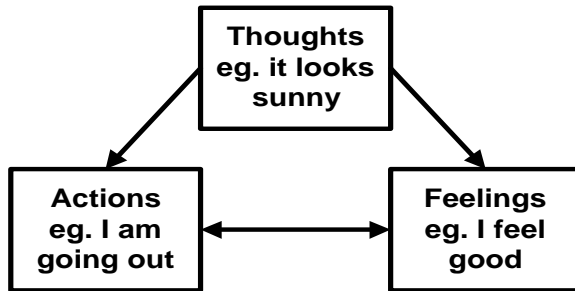
Try this relaxation every time you can, the more you try it the easier it gets. You can also play soft music to help you relax even more.

Thoughts and Feelings

Thoughts and feelings make you do the things you do everyday. This is the same for sickle cell and pain. What you think makes you feel and also do things in a certain way.



Brain power



For example, if the sun is out you say to yourself *"it is a nice day today."* This makes you feel good and want to go out. If it is dull you say to yourself *"it is cold today."* You may not feel so good and want to stay indoors.

Self-Talk

Quite often you say things to yourself without thinking much about it. These thoughts are also called 'self-talk.' They pop up in your head very quickly, and are very strong. Self-talk is also called 'automatic thoughts.'

Self-talk can make you feel good or bad so it is important to think about them. This may be hard at first but if you keep trying, you will be able to do it.

Think about some of the things that pop up into your head or you say to yourself when you are ill or in pain and write them down. Try and see how you feel and the things you do when you self-talk.

Self-talk is strong and makes us feel and do things in a certain way

Strong Feelings

Here are some examples of what some people think about sickle cell. These make them have strong feelings:



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."*

Why me?

Anger

The "Why" questions can also bother you and make you angry because you cannot answer them. It is hard to say why it is you. It is bad to think why because it does not make you feel good.

Also, think and ask yourself if you have been angry about your sickle cell for a while. What thoughts or self-talk 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

Good Self-Talk

Try and say some nice or good words to yourself when you are in pain, for example "*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-talk and help take away some fear.



Some nice things

Remember the number of times you have talked yourself into something bad. You can also talk yourself into something good or nice.

Bad Self-Talk

Sometimes you say bad things to yourself. It is not you alone, everybody does it. Some people do this a lot, some people do this once a while.

When you say bad things to yourself it makes some things look real when they are not.

A lot of bad self-talk is not correct, and does not help you because it will change the truth. Things can look very bad when they are not so bad, and make you feel as if there is nothing you can do.

This is not very good when you are ill or when you are in pain.

Again, think of your self-talk when you last had a crisis, and see how many bad things you said to yourself.

Bad thoughts do not help. Think more about good things.



A dark place

Thinking About Thoughts and Feelings

Thinking about your self-talk (thoughts) when you are ill or in pain may look hard. Why not start thinking about your self-talk every day. You should think about everything, not only sickle cell.



A thought diary

Use Thought Diary 1 in this manual to write down your self-talk (good and bad), feelings, and the things you do as they happen.

Also write down self-talk that is good for your health and makes you feel well in Thought Diary 2.

If you write down your self-talk it will help you find out what makes you feel better and do things that help. Also, it will help you find out what self-talk makes you feel worse and do things that do not help.

This is very important because when you are ill or in pain you will be able to think about your self-talk.

This is important

It is easier to try to think about your self-talk when you are well, so that you can do something about it when you are ill.

Also, if the pain is so bad that you cannot think at all, you can always read your diary and see what good self-talk can help you feel a bit better.

If you think more about your thoughts and feelings, you can also close the 'gates' in your body. That will help you with your illness and pain.

**It is important
to think about
your thoughts
and feelings**



Thinking about
your thoughts

Changing Thoughts

Thoughts or self-talk make you feel a certain way, therefore if you can change your bad self-talk you can change how you feel.



No way out?

When you are in pain, you may also be unhappy, but bad self-talk can make it worse and has to be changed.

Here are some examples of thoughts that some people have for a sickle cell crisis:

Some People's Thoughts

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

When 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 be better quickly.

3. *"Nobody cares."*

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

Some thoughts are not right, they need to be changed



Some thoughts

Thoughts That Are Not Correct

Thoughts come from a lot of different things. Some may come from things that have happened to you. Also, some thoughts may come from watching television or listening to the news. Wherever your thoughts come from, they may not always be correct.

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

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 always 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 go to school or do my homework."*

5. *"I shall never get over this sickle cell. I will not be able to do what I want."*



Where do your thoughts come from? Are they correct?

Changing Thoughts

You can change your self-talk that is bad or does not help. Find out if they are true. Think about them. Look at the examples on page 16.



1. and 2. Is it all true? -

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. *"Maybe 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 true. 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. I can keep well and stay out of hospital."*

4. Are you blaming yourself for nothing? - eg. *"When I am not well, I cannot go to school or do my homework, and that is not my fault. But I can still try and catch up when I am better."*

5. What is the worst that could happen? -

eg. *"I shall go on getting more and more crises and doing less and less. But, this may not be true. I can learn how to cope better, and so be able to do the things I want to do."*

Change your thoughts.

Try and see if they are right

This is Important

You do not have to change every bad thought to become good. What is important is to change them to make sense and so that they can help you.

Activity

Doing things and having fun is very important! Playing games or sports, going out with family or friends, shopping, and school trips are fun.

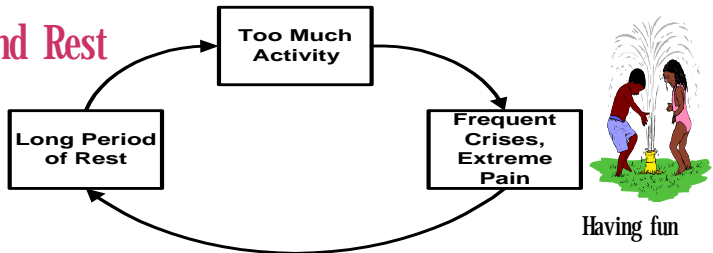


Out playing
with friends

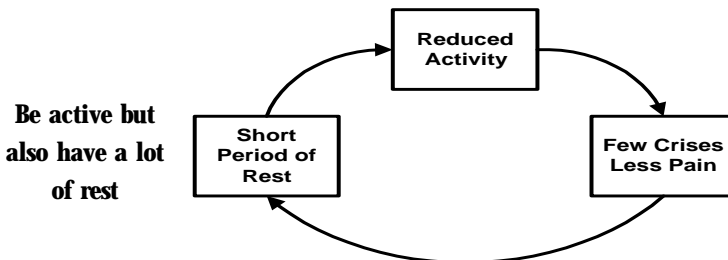
Activity is good, so if you are not active you should try doing a bit more. This would make you feel a lot better, but if you do too much without rest you may fall ill.

This means you cannot do anything for a while. You will need to stay in and rest. When you are better, you want to catch up so you start doing too much again and the cycle goes on.

Activity and Rest



This cycle may sometimes be hard to stop. For example, you may have a lot of things to do and nobody to help you. You may also want to be with your friends and not be left out.

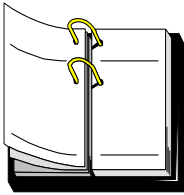


Try not to do too much at once. You will not have a lot of crises and will not need to rest for a long time. This will make you to get on with things.



Thinking About Activity

It is quite easy to write down the things you do, and how much you can do without starting a crisis. Look at the Activity Sheet in this manual.



Activity Sheet

Think carefully about the things you do everyday in a week to see how best you can arrange them. For example, homework, games, going out with friends. List them:

1. Very Important – Need to do these now, cannot wait
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 is anything that bothers you, and makes you feel tense, angry or unhappy. **causes pain**

Stress

There are a lot of things that can make you feel stressed. For example, homework and exams, or if you are being teased and bullied.

What Stress Can Do

Too much stress is not good for your health because it can make different things happen to you.

You may become very tense and unable to relax.

You may not be able to eat or sleep well.

You may not enjoy the things you do.

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



Stress

Thinking About Stress

Stress may be due to some of the things that you do. So, it is important to think about the things that you do to see if they make you stressed.



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

What Makes You Feel Stress

Try and find out what makes you feel stress. Start by writing down the things you do for the next few weeks. Use the activity sheet in this manual.

Also, write down if any of these things make you feel stressed. That is, things that bother you, and make you feel worried, tense, angry or unhappy.

**Do you know
what makes you
feel stress?**

If you know the things that make you feel stress, you can try and stop them so that you do not fall ill.

Dealing With Stress

Sometimes stress happens because of something you cannot do anything about. For example, if you are told some bad news. In such cases, you cannot stop it but try to deal with it.

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

Relaxation can help you.

Sleeping

Sometimes when you are not well you may not sleep well. When you are in pain falling asleep may be quite difficult. You may wake up often and not get enough rest.

Also, you may not sleep well because of other things. For example, you may have some things on your mind such as bad self-talk, or maybe you are feeling stressed.



The things you do or what is going on around you may affect your sleep.

Thinking About Sleep

If you are finding it difficult to sleep, it is important to find out how much sleep you do get at night. Using a diary may help you. Sometimes, you may have more sleep than you think.

Also, write down anything that bothers you, or make you feel tense and unhappy. Use the Sleep Diary in this manual.

What To Do About Sleeping

If you are at home, go to bed as soon as you are sleepy, even if it is not at night. You can have a nap in the afternoon. Try not to stay up too late. Also, try these:

1. Eat well and do light exercise.
2. Think and change your self-talk about sleep.
3. Do some relaxation.

**Eat well,
exercise, and
relax to help you
sleep**

Muscle Relaxation

This type of relaxation is to do with making your muscles tense and relaxed and breathing heavily and deeply. If you tense your muscles gently you can 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 doing this, you must make yourself comfortable as is shown on page 10.

Go through the muscle groups, as shown below, a few times. Try and see how you can tense your muscles. Relax them after each step.

This is important: See how it feels when a muscle is tense and when it is relaxed.

Muscle Groups

1. Lower Arms and Hands – *Hold both arms out over your lap and clench your hands, then relax them.*
2. Upper Arms – *Raise both arms to your shoulder, and pull as if you were making 'muscles', then relax them.*
3. Shoulders – *Draw your shoulders up toward your ears, then relax them.*
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. You should continue deep breathing after you have tensed and relaxed the chest muscles.

Also try doing more relaxation as it is shown on page 10. By now it should be a bit easier for you to do this.

I Can't Do Relaxation

You may find it hard to practice relaxation. There may be reasons for this, but you have to remember the promise you made to yourself.

That is, you would try out the things 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?

**Practice
relaxation. Don't
Make Excuses**



Why You Cannot Do Relaxation

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

Have you taken time in your busy day to do relaxation? Simple relaxation does not take very long to do. You can try it out for about 5-10 minutes every day to start even when you are in school.

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

Try and find one. Can you ask others in the family to stay in another room and not disturb you for a short while? Can you practice when they have gone out?



3. "Relaxation seems too slow and boring."

Are you too busy or too active? 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 makes you calm, and when you are not used to this it can make you feel anxious. Practice for a short 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 can't do it."

Is it like a new habit? To practise relaxation is like learning to change something that you always do. This is difficult at first, but practice makes perfect.

You can do it!

No matter your situation, just keep trying. Think about how relaxation can make you feel better.



Distraction

When you are in pain there are some things that you do to take your mind off the pain. Try and think more carefully about these.



Ghetto Blaster

For example, you may watch television, listen to music, read a book, or play computer games. This is called distraction. You are taking your mind off the pain, and onto something else.

It is important to find out what types of distraction works well. That is, how long your mind is taken off the pain, and when different things work best.

It may be useful to keep a diary to do this.

Distraction Skills

Remember that, if you think of other things the 'gates' in your body get filled and block out pain messages. This makes you feel less pain.

You can do more to take your mind off pain. You can also think of something other than pain.

Mental Tests

Some mental tests can help distract you. For example, 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 look hard at first, but when you try hard to think about the task and not the pain you will feel less pain.

Pleasant Imagery

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

Think of a pleasant scene in a place where you have been. Maybe a nice place you have been on holiday, or a place where you would like to visit.



Paradise

For example, a warm sunny beach, a waterfall in a rain forest, a flower garden, or a lake.

Try to use 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.

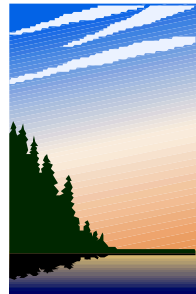
**Pleasant scenes
lead to pleasant
thoughts**

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.

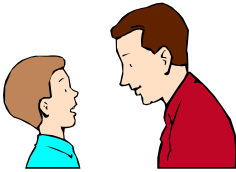
Write down some of the most enjoyable places you go so you can re-visit them in pleasant imagery.

Sometimes, it is nicer if you do relaxation before using the imagery.



Communication

Communication is a set of skills you learn so you can get a message across. This lets others know how you feel, makes you to listen to others, and get others to reply to you. These skills can be things you say or do.



Do they understand?

Sometimes it may be hard for you to let others know about your sickle cell and how you feel about it. Doctors, nurses, friends, family members, or even strangers need to be communicated to properly.

People sometimes think about others in a wrong way. This can be changed by good communication.

Effective Communication

You have sickle cell, and sometimes you are not well and are in pain. You want others to understand you, and you also want to understand them.

You have to be able to communicate well with others so as to make things work out for you.

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

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

**Good
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 think 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 think that you know what the other person is trying to say.



Shouting at who?

3. Do not keep quiet about how you feel, but it is better to say how you feel to other people without becoming angry. Be polite.

Ways to Communicate

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

**There are
different ways to
communicate**

Write these down on a sheet of paper. Also, decide what type of communication you find better for you.

Be Assertive

Being 'assertive' is important in communication because it is a way of saying exactly what you feel, but with respect for others.

This gives you the chance to say how you feel without being angry or loud, and also stops you from being quiet or timid.

Role Play

Try and practice. Communicate 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.

Lets say 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 scene

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."*



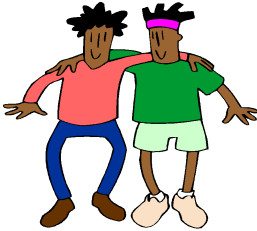
Does it help?

Now ask in a better way.

Version Two

You: *"My pain is worse, I'm scared. Can you get the doctor to look at 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?"*



This is just an example, but it shows that if you communicate well and are more assertive, you are likely to get a better reply from others.

Good Communication

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.

For example, you can write down some questions you want to ask the doctor. List the most important ones first. What you want is to help others to help you, not make things worse.

**Be assertive
without making
things worse**

Practice

Think more about the way you communicate with others. Remember how you did this with your self-talk.

It becomes easier when you practice.

General Self-Help

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. Try not to be stressed.
5. Do things that you like and make you feel happy, but do not over do it to make you feel too tired.
6. Try not to get infections. Take your antibiotics to help you keep well.
7. Eat well, have lots of vegetables and fruits. Do not take any medicines when you have not asked your doctor or pharmacist about them.
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. If you believe in it prayer may help you too.

You can use prayer as one of your skills to cope with sickle cell and pain. Use prayer with the other skills in this manual.



**A word of
prayer**

Other Treatment

Other treatment such as physiotherapy and massage can help people with sickle cell. These may be done by health workers who work with the doctors and nurses.

Remember This:



Natural Medicines

Other treatment are meant to go along side your medical treatment, not to replace them. It is important to check with your doctor first to see if they are okay.

These types of treatment may sometimes feel a bit harsh on the body, so it is important that they are done by a qualified person.

In the hospital

Physiotherapy— exercises to help you move and to help your muscles relax.

Hydrotherapy— special exercises in a warm pool that may or may not be done with physiotherapy.

**Try some other
treatment for
pain**

Outside the hospital

Aromatherapy— natural 'medicines' found in some oils that are used to massage the body.

Acupuncture— ancient Chinese treatment, gives energy and heals by using fine needles at certain points on the body.



Warm bath
with oils

Keeping Skills

A lot of different things have been shown in this manual, you may find that some may be more helpful to you than others. The important point is to find out what works for you. Try to practise these self-help skills so that you can use them when you need to. You do not want to forget them.



Set of tools

You have sickle cell but you now have ways to take care of yourself. There is something you can do!

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

Plan Ahead

Now, you have to plan ahead. You can fall ill or have sickle cell pain at any time, so you have to know what to do.

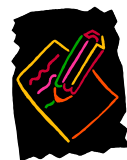
You do not want to feel that there is nothing you can do.

Goals

You have to set goals. Write down some of the things that can get in the way if you want to practise the skills. What can do to stop this.

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

**Practice makes
perfect**



Set your goals

Things To Do

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

Do you phone a close friend? – Keep their phone number in this manual.

Do you remember your good self-talk? – Keep a list of all them.

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 get it out quickly.

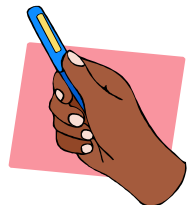
Always Remember

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 beat any illness and pain, and to have a good life. It is even more important to know what to do to stay well. This is the best thing that can happen to you!



Notes



Notes

