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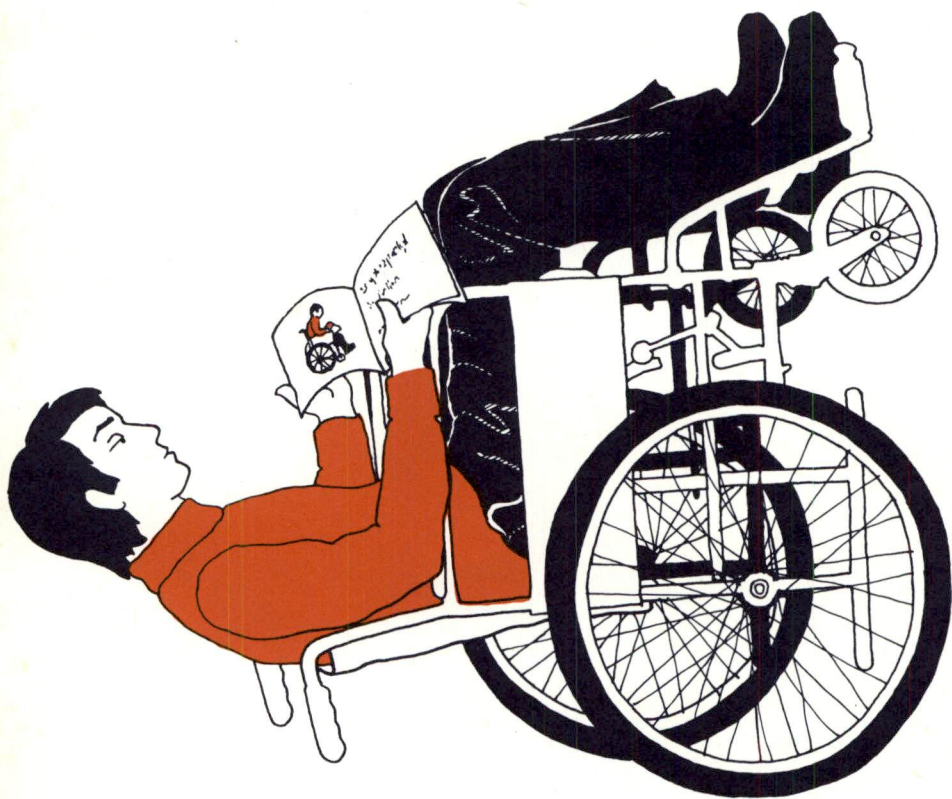
Bernadette Fallon

so you're paralysed . . .



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so you're paralysed . . .



so you're paralysed . . .

Bernadette Fallon

designed and illustrated
by Liz McQuiston

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Spinal Injuries Association

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*denotes
wheelchair
user

A retired consultant with thirty years' experience of the speciality of paraplegia and tetraplegia.

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..... so you're paralysed.

At the moment you probably feel bewildered, depressed, frustrated, and afraid, wondering how you're ever going to cope with going back to work, running a home, getting around, making love, everything you enjoyed doing before. There are many new things to learn and remember, and the aim of this book is to help you to learn some of them and to explain how you can do these things.

The first thing is the most important, and at times seems the most difficult. It's simply to remember that you are still the same person as you were before your body became paralysed. No one's trying to pretend that some things haven't changed. Parts of your body don't work as well as they used to, but all the things that made you **you** before are still there - your personality, your likes and dislikes, your hopes and fears, even your sense of humour. You're still an individual, and realising this is the first and biggest step in adjusting.

Then you can begin to find out about your body,
and what's happened to it.

A paraplegic is a person whose lower extremities and part of the torso are paralysed as a result of injury or disease of the spinal cord.

A tetraplegic has in addition a paralysis of the hands and a partial paralysis of the arms.

What is the spine?

It consists of a chain of bony rings, the vertebrae, rather like the metal rings around the hose of a vacuum cleaner, each with a bony 'body' in front. There are 24 such rings, seven in the neck (cervical), twelve in the chest part of the back (dorsal or thoracic), and five in the small of the back (lumbar). The vertebrae are held together, one above the other, by strong bands. Between their 'bodies' lie the discs, elastic buffers to take the jolts of daily life. At the base of the spine are the five sacral vertebrae, fused together, and the coccyx or 'tail'.

What is the spinal cord?

A grey 'tail' hanging down within the spinal canal (through the rings in the vertebrae) from the brain to the upper part of the small of the back. It is about as thick as a finger and some twenty inches (50cm) long. It is almost round, soft and flexible. About every one-fifth of an inch (5mm) it has thinner cables - the roots joining it or coming out of it, one on each side.

The cord works like a two-way telephone cable serving the 'telephone exchange' part of the brain, where incoming messages (feeling, sensation) are switched to outgoing messages (movement) - that is, it forwards messages from the brain to the muscles, either to move or to stay still, and messages from all over the body to the brain about feeling, touch, pain, hot and cold, and so on. The roots carrying messages down for

movement lie nearer the front, those carrying messages of feeling upwards lie nearer the back of the cord.

What is CSF?

Like the brain within the skull, the spinal cord within the spinal canal swims in a colourless fluid (cerebro-spinal fluid or CSF) which serves two purposes - to nourish the brain and the cord and to protect them by acting as a water-cushion.

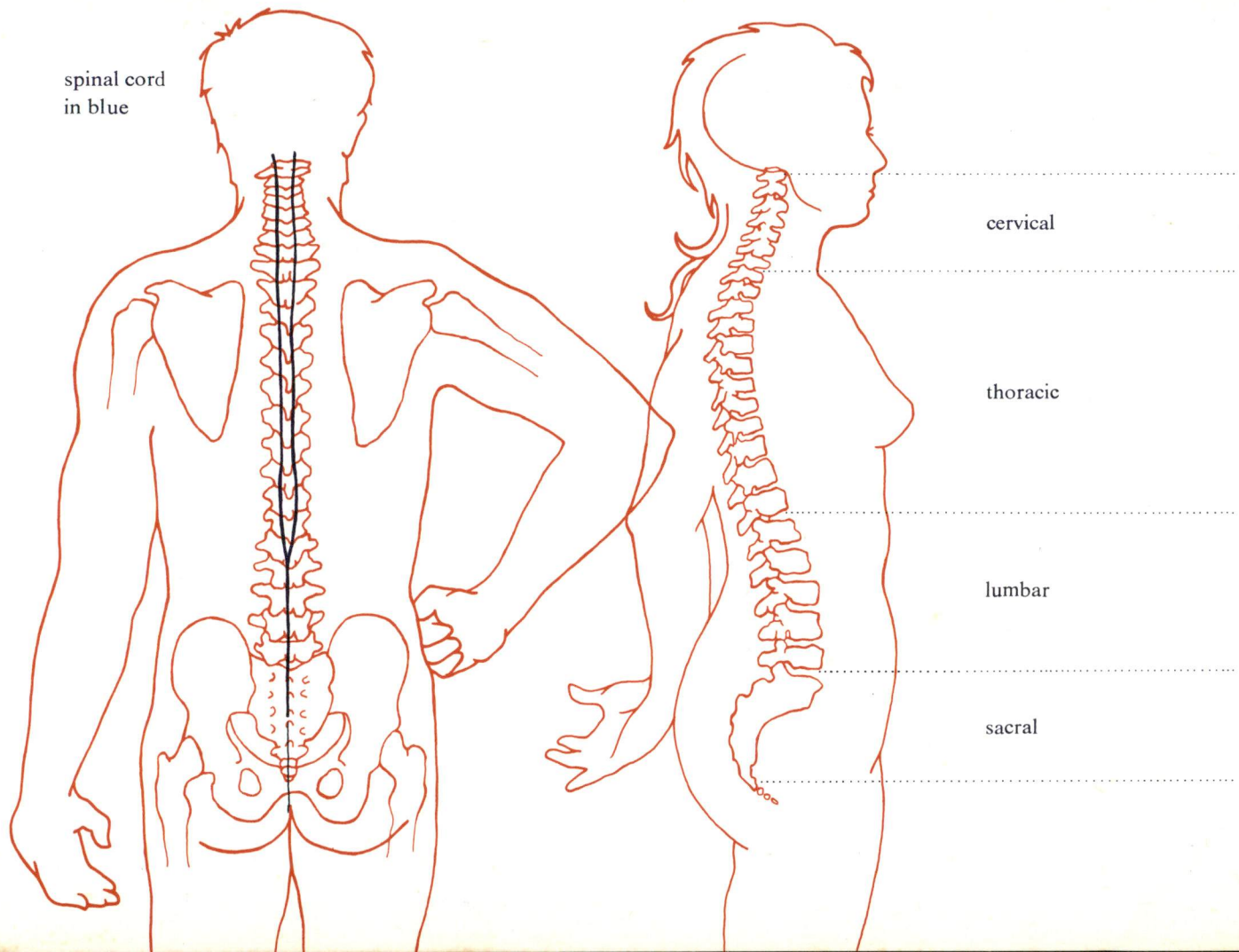
What are meninges?

These are the silky linings of both the skull and the spinal canal, containing both the CSF and the brain or cord.

What is the cauda equina?

The name means 'horse's tail'; it is the bundle of nerve-roots leaving or entering the lowest part of the spinal cord. This bundle lies within the last three inches (7.5cm) of the spinal canal, below the end of the cord.

spinal cord
in blue



cervical

thoracic

lumbar

sacral

DAMAGE TO THE SPINAL CORD

This may be sudden, due to accident crushing the spine and the cord (the most common causes are traffic accidents, industrial accidents, gunshot and stab wounds, and accidents resulting from sport, especially diving. Sometimes paralysis can result from operations performed for reasons not connected with spinal injury). Damage to the spine as the result of an accident is generally referred to as 'trauma' or 'traumatic' - the injury is a 'traumatic lesion' of the spine. In an accident one or more of the bony rings of the spine will have been broken or forcibly displaced and particles of bone pushed into the spinal cord. This will cause it to stop functioning - the more violent the injury, the more complete the interruption. Sudden damage may also be caused by disease which has no effect on the bony structure of the spine but damages the cord. This sudden damage generally either gets better or remains the same. Doctors call this 'non-progressive' paralysis.

Damage to the cord may also be gradual, due to disease of the spine or the cord or both (multiple sclerosis, growths, etc.). This tends to get worse, and is called 'progressive' paralysis.

What happens when the cord is injured?

The effects of trauma vary according to the particular part of the cord injured and the severity and extent of the damage, and how quickly it occurs. People sometimes say they have broken their neck or their

back, meaning that the vertebrae are displaced and some may be crushed.

DAMAGE TO THE SPINAL CORD

Paraplegia means that the spinal cord is injured below the neck. This leads to the interruption of messages sent through the cable, both for movement and for feeling. The interruption may be complete (no messages getting through at all, as often during the first few days or weeks) or incomplete (some messages getting through at once after the accident or sudden disease, or after some days or weeks, after 'spinal shock' (1) has been overcome and recovery may start).

(1) see page 12

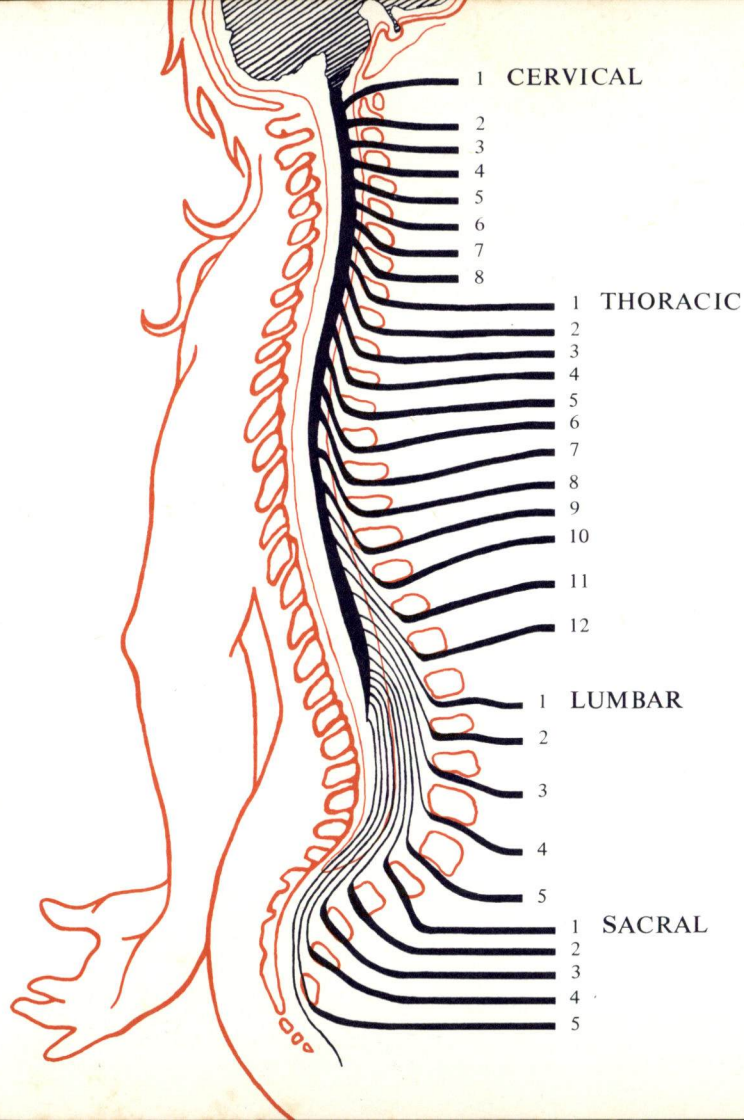
Tetraplegia means the same interruption of the cable higher up, at the level of the neck. 'Tetra' is the Greek for four, and indicates that all four limbs are affected, and may not be able to move or feel. Because of the paralysis of the chest muscles, breathing, especially deep breathing, is affected, and coughing up and clearing the lungs may be very difficult. Tetraplegia is also known, particularly in the United States, as 'quadriplegia'.

Autonomic paralysis is combined with paraplegia and even more with tetraplegia. Besides the cord and the brain (the 'central nervous system') there is another 'autonomic' or 'vegetative' nervous system outside of but close to and connected with the cord. It also is damaged in sudden interruption by accident or disease. Its messages are largely responsible for the ability to empty the bladder and

bowels, for male sexual function (female sexual function is generally unaffected), for the circulation of blood through the blood vessels, and for sweating. All these functions will be either abolished or disturbed by damage to the cord or cauda equina.

What is meant by the 'level'?

This is so called because the 'wires' within the cable, distributed along the cord into nerve-roots and collected from various parts of the body, indicate which section of the cord is the lowest still intact, while below it feeling and movement are disturbed or absent. This may be total or partial, permanent or temporary. The following diagram will make this more clear. It shows the cord within the spine and the roots arising from it or entering into it. On the right are given the numbers of the roots responsible for sending messages to individual muscles and muscle groups. Interruption at a particular level means that all the functions below that level are affected. For example, an injury below T.12 would mean that the leg muscles and the bowels and bladder would be partially or completely paralysed, while abdominal and chest muscles and the arms and hands would be unaffected. You will have been told the level of your paralysis.



VERTEBRAL COLUMN AND NERVE SUPPLY

spinal column and nerve roots in blue

C4 Diaphragm

C5 Deltoid (lifts arms sideways)
and Biceps (bends elbow)

C6 Wrist Extensors

C7 Triceps (straightens elbow)

C8 and T1 Hands and fingers

T2-T8 Chest muscles

T6-T12 Abdominal muscles

L1-L5 Leg muscles
and S1

S2 and below Bowel and bladder



What is spinal shock?

This is the early stage of the response of the body to the injury of the cord and autonomic nervous system. It lasts about three to six weeks, sometimes less. During spinal shock it is often impossible to predict whether paralysis will remain complete, become incomplete, or, for the lucky few, disappear altogether in the next few months.

If your paraplegia or tetraplegia is due to an accident (trauma) time must be given to the broken bones to heal in the best possible position. This will require between eight and fourteen weeks during which neither sitting up in bed nor getting out of bed can be permitted because of the danger that the still unhealed bones might damage the spinal cord further.

Experience has shown that with very rare exceptions operation on the spine or spinal cord does not help the cord to recover or the spine to heal.

CHECKLIST: IMMEDIATE EFFECTS OF SPINAL INJURY

see page 33

In the paralysed part of your body you cannot feel pressure, and even if you could feel it you couldn't move to relieve it. At the same time the supply of blood needed to nourish your skin is very much slowed down. This endangers the skin and means that whoever is looking after you has to protect it by turning you at two-to-three-hourly intervals so that the points of pressure are changed.

see page 52

You won't be able to feel when your bladder is full, and won't be able to empty it. This means that your doctor or nurse will have to empty it for you at regular intervals. This will last for a number of weeks, but eventually you'll learn to do it yourself.

see page 62

The same applies to your bowels, the regular emptying of which has to be assisted in a variety of ways.

While you will be able to move the non-paralysed parts of your body, movement of the paralysed parts has to be done for you by the physiotherapist so that they don't get stiff or deformed.

CHECKLIST:
IMMEDIATE EFFECTS
OF SPINAL INJURY

Your legs and, if paralysed, your arms, hands and fingers, must be put and kept in certain positions to make sure that later they will be kept as mobile and efficient as possible.

Younger women may find that their periods stop for a time, but they will return sooner or later in the normal way.

see page 81

Men may find themselves unable to get an erection, but in the majority of cases this ability returns at least in part during the first few months.

see page 86

Apart from the help which your attendants have to give to you, your doctors will have to make sure that your blood has a normal composition by taking samples and testing them and, where necessary, helping you with blood transfusions. They will also have to check your blood pressure which may be, particularly in tetraplegia, lower than it should be or, less often, higher. They will have to check your temperature which, again particularly in tetraplegia, may for a few days be very much lower than normal. In cases of trauma they will also need to make sure that you have no other injuries (since the messages can't get through you wouldn't feel it if, say, you had broken your leg).

Together with all the other interruptions of function there may in cases of cervical lesion (tetraplegia) be a disturbance of temperature regulation leading to shivering, feeling hot, and being unable to sweat.

You will see that this is a formidable interference with the normal working of your body. Given proper treatment you can expect, even if the interruption of cord function remains complete, to return to complete or nearly complete independence in anything between four and twelve months. Only in the most severe cervical lesions (tetraplegia) will as much as a year be needed.

SITTING UP

Sitting up for the first time after having been flat on your back for so long can be a strange experience. It's something that has to be done gradually. At first you will sit up in bed, when your doctor permits it and with the help of the Sister or physiotherapist. To begin with you will just be raised slowly to an angle of 45° for ten minutes, then to 90° (fully upright) for half an hour. After you've got used to this you can get into a chair, for a few minutes at first, and gradually for a longer time. Here you'll be taught to lift yourself to avoid pressure sores (1). If yours is a low lesion sitting up may take three days; if it's a high one it may take ten days, because of the need to adjust your circulation to being upright. If you sit up too soon for too long, you'll probably faint. This is because your autonomic nervous system, which controls your blood pressure, is damaged. It's most likely to happen if yours is a high lesion. If you do faint, you can be brought round by having your chair tilted back until your head is level with your knees.

SITTING UP

(1) see page 33

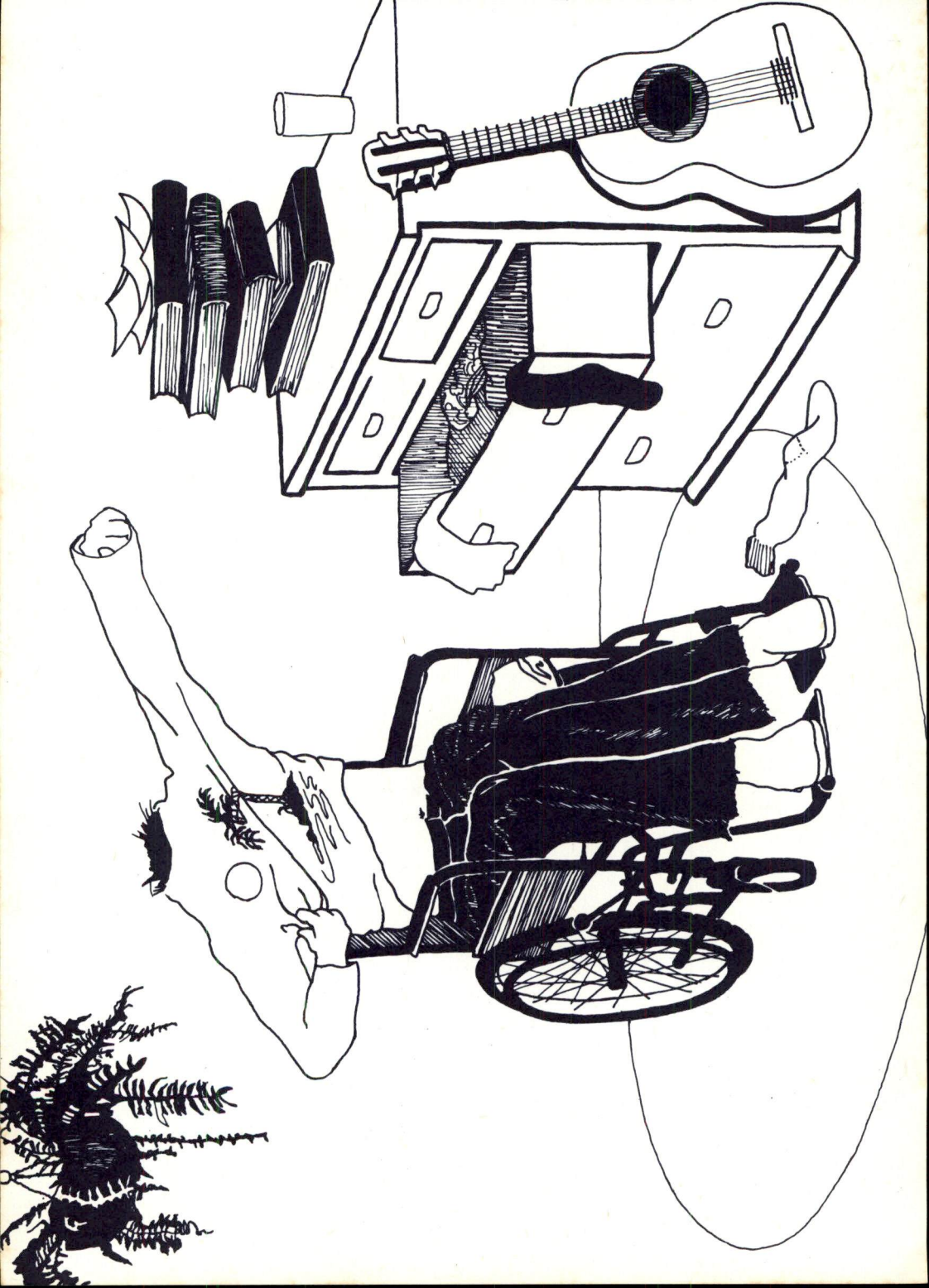


BALANCING

BALANCING

When you can sit in a chair for two hours you are ready to learn to balance. This will take from two weeks to two months, depending on the level and completeness of your paralysis. As well as messages of feeling and movement, the spinal cord carries messages telling you where you are in relation to things around you, and what position the various parts of your body are in. When the cord is interrupted, these messages can't get through to the brain from below the level of injury, and the higher your lesion is the more difficulty you'll have in balancing.

First of all you will learn to make up for the lost sensation of balance by using your eyes to tell you if you're not keeping upright. If you sit in front of a large mirror you can see any swaying of your body when it begins, and by using the muscles above the level of injury you can pull yourself back into an upright position. This takes quite a bit of practice, but after a time you'll be able to sit upright without support quite happily, even with your eyes closed, because you'll have learned to use your non-paralysed muscles to tell you what position you're in. By this time you'll be able, too, to catch and throw a ball while sitting unsupported, and do all sorts of exercises in the same position.



DRESSING

DRESSING

While you are learning to balance again, you will also be trained to dress yourself. At first you'll probably find this quite difficult, but your physiotherapist or occupational therapist will be able to help you, and give you lots of tips about the easiest ways of getting your clothes on. As you get more practised, paraplegics should reach a stage where it takes you no longer, or only slightly longer, than it did before you were paralysed. It's worthwhile for paraplegics to make the effort to learn to dress in a wheelchair. You are then fully mobile and can get your own clothes out and put them away without having to rely on someone else for help. If you are tetraplegic and haven't the use of your hands, you'll have more difficulty in dressing, but even so you may still be able to get on the top half of your clothes, and possibly the bottom half - leaving perhaps only shoes and socks or stockings with which you need help. It may be easiest for you to make adaptations to some of your clothes - like putting on fastenings that are easier to do up. Your occupational therapist or physiotherapist will be able to advise you about this, and there are several useful books and leaflets about clothing problems available from the Disabled Living Foundation.

STANDING AND WALKING: EXERCISE

When you're really good at sitting and balancing, the time comes to get on your feet again. You may find it difficult to balance at first, but will get over this in time. You need something to keep your knees straight (at first it'll be a pair of plaster-of-Paris splints, but later you'll get a pair of calipers - metal or plastic supports - with a locking joint), and springs to prevent your feet dragging on the floor. Then you will be helped to stand between parallel bars in front of a large mirror, and paraplegics will learn to walk between the bars, holding on to them. After a while you will progress to crutches and, if yours is a fairly low lesion, will eventually be able to get up unaided from your chair, walk several hundred yards, and even climb a few steps.

If you're tetraplegic, things are more difficult, as you can't rely on your upper body muscles or your arms to give you much support. It used to be thought that tetraplegics weren't able to stand at all, but this was wrong, and most tetraplegics now learn to stand between parallel bars for a short time each day. It's important that you keep practising this every day when you get home, even though you may need someone to help you to get on your feet and to stand by in case you run into difficulties.

STANDING
AND WALKING;
EXERCISE

If your lesion is below L3, you'll be able to walk a lot in your everyday life, and will find that the more practice you have the easier it becomes. If it's a higher lesion, from T12 up to T2 or 3, you're not likely to walk so much in everyday life. However, walking is the best exercise you can have. It keeps your muscles and sense of balance in good order, prevents contractures (1), improves your circulation, and helps your kidneys to work properly. It's also an extremely useful thing to be able to do, because there may be times when it's much more convenient for you to be able to stand, and perhaps walk a little. So you should practice standing and walking every day. Even if you're doing a busy full-time job, you should be able to find half-an-hour a day for this. Don't get out of the habit of walking when you get out of hospital - if you do, you'll lose the ability to walk at all. It's a great help if you can manage to have a pair of parallel bars at home, but if this isn't possible, practice with crutches. There are various standing aids now available which enable you to be supported in the standing position without calipers and with your hands free.

If you are tetraplegic, it may be that you find standing and walking very difficult, and almost impossible to fit into a daily routine. If this is the case, don't worry about it. It's up to you to decide whether or not this exercise is a practical proposition for you.

(1) see page 71

(1) see page 108

There are many exercises which are useful in keeping you fit. In the first few weeks after getting out of bed, you'll spend a lot of time doing muscle-building exercises, because you need to train the non-paralysed parts of your body to take over some of the work of the paralysed muscles. In particular you need to develop the muscles of balance and those which help you propel your wheelchair, if you can. So you need to exercise your arms and upper back and shoulders, using springs and chest expanders. Sport (1) is also very useful for improving muscle power and balance. It's important that you keep up this regular exercise when you leave hospital.

It's possible to reach a really excellent level of independent mobility by the skilled use of a wheelchair, so you should concentrate on developing this as fully as possible.



DIET

In the early days of paralysis you may need a special diet, and later on you might need one if you have complications, particularly pressure sores or kidney damage. Apart from this you can eat normally - except for remembering one very important thing. If before you became paralysed you were very active and took lots of exercise, you probably had a healthy appetite and usually ate quite a lot. Now you are paralysed you may still have that healthy appetite, but you don't get nearly as much exercise. So if you continue to eat the same amount, you'll put on weight - possibly a lot of weight. Apart from this being bad for your morale, it's very bad for your health. If you become too fat, you'll be much more likely to get all sorts of complications. Also, if you need to be lifted and helped to move, you'll put an enormous strain on your attendants. If you start putting on too much weight, don't just go on a crash diet, as this can be dangerous; see your doctor, and get proper advice about a safe diet.

The best way is to begin by eating sensibly and avoid getting too fat. You should eat mostly protein - which is found in eggs, milk, cheese, nuts, fish and meat - and fresh vegetables and fruit, and cut down on sweets and cakes, potatoes, bread and starchy foods. Ideally you should weigh yourself regularly to make sure you're keeping to a reasonable weight, but in practice this can be difficult, as you won't

be able to use ordinary scales. Many hospitals have a type of scales in which you sit on a chair, and these are easy for you to use, if you can arrange it; this may have to be done through your family doctor.

Another advantage of eating lots of fresh fruit and vegetables is that they help to prevent constipation. Choose wholewheat rather than white bread and flour for the same reason.

You should avoid drinking spirits or any strong drink, as these can seriously damage your kidneys and might cause you to fall from your wheelchair, causing perhaps the fracture of a paralysed limb, which would mean many weeks in hospital.

SWEATING

Some tetraplegics suffer from profuse sweating attacks which make them feel cold, shivery and miserable. Sweating usually occurs only in areas of the body where there is still sensation, although sometimes it occurs in parts where there is no sensation. Attacks may be triggered off by a mental state of apprehension, indecision, or insecurity, or sometimes by pain. Sometimes sweating is a result of disturbance of the bowel or bladder and if you get an attack it may be worthwhile to consider whether your bladder or bowels might need emptying. Your doctor may prescribe tranquillizers, but unfortunately these have little effect. If a sweating attack happens while you are in bed it may be possible to stop it by getting someone to change your position.

DIET

SWEATING

If it happens when you are in your wheelchair, you may be helped by someone adjusting your position and if necessary putting dry clothes on you.

GETTING ON AND OFF THE TOILET

This is something which your physiotherapist will teach you. It's not difficult when you know how, although you may need a bit of practice to get it right. The basic things you need are a chain with a handle attached, hanging from the ceiling, a handrail at one side, and an aircushion on the toilet seat. The chain is to hold on to while swinging yourself on to the toilet; the handrail is useful for this too, and also for keeping your balance while on the toilet, especially if yours is a high lesion; and the aircushion is to prevent your skin being damaged by the toilet seat. Never sit on an unprotected toilet seat - in an emergency you can always pad it by wrapping a thick towel round it.

You must be able to get your wheelchair close to the toilet, in a position from which you can lift yourself easily and safely on to the toilet and back again. For this reason it's often best if possible to have a combined bathroom and toilet, as this gives more room for manoeuvre. Ideally the chair should stand beside the toilet, but even if this isn't possible you should be able to work out a method of swinging across. If yours is a low lesion and you can take weight on

GETTING ON AND
OFF THE TOILET

your feet, you may prefer to have the wheelchair facing the toilet and pivot on your feet when swinging across.

If you have to use a toilet in a room in which there isn't space for your chair, you may find it easiest to use a special toilet chair. This is a chair frame on small wheels with a soft rubber toilet seat replacing the usual seat. You transfer to this chair where there is room, and then it is wheeled backwards by an attendant to a position over the toilet.

Nearly everyone can learn to transfer successfully on to the toilet. Even if you are tetraplegic, you may be able to manage by hooking your elbow through the handle on the chain. The main danger is that you'll have spasms which cause you to fall, and you might not be able to pick yourself up. It may be that because of this, or because yours is a very high lesion, you can't manage to get on to the toilet. In this case probably the best solution is for you to arrange to have a bowel action in bed. You'll need to have someone to help, either a member of the family or the district nurse. Your assistant must put in a suppository and put a rubber drawsheet and a wad of cellulose under your buttocks, and clear everything away when you have finished, possibly also checking with a gloved finger that your bowel is quite clear. This is much easier and safer than using a bedpan, as a metal, plastic, or china bedpan can easily damage your skin and cause pressure sores.

As with most things, this is a process of trial and error, and you'll be able to work out your own best ways of doing things, which may be quite different from anyone else's ways - the important thing is to accept the need to experiment.

DEPRESSION

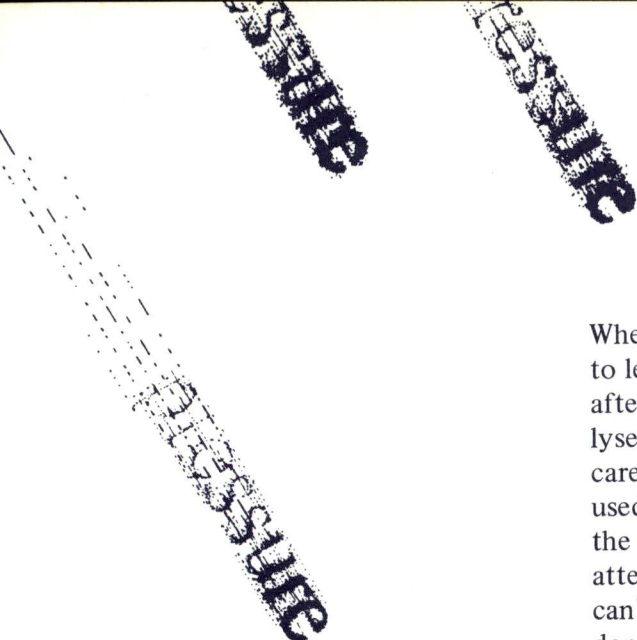
It would be a very unusual person indeed who didn't feel depressed after the accident or illness that made him or her paralysed. Of course you get depressed, and while you're feeling miserable there's not much anyone can say to cheer you up. Possibly the worst advice you can be given is to 'snap out of it' - even if you wanted to you don't know where to start, and this makes you feel even more unhappy. Don't try to 'snap out of it' - don't force yourself to hide your feelings as though they were something shameful. Accept that you are depressed, and that this is the most normal and natural reaction to the shock you've had to your mind and your body. Don't wallow in it, but don't try to pretend it's not there. Accept, too, that it will pass. No matter how you feel at the moment, it always does pass. Cry if you feel like crying, and don't be ashamed of it - it gets rid of some of the tension you're feeling, and it's high time the 'stiff upper lip' was done away with anyway. But do it now; once you're up and about there'll be so much to do you won't have time to cry.

DEPRESSION

However bad you feel, try not to take it out on your family and friends. They've suffered a severe shock, too, and they need your help and comfort just as much as you need theirs.

Depression arises from boredom as much as from anything else. Lying flat on your back for a couple of months isn't the most exciting thing in the world, and it gives you plenty of time to feel sorry for yourself. But once you start on the process of getting back to independence, things really do get better. All you have to do is wait.

pressure
pressure
pressure
pressure
pressure
pressure
pressure
pressure
pressure
pressure
pressure



When you're paralysed you have to learn new ways of looking after yourself, because the paralysed parts of your body can't care for themselves the way they used to. In particular, the skin of the paralysed parts needs special attention and care; since you can't feel it, it's in much more danger than before. The main danger is that of pressure sores.

What is a pressure sore?

When there is prolonged pressure on one part of the body, the blood can't circulate through that area. This means that life-giving oxygen, which is carried in the blood, cannot get through to the compressed area. Because of this the tissues die and decay; the dead tissue becomes infected, and a discharging ulcer is formed.

A non-paralysed person would begin to feel uncomfortable if there were pressure on one area of his body for too long, and would move to relieve it; but because you can't feel these parts you don't know the pressure is there, and in any case can't move to relieve it. This is why you are in special danger of pressure sores.

What does a pressure sore look like?

The first sign is that the skin looks red. If you've been putting pressure on a particular area, it's bound to look red at first, but normally this soon fades; if the redness remains for more than an hour after you have removed the pressure, this indicates that unless you avoid all further pressure on the area until the redness has gone, a pressure sore will develop. If the pressure is not relieved at this stage, the skin darkens to bluish-black, indicating permanent damage to the tissue. In its fully developed state, a pressure sore is a horrible sight. It's a gaping hole in the flesh, lined with dead matter and

PRESSURE SORES

blood. Your aim must be that you will **never** develop such a horrible sore - and they can be avoided. Later in this section you'll be told how you can make sure you never get one.

Where are pressure sores most likely to occur?

Any part of the body on which there is continual pressure is likely to develop a pressure sore, but the most dangerous places are those where bones, and particularly bony points, lie fairly near the skin in places which support the weight of the body.

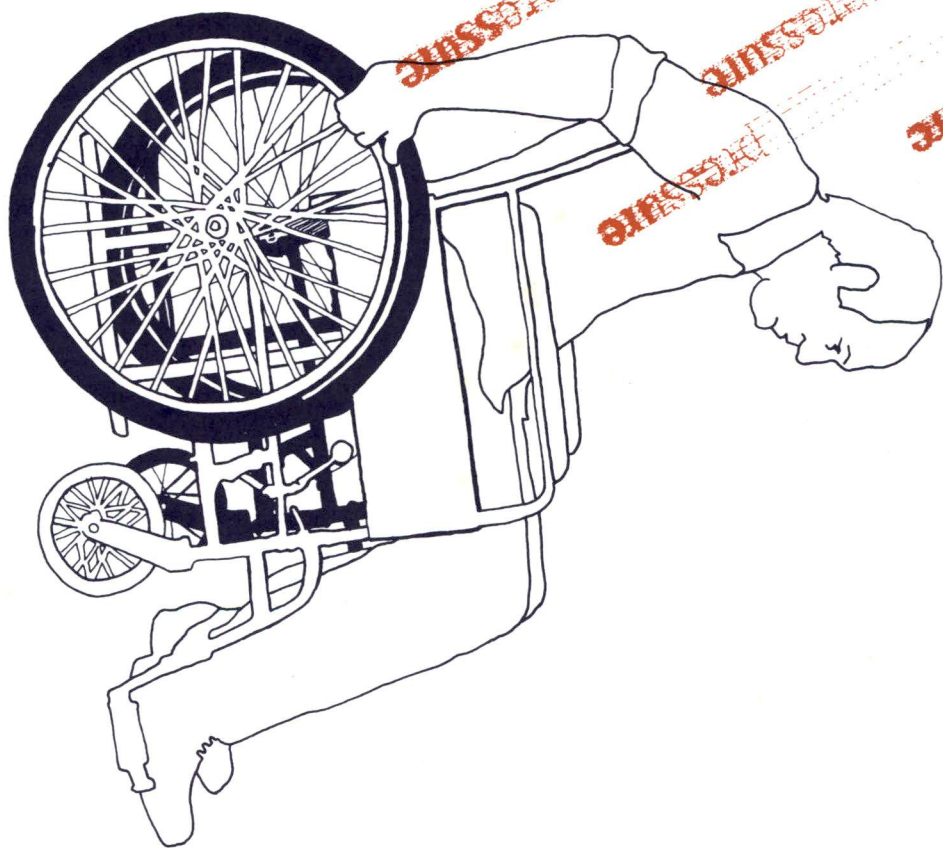
If you are lying on your back, the most vulnerable places are the backs of the heels, the lower part of the back, and the shoulder blades. If you lie on your side, the most dangerous areas are the bony part of the outside of the ankle and the top of the outside of the thigh, where the top of the thighbone is close to the skin; also the insides of the knees - always put at least one pillow between them to stop them pressing on each other. In the sitting position there is special danger because almost all the body weight is pressing on the bones of the seat (there are two - one on each side of the anus, the entrance to the bowel).

If you are tetraplegic, there is another danger area for you - the insensitive parts of your hands and arms. If you leave your arms for

too long in one position on the arm-rests of your chair, or on your mattress when in bed, you may develop pressure sores on your arms. Another susceptible area for tetraplegics is the inner part of the palm of the hand, which may be subject to pressure when you are propelling your chair. It's a good idea to wear soft leather pads on your hands when wheeling yourself around, to avoid this pressure.

How serious is a pressure sore?

As you can't feel the part of your body on which pressure sores might occur, it may seem that it doesn't really matter very much if you get a sore -after all, it doesn't hurt. But it can't be stressed often enough that a pressure sore isn't just rather a nuisance. If left untreated, a pressure sore will, at best, mean several months in bed. At worst, it will kill you. Infection from the sore spreads to the bone, then to the whole body. It's that serious. But on the other hand, you don't have to get pressure sores - it's quite easy to learn how to avoid them, and this soon becomes a matter of routine, like cleaning your teeth.



How can pressure sores be avoided?

It's easy to see that the harder the surface on which you sit or lie, the more pressure there is on the vulnerable parts of your body. So you must never sit for any length of time on a hard seat, or lie on a hard or lumpy mattress. The best type of mattress for you is one made of thick foam rubber; a good interior sprung one is second best. Make sure that your sheets are clean and smooth - creases can cause pressure on your skin. In a chair, always sit on a thick foam cushion with a soft cover. If you have scars of previous sores, or are very thin, or are suffering from an acute illness, it's a sensible precaution to ensure even less pressure by putting soft pillows or foam rubber cushions above and below the bony points so that practically no pressure at all is put in the danger areas. Various special cushions are available to help you avoid pressure sores. Ripple cushions are ridged like miniature airbeds; an electric pump pushes air through one set of ridges, then another, to transfer the pressure from one area of skin to another. Gel cushions contain a sort of jelly which adapts to the shape of your body and distributes the weight evenly. Cushions filled with polystyrene granules act in the same way. Some people find that sitting on a sheepskin helps them to avoid pressure sores. Tetraplegics might find a ripple cushion best, as it saves your attendant extra lifting to take pressure off your buttocks.

It's also necessary to change your position regularly, every few hours. In bed you may need help with this, especially in re-arranging your feet and your pillows. If you are paraplegic, you should lift yourself in your chair every few minutes, by placing your hands on the arm-rests of the chair, raising your body off the seat, and staying in this position for ten or fifteen seconds, then slowly letting yourself down again on to your cushion. When you are first out of bed after your accident or illness, you should do this every three or four minutes; after a time you can extend this to every seven minutes, then to every ten minutes, always checking to see that there is no permanent reddening of the skin. After a while this lifting becomes a habit, which you do without thinking. Most tetraplegics are not able to lift themselves, and must arrange if possible for someone to lift them regularly.

In a wheelchair it is often convenient to carry small things tucked down beside you on the seat. From here they can slip down unnoticed on to the cushion, and cause pressure on your buttocks or legs which can lead to sores. For this reason it's wise to avoid carrying things in this way -if you must, keep a constant check on them to make sure they haven't slipped under you. It's best not to put anything in trouser pockets, as they might cause pressure sores on your thighs.

Also in a chair you have to be careful about your feet and legs; don't let unprotected feet rest on the hard footplates or allow your ankles to rest against any metal part of the chair.

Tetraplegics, who have no feeling or incomplete feeling in their arms and hands, should use padded arm-rests and remember not to leave their arms too long in one position.

Pressure sores can also be caused by badly-fitting clothing - don't wear anything that is too tight or restrictive. Small sores on the feet and toes can be produced by badly-fitting shoes - be careful to ensure, by feeling with your fingers or getting someone else to feel, that your toes are lying in the correct position in your shoes and are not doubled up. This can easily happen when putting on shoes, and as you can't feel your toes you can't tell without checking whether or not your toes are lying flat. You should wear soft, pliable shoes, at least one size bigger than you actually take, and certainly bigger than those you wore before you became paralysed. If you get marks of pressure on your toes, you must either give up wearing shoes or wear soft old slippers until the marks have gone. Ankle boot styles are good for protecting feet and ankles.

Men must ensure, if they wear a rubber urinal, that this is carefully positioned once they are seated in a chair, otherwise it can cause pressure sores on the penis and scrotum. Make sure that the 'kipper' (the bag part of the urinal) isn't strapped to your leg too tightly.

It used to be common practice, especially in hospitals, to rub and massage the skin with creams or spirit, with the aim of preventing pressure sores. The idea was that this brought a good supply of blood to the skin and stopped the tissues dying. In fact all it did was damage the skin and make it more likely to get pressure sores. This practice is very harmful, and you must never allow anyone to rub the skin on the paralysed parts of your body. To keep the skin healthy it's a good thing to have a bath every day - in the bath if you can manage it, a blanket bath if not. Do make sure that you are very thoroughly dried afterwards - it's tempting to skimp drying and just put on lots of talcum powder, but if you keep doing this it makes the skin very dry and it will eventually crack. Always sit on a rubber ring in the bath, to avoid damaging your skin.

It's vital that you get into the habit of checking your body every day

tetraplegics may have to
ask an attendant to do it
for them

paraplegics should find
this reasonably easy with
the aid of a hand mirror

for any tell-tale sign of redness that doesn't fade when you relieve the pressure.

If you find a red patch, you must take it that this is the first sign of a pressure sore. Then you must make sure that this area remains absolutely free from pressure until the redness has completely disappeared. For example, if you have a red patch on one hip, you must be careful to avoid lying on that side in bed. If the redness is on your buttock, you must not sit in your chair. This may seem rather drastic, but it is well worth the inconvenience when you consider the terrible results of ignoring this early sign. It's no exaggeration to say that sitting up for one further day on a reddened buttock can result in two or three months in bed in order to heal a pressure sore.

What should you do if you get a pressure sore?

If you haven't taken all these precautions, and have developed a pressure sore - and it does happen - don't panic. The first thing to do is to see your doctor straight away. If you have a large sore, or more than one, it will probably be necessary for you to go into hospital where you can receive proper treatment. This generally involves the surgical removal of dead tissues, careful dressings daily or even twice daily, blood transfusions, and special diets. Smaller and less serious sores can be treated at home by your doctor - but this will need your full co-operation.

Part of the treatment of a sore is ensuring that there is no further pressure on the affected area. This nearly always means that you

will have to stay in bed until the sore is healed. In bed you can be carefully positioned to avoid pressure on the sore area, with foam rubber packs to help this.

The sore must be properly dressed every day. This is best done by a trained person (usually the district nurse if you are at home), but if it is done by an untrained person you must make sure that only sterile (not just clean) dressings are used, together with any solution prescribed by the doctor. If you're not careful about this, you run the risk of letting further infection get into the sore.

Only when the sore has been completely healed for at least three days should you start getting up again, and then only for a short time at first, frequently checking the healed scar to make sure it hasn't been damaged at all. If it has been damaged, you'll have to go back to bed until it heals again. When the scar is fully healed, and you can get up again, it's a good idea to keep a dressing of dry gauze and elastoplast over the scar for a few days to protect it.

Sometimes a particular scar gives trouble by repeatedly breaking down - usually in an area on which it's very difficult to avoid pressure. It may be necessary to have an operation to cure this, though sometimes if a little careful thought is given to the problem it's possible to devise ways of keeping pressure from that particular spot - perhaps by a different arrangement of cushions.

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BURNS AND SCALDS

Burns and scalds on the paralysed parts of your body are a hazard against which you must constantly be on your guard. If a sensitive part of your body touches something hot, you draw away from it instinctively. But if an insensitive part comes into contact with heat, you don't feel the heat, and can't know that you should move away.

Although they cause you no pain, burns and scalds must by no means be treated lightly. Even a small area of blistering can become infected if not properly treated, and can make you very ill indeed. If you get a burn or scald, however small, always see your doctor - don't just cover it and hope it'll go away. If you have a large burn or scald, especially if it is on your seat and may become infected when you go to the toilet, it may be necessary for you to go into hospital for treatment.

There are many ways in which you might burn yourself, including some that most people would never think of as hazards. For example, there are often unprotected hot water pipes under washbasins; if you push your wheelchair conveniently close to the basin while you run the hot tap, your knee may rest against the hot pipe and may be badly burned. Always make sure that such pipes are well lagged, to guard against this (it saves heat, too). This is easy to ensure in your own home, but if you are in a strange place you can't be sure which

BURNS AND SCALDS

pipes are hot. To be on the safe side, never allow your legs to touch any pipe that you're not a hundred per cent certain is cold. The same goes for radiators; never rest against one or sit so close to one that your legs might touch it.

Sitting in front of a fire is another common way of getting burns. If it's a cold day, people tend to sit as close to the fire as they comfortably can. But if you're paralysed, you may tend to sit as close as is comfortable for the non-paralysed parts of your body, your face or hands. This means that your legs will be very close indeed to the fire, and as you can't feel the heat, they may be badly burned. It's best to sit sideways on to the fire, or further away, to make sure you won't be burned. Don't try to protect your legs with rugs or blankets; this is a very dangerous fire hazard.

The kitchen can be a hazardous place when you're paralysed, but with a little thought you can make it much safer. If at all possible it's a great help to have the cooker, worktops, and sink lowered to a level which is comfortable for you - this is not only safer but less tiring and easier to work with, if you spend a lot of time in the kitchen. There should be enough space in the kitchen for you to manoeuvre your wheelchair without knocking things over.

There are many tips for avoiding burns and scalds; here are a few:

Never balance a hot drink or plate of hot food on your lap while you propel your wheelchair, even if it doesn't seem very hot.

Never take hot dishes out of the oven and rest them on your knees while you close the oven door. If you haven't got an oven with a door that opens downwards to rest things on, have a shelf at the right height beside the cooker, so you can put hot dishes straight on to it.

Never get into a bed in which an electric underblanket is switched on (this is dangerous anyway), or switch on the blanket if you are cold in the night. There are electric overblankets which are safe to leave on all night; if you have one of these, make sure it is set at the lowest temperature overnight.

Never use a hot water bottle. In bed this could easily slip down and lie all night against a paralysed part, where it would cause a very nasty burn.

Never let your feet rest against the hot tap in the bath, or under the hot tap if it is running. A bath with taps at the side is much safer, and easier for you to use.

If you **must** smoke, and are tetraplegic, it's wise to use a cigarette holder to avoid burning your fingers.

If you are tetraplegic and lift a cup with the insides of your hands, always check with a sensitive area of skin that the cup is not too hot. An insulated cup is a good idea - it does not feel hot on the outside, and keeps your drink hot longer.

It may seem that now you'll be able to get lovely and brown in the summer, because however long you lie in the sun your skin will never feel sore. But, although you feel nothing, your skin can still get badly sunburned. Unless you can keep a very careful watch for the slightest sign of redness, or have someone who can watch out for you, don't let the paralysed parts of your body be exposed to the sun. This is particularly important for tetraplegics who wear short-sleeved or sleeveless clothes in summer. If you can't avoid sitting in the sun with bare arms, a suncreening cream smoothed on to your arms will help to prevent burning, but even so you must be careful not to stay in the sun too long.

All tetraplegics should wear a sun hat when sitting in the sun. If your head and neck get overheated this can cause a severe upset.

FROSTBITE

Even when the weather does not seem to be nearly cold enough for frostbite, you may still be at risk. In cold weather an able-bodied person moves around, wiggles his toes, stamps his feet, and so on, to keep the blood flowing quickly round his body. As you can't exercise your feet and legs (and fingers if paralysed), the effect of even slight cold on tissues whose circulation is already slow because of paralysis can be dangerous. The first sign of frostbite is that your skin looks unnaturally blue, then pale; it then becomes red and is very easily damaged.

Pressure sores are much more likely to develop on the affected part at this stage. If left untreated, the tissues die and the frostbitten parts turn black.

To avoid frostbite you should always wrap up warmly, and in cold weather wear a good pair of loose fur-lined boots, with soft woollen socks or stockings, and thick fur gloves if your hands are paralysed. If the weather is very cold, avoid long periods out of doors or in an unheated car. If you suspect you've got frostbite, see your doctor immediately. Frostbite may be just as serious as a burn, and may take even longer to heal than a pressure sore.

We have in our bodies four systems through which we take in what we need and get rid of what we don't need. With the lungs we breathe in air, mostly oxygen, and breathe out used air, mostly carbon dioxide. With the skin we rid ourselves of more used air and some chemicals through sweating. But the two main 'filters' are the stomach and bowels through which we get rid of unwanted solid materials, and the kidneys through which we dispose of liquid waste - the urine. All these systems are upset by paralysis, but the greatest interference happens in the urinary tract - that is, the kidneys, the ureters (tubes leading from the kidneys to the bladder), and the bladder. If your bladder is paralysed you can't tell when it is full, and it can't empty itself unaided as it used to.

Finding
themselves
unable to
control
their
bladder is
something
that often
upsets
people
when
they are
newly
paralysed,
it makes
you feel so
helpless and
undignified.

*The
important
thing to
remember
is that,
in the vast
majority
of cases,
paralysed
people
can learn
to cope so
well with
incontinence
that it
causes them
practically no
inconvenience,
and no one
would ever
suspect
that they are
incontinent.*

As well as learning to control your urinary system, you will need to learn how to take great care of it, because when your bladder is paralysed there is a danger of urine in it stagnating and getting infected, and of the infected urine entering the kidneys from the bladder. Once infected urine gets into your kidneys they will be at risk of not being able to do their job of getting rid of substances which you don't need. If you don't get rid of these substances they will make you seriously ill. More paraplegics and tetraplegics die of kidney infection than of anything else.

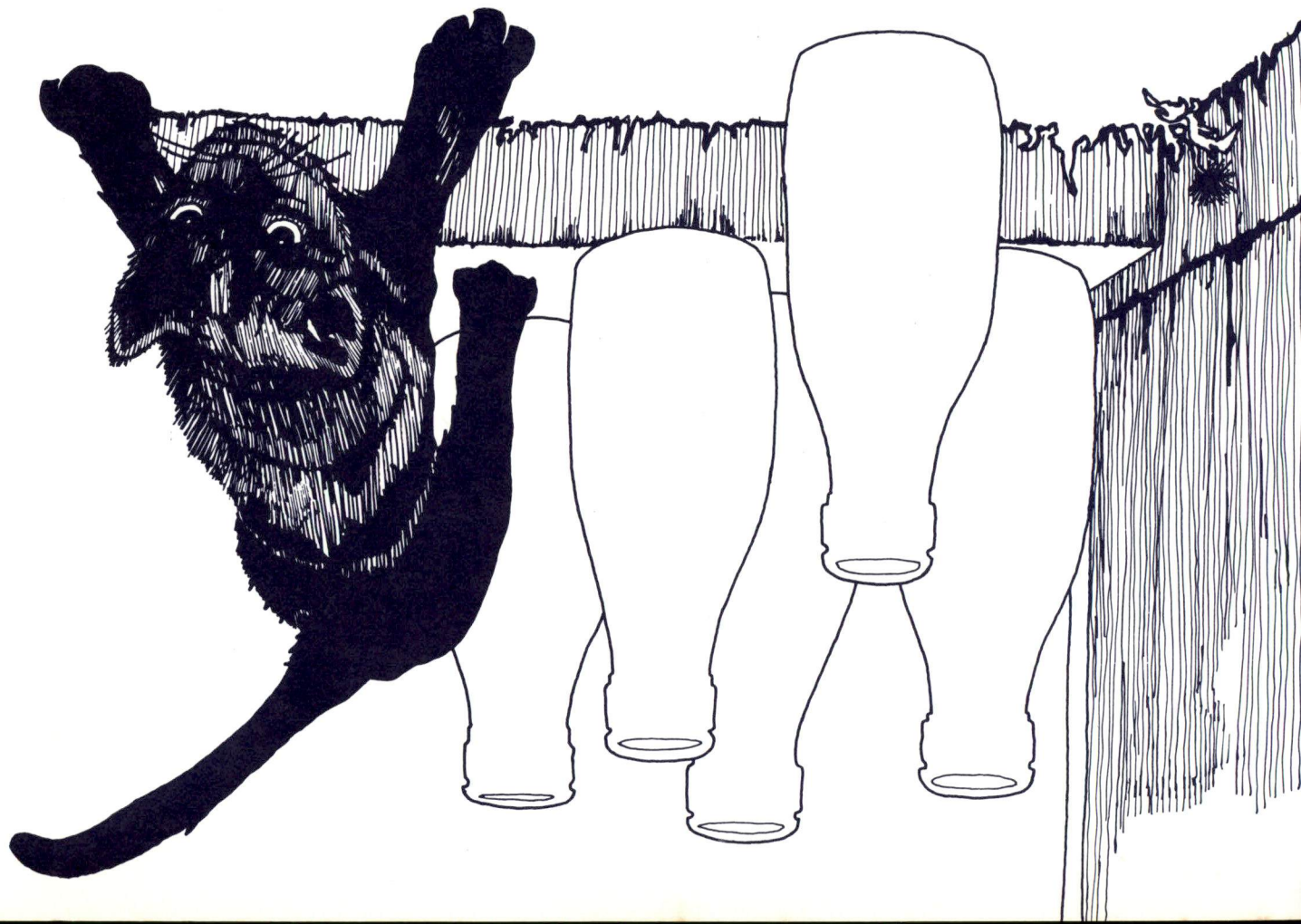
So its vital that you do everything possible to prevent infection of urine in the paralysed bladder. When you are newly paralysed your doctor will take care of this for you by draining your bladder through a catheter (a very fine drainage tube) put into your urethra - the tube which leads from the bladder to the outside opening through which you urinate. This is done in the most carefully gentle manner and under sterile (infection-free) conditions.

After the first few weeks of this 'catheterisation', done three or more times daily, you will be able to learn to empty your bladder by yourself. It's not hard to do, but like anything new it takes a bit of practice. There are several different ways of doing it, and you'll be able to try them all to see which suits you best. If yours is a low lesion you may find that pressing with your hand on the lower part of your tummy makes your bladder empty. If it's a higher lesion your best

method will be to find some sort of signal that makes your bladder empty by reflex action. The most usual signals are tapping your tummy below the navel, or stroking the skin there or at the top of your thigh, or pressing on the area called the perineum, which is just in front of your anus (the opening of the bowel).

GETTING INTO A ROUTINE

Whatever method you use, your aim is to reach a stage where you can remain dry for up to four hours at a time by deliberately emptying your bladder at regular intervals. Eventually you will learn to time your drinking so that you only need to empty your bladder at times when it's convenient, remembering of course that it must be emptied completely three or four times a day. For example, if you are working, you can empty your bladder first thing in the morning, say 7.30, and have a drink before you leave for work. Then you can empty it at the start of your tea-breaks, and have your drink. Have your last drink of the day around 7pm, then you can make sure your bladder is quite empty by the time you go to bed. All paralysed people need to drink a lot of liquids - about five or six pints a day - to flush out the kidneys and the bladder and the tubes between them. This is because your kidneys work less efficiently than those of an able-bodied person, and if you don't drink enough, waste products collect in them and may remain there long enough to cause infection



or stones. The liquids you drink can be anything you like - water, fruit juice, tea, soup, etc., and a daily pint of beer will do you no harm if you like it. You should avoid drinking spirits or a great quantity of beer, because a large amount of alcohol in your bloodstream can damage your kidneys, and it's essential that you keep them in the best possible working order. On a special occasion, such as an evening out, when you want to avoid having to go to the toilet, if you drink nothing at all for a few hours and empty your bladder before you go you shouldn't need to empty it during the evening. Remember to have a big drink when you get home to make up for the time you've been without a drink.

SIGNALS

When an able-bodied person needs to pass water he feels a sensation in the area of his bladder. Because this signal is a very obvious one, people tend not to notice other signs in their bodies that can tell them that their bladder is full. As you can't feel directly that you have a full bladder, you need to take notice of any other signs in your body. Some people get a headache when their bladder is full; others get a stuffed-up nose, or become flushed, or sweat heavily, or even vomit. When you notice one of these signs you must empty your bladder straight away.

SIGNALS

If you find you can't empty it, you may have what is called 'acute retention', either complete or partial. This produces unpleasant symptoms and at the first sign of it you must take action. First of all, check that there's nothing actually preventing you from passing water - that is, that there's no kink or blockage in the tube of your urinal if you wear one, and that you're not in a position which might be making it difficult for you to urinate (you will have learned the best position for emptying your bladder). Try changing position - sitting if you've been lying, lying if you've been sitting, and try again to get your bladder to work; this may help. If not, call your doctor immediately so he can take steps to get your bladder to empty. First he will try the usual methods - tapping your tummy, stroking your tummy or thigh, and so on, to try to provoke a reflex action. If this is unsuccessful, he will, with great care and using a facemask, sterile gloves, two instruments and four swabs, insert a very fine rubber or plastic catheter (drainage tube) into your bladder through the outside opening. Through this he can empty your bladder, and when he is sure that it is completely empty he will remove the tube. If there are signs of a more severe infection he will use a 'Foley' catheter, which has a small balloon at the end. This is blown up inside your bladder so that the tube does not slip out. This catheter should be changed after three days or removed if the retention was only temporary and infection has been cleared up by washouts and antibiotics.

OTHER WAYS OF TACKLING INCONTINENCE

Some people find that it is not possible for them to remain dry for a convenient length of time. In this case, there are other ways of tackling the problem of incontinence. It's easier for men, because they can wear a urinal - this is a device which fits over the penis to catch the urine, and drains it through a tube into a plastic bag ('kipper') strapped to your calf or thigh. When you are dressed, the urinal can't be seen at all. There are several types of urinal - you'll learn about them in hospital, or can get details from the Spinal Injuries Association. If you wear a urinal, you must always make sure that it's put on correctly, otherwise it may rub against your skin and cause pressure sores on your penis or scrotum.

As yet there is no satisfactory urinal for women, so women who need some sort of protection generally wear incontinence pads and plastic pants. The pads should be thick, soft, and absorbent, and you may check every time you put them on that the pants are not rubbing your skin anywhere. People who wear incontinence pads sometimes worry that there might be a smell that other people notice, but as long as you change the pads frequently - at least three or four times a day - and keep yourself very clean, there is no smell at all. As far as possible, wash yourself thoroughly every time you change your pad, and use lots of talcum powder. This will help to prevent soreness, which can be a problem, especially if you don't change your pads

OTHER WAYS OF
TACKLING
INCONTINENCE

often enough. A good idea to prevent soreness is to wear a 'one-way' nappy liner inside the pad, next to your skin. This is made of a special material which lets moisture pass through into the pad but stays dry itself, so your skin is kept dry.

Even if you don't need to wear a urinal or pads all the time, you'll probably find it's necessary sometimes - for example on a long journey, when you can't be sure of finding an accessible toilet.

For some men and women the best way of coping with incontinence is to wear a Foley (in-dwelling) catheter. This is a tube which goes into the bladder through the outside opening and is held in place by a small balloon in the bladder. It remains in the bladder and drains it through the tube into a plastic bag. It should be changed twice or three times a week, otherwise it may tend to cause stones in the bladder. (Some modern or silastic - **not** Foley - catheters only need changing about every three weeks. Ask your doctor about these long-stay catheters.) If you need to use an in-dwelling catheter, you'll be taught how to look after it and change it while you're in hospital. You may need help to change it, particularly if yours is a high lesion, and district nurses usually do this if you haven't someone at home who can help you with it. It's very important to make sure that the catheter and bag are kept scrupulously clean and sterile, or infection may get into your bladder. Further points to take care of are that, whatever position you're in, the catheter is placed so that it isn't causing pressure on the surrounding area

or in the urethra (the tube from your bladder to the outside), and that the catheter tube doesn't get kinked or blocked so it can't drain into the bag.

bowel incontinence

Just as you can teach yourself to control your bladder, so you can re-train your body to enable you to cope with bowel incontinence. In the first few days or weeks of being paralysed you are likely to be constipated, and special measures will have to be taken to clear out your bowels. This is generally done by hospital orderlies, who carefully put a gloved finger into your anus (back passage) and empty your bowel. You may also need to have enemas (injections of liquid into the anus to wash out the bowel). Later on you will empty your bowels by putting a suppository (a small soft cone which dissolves and encourages emptying) into your anus, then lying on your side on disposable cotton wool or wadding, to avoid soiling the sheets, until your bowels empty - about half an hour later. The gloved finger is still used, to check that your bowel has cleared completely, or to help it if this doesn't work or if you are constipated.

This clearing-out must always be done at the same time of day, whether morning or evening, and is usually done every other day, or sometimes every day. It's vitally important that right from the start you establish a strictly regular routine, keeping to the same time of day, as this is the way in which you can regain control over your bowels.

It's by no means inevitable that you'll continue to be constipated. Some paraplegics get into the habit of taking a mild laxative every

day, but this is not a good thing, as it means that the bowel is always in a state of slight irritation. If you are constipated, you must look to your diet. If you eat lots of fresh vegetables and fruit, especially things like figs and prunes, and wholewheat bread, you should never be constipated. If it's really necessary for you to take a laxative, ask your doctor about it and he will recommend one which is safe for you to take. Nearly everyone has some food they react to, and some paralysed people make use of foods that 'upset' them to produce a laxative effect, and help them to gain excellent regular control of their bowels. Once you are up and about you must be careful to stick to a strict routine of bowel emptying. There are different methods of actually making your bowels empty - perhaps the most usual is as follows. At the same time every day, or every other day, about ten or twenty minutes before going to the toilet, put one or two suppositories into your anus. You'll work out what time you need to put them in by trial and error - people vary. This, together with sitting on the toilet, is all that's needed in most cases to produce a bowel motion. You may, however, find that you need to help it along by inserting a gloved finger. This helps to relax the muscle which keeps the anus closed. Many paraplegics get into the habit of using a gloved finger to empty their bowels, and sometimes it is necessary, but it's best to avoid doing this if possible because sooner or later it can cause small tears in the delicate lining of the bowel, and this can lead to further trouble. It's often a help to

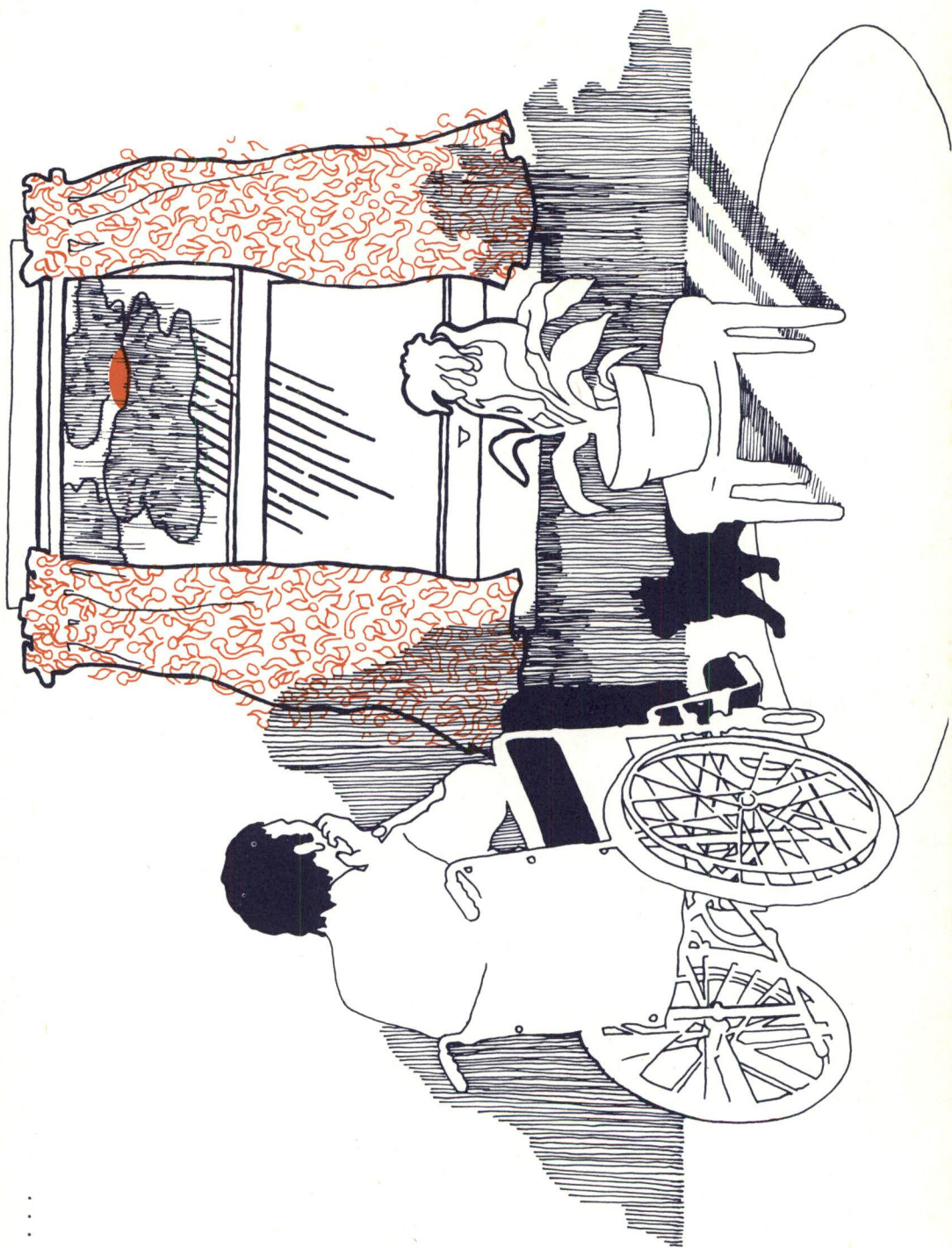
have a warm drink or a meal just before you go to the toilet, because when food and drink go into the stomach they cause the lower bowel to contract, and this can be helpful in producing a bowel motion.

Most paraplegics and tetraplegics are successful with this method, but if yours is a high lesion you may have some difficulty, and may need to spend a long time trying different methods with your doctor's help.

Once you've established a good routine, it's important not to let anything upset it. If you change your daily pattern of life, you must still be sure to empty your bowels at the regular time. If you alter your routine suddenly you may become unable to regulate your bowel movements, and this is not only inconvenient but a backward step in your return to independence. Should you go abroad, it may be that the different food causes diarrhoea, which can be very messy and unpleasant. See your doctor before you go, and he will be able to suggest ways of avoiding this.

There are several problems connected with the bowels which you must look out for. These are more likely to occur in paraplegics and tetraplegics, because when you are paralysed your veins and the lining of your bowels becomes slack and more easily damaged. These problems are dealt with in the 'Warning Signals' part of the book(1).

(1) see page 102



SPASMS

SPASMS

About three weeks after you become paralysed, you may notice that the paralysed parts of your body seem to be moving slightly by themselves - rather like a nervous twitch that you can't control. These movements are called spasms or spasticity, and are caused by new reflexes which have been set up in the spinal cord below the level of injury. Normally your brain can control all the movements of your body, but as the cord which carries messages has been interrupted, the brain can't co-ordinate these movements, and they work by themselves. Spasms are a direct result of your injury, and if they remain as slight as they are to begin with (called 'basic spasticity'), they can be useful to you. They help to prevent your muscles from wasting due to lack of exercise, keep the muscles of your bladder in good shape, and men may get spastic erections which they can make use of. If yours is a very low (cauda equina) lesion, you won't have spasms, because the actual cord isn't damaged, so your legs and bladder will remain flaccid (flabby).

Some paraplegics and tetraplegics develop more severe spasticity (called 'excess spasticity'), and this can be a great nuisance and often an embarrassment. It's always caused by complications below the level of injury. Most of these complications can be prevented by proper management from the start.

see page 71

(1) see page 33

(2) see page 45

(3) see page 104

The causes are (starting with the most important):

Contractures

Constipation - either for a few days only, which will mean a sudden increase in spasticity, or continuously. The treatment is by laxatives or enemas (bowel washouts) to clear the bowel.

Infection or stones in urinary tract ('waterworks').

Pressure sores (1), burns or scalds (2), varicose ulcers (holes in the skin of the legs sometimes found in people with varicose veins), ingrown toenails.

Piles, fistula (3), contraceptive device left in (either a cap which you've forgotten to take out, or an IUD which is meant to be left in but can have this effect on some women).

In high lesions; ulcers in stomach or duodenum (tube from stomach to small intestine), stones in gallbladder.

Stress, depression, anxiety, bad news, family trouble or trouble with boy- or girl-friend. This is best treated with Valium tablets, but you must take care as some people tend to feel sleepy after a very small dose. A chat with a sympathetic doctor can help a great deal.

The treatment for excess spasticity is to find the underlying cause, and treat that. When the cause has been removed you shouldn't suffer from excess spasticity any more, and should once more be able to use the advantages of basic spasticity.

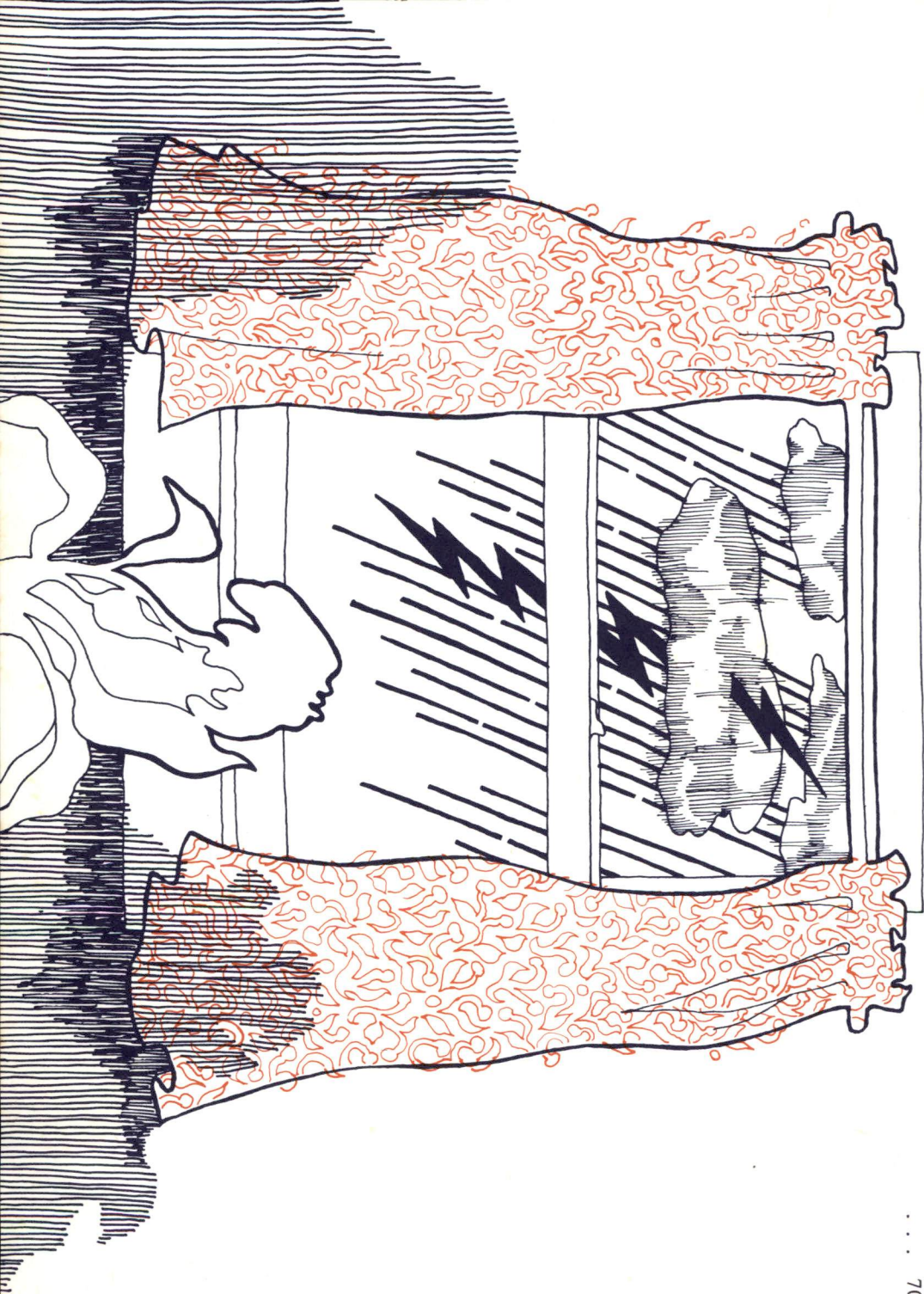
Some people find that violent spasms of the feet and legs are very troublesome, and sometimes embarrassing if, for example, you suddenly kick your shoe off and it flies across the room. If this is a problem with you, you can get a special attachment to the footrests of your wheelchair to prevent your feet from slipping off them. This may be a rim on the back, where the heel of your shoe rests, and/or a padded strap across the back of the foot pieces at the level of your calves. If your feet tend to slip suddenly off the footrests you can get small individual straps for each foot.

Some tetraplegics who have strong hip and leg spasms are afraid the spasms will throw them out of their wheelchair. Fear and insecurity tend to trigger off more spasms. If you have this problem it is safer, and you will feel more relaxed and independent, if you are secured in your chair with a safety belt. You may have to experiment to find out which type of safety device suits you best. The lap part of a car seat belt can be attached to your wheelchair and fastened over your thighs to stop you sliding out.

ROOT PAIN

In the early days of paralysis it's quite usual to suffer local pain, as a direct result of your injury or illness. There is, however, another sort of pain, called root pain, which may affect you later on. This is intense pain in the damaged nerve-ends or nerve-roots. It's becoming increasingly rare, so if you do have pain, make sure that it's not pain from some other cause which can be treated easily (by physiotherapy, local or spinal injections, or Vitamin B tablets - but **not** strong drugs, for the reasons outlined below). True root pain is difficult to treat. Mild painkillers are often not strong enough to stop the pain, and stronger drugs should be avoided - because you would need to take them over a long period of time, and would almost certainly become a drug addict, and because drugs of this kind taken over a long time would do your body lasting harm, especially as your bodily systems are already upset.

It may be that you just have to learn to live with root pain. However, many paraplegics and tetraplegics find that as they start to take up outside interests, and get involved with work and hobbies again, the pain starts to prey less on their minds, and even to fade. Fortunately, in many cases the pain tends to reach a peak - sometimes after a few weeks, sometimes after a longer period, and after that the attacks become less frequent.



CONTRACTURES

When some of the muscles which move a joint are paralysed, the joint may become very stiff because of lack of movement. For example, a tetraplegic with a lesion below C5 will be able to bend his elbow but not to straighten it out again. So, unless the proper precautions are taken, a contracture (shortening of the muscle) may develop, making it more and more difficult and painful for him to straighten his elbow, even when quite firm pressure is put on it.

An important part of your treatment in hospital is the prevention of contractures, and this must be practised for the rest of your life. Part of your daily routine must be moving all the joints of each limb in every normal direction, to keep them flexible; this can be done before you get up in the morning or last thing at night. If you are paraplegic, you should be able to manage this by yourself; tetraplegics will probably need help. It's important to remember to move all your joints - people tend to forget their toes, and if these are not kept flexible they become rigid and are at risk of being damaged when you put on your shoes.

You should avoid keeping the joints of a paralysed limb in one position for too long. In your wheelchair, your knees and hips are kept at a right angle all the time. So when you are lying in bed you must make sure that your knees and hips are kept straight. If you have spasms (1) you may need to fix your legs in the right position by

(1) see page 66

CONTRACTURES

tying them to the bed frame - use a soft wide tie, like a sheet folded to six inches (15cm) wide, so it doesn't rub or cut in. This helps to ensure that while you are asleep your legs will not be pulled into a wrong position by a spasm. If you are bedfast for a long time, make sure you change the position of your joints often, for example by having your knees and hips straight when you lie on your back, and bent when you lie on your side.

There is often a tendency, particularly in people who have spasms, for the feet to be pulled downwards, and eventually to be fixed in this position. You must take care to move your ankles every day through a full range of movements, and apart from this you should keep your feet at right angles to your legs - this is the most convenient position for them to be in. When you are sitting, your feet should be flat on the footrests of your chair; in bed you should use pillows or a well-padded foot board to keep them in position.

For tetraplegics, the most important place to avoid contractures is in the fingers, hands, and arms, as previously mentioned. To avoid getting stiff shoulders, move them every day. You may need someone to help you move your arms; these movements are easily learned, and anyone can do them.

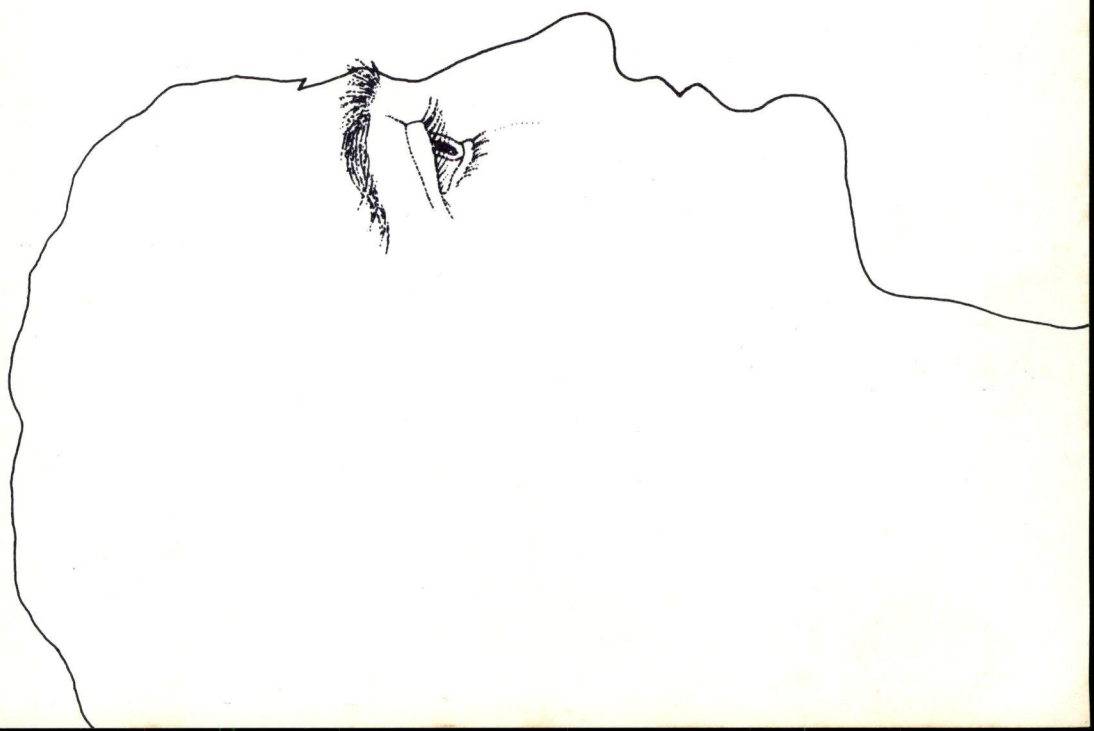
Contractures tend to creep up on you . . .

you may not even notice that movement in a joint has become limited until you go for a medical check-up. This makes it very important that you start a daily routine of movements once you are out of hospital.

It's also necessary that you keep your spine as flexible as possible - this helps you to balance and to keep fit. Unless your doctor has forbidden it for medical reasons, you should do regular bending exercises of the spine - bending forward and sideways as far as you can. In daily life, many paraplegics get this sort of exercise by doing things like putting on shoes, picking things up from the floor, and so on.

If a contracture is very severe, the tissues around the joint and even the bones themselves become deformed. It may be that, if things have gone this far, the contractures cannot be fully corrected. But it is vital to keep what movement is left in the joint and to prevent any further deformity by frequent passive movements (these are movements which someone else helps you with or which, for example, a paraplegic does by using his hands to move his legs). You should be careful to ensure that the joint is always positioned in such a way as to improve the contracture (for example, if the contracture has pulled your feet downwards, always try to keep them at right angles to your legs).

Sometimes it is helpful to use splints to improve contractures. These must be very well padded, and not left in place for more than a few hours at a time, to avoid the risk of pressure sores. If a contracture is very far advanced, it may be necessary to have an operation, but if you take the proper precautions and do not ignore the first signs of contractures, this should never happen to you.



At first when you find that you are paralysed it seems unlikely that you'll be able to have any sort of sexual relationship with anyone. It's not unusual to be preoccupied with this thought, and it's a distressing and worrying one. However, although you may have to modify or change some of your sexual activities, you can still have a meaningful sex life and continue to be a sexually active human being.

The need to love and be loved is important to most of us. One way of expressing this love is through physical contact. With or without an erection or orgasm, physical contact can provide a profound sense of well-being and intimacy and bring pleasure and excitement to you and your partner.

WOMEN

For women the main problem is not that you can't manage to have sexual intercourse - this is not difficult at all - but that if yours is a complete lesion you can't feel anything below the level of injury. It may seem at first that because of this you won't be able to get any pleasure at all out of sex, but this isn't so; what it really means is that you'll need to learn and practise new methods, new techniques, that can make sex just as enjoyable for you as it is for an able-bodied woman, though not necessarily in the same way. The important thing to do is to make sure that you know your own body very well, find out which are the most sensitive areas and which arouse you sexually when they are caressed or stimulated. Many paralysed women find that the parts of their bodies above the level of injury become much more sensitive than they were. Some experience a 'phantom orgasm' at the same time as their partner has an orgasm - this produces the same feelings, and the same after-effects of relaxation, slower heart-beat, and drowsiness as a 'real' orgasm.

So, as long as you're not afraid to make sure that your partner knows what you enjoy and where you are most sensitive, you can get a good deal of satisfaction from sex. Men are sometimes afraid of hurting a disabled woman when they have intercourse with her - it's up to you to reassure your partner, and let him know what is comfortable and enjoyable for you.

Nothing is 'abnormal' as long as you and your partner are both happy to do it. Sex involves your whole body, not just the genital area (the area around the sexual organs), and you may get great pleasure from using the non-paralysed parts of the body - your mouth, for instance, or your hands, in intercourse.

You will need to experiment to find out which positions it is most comfortable for you to make love. The 'missionary' position (where the woman lies flat on her back with legs apart, man on top) isn't necessarily the only or most comfortable position. It may be easier for you to put pillows under your knees and buttocks. Or you may find it better to lie on your side, either facing your partner or with your back to him, or lie on your stomach with the man on top, entering you from behind - whatever is pleasing and comfortable for you both. If you find that spasms are a problem, it's helpful for you to seek a position in which you don't have so many spasms - for example, lying face down.

If your vagina tends to be dry, use a lubricating jelly, like KY jelly; don't use Vaseline, as this doesn't dissolve in water and can carry infection into the vagina.

If you have an in-dwelling (Foley) catheter, you may wonder what to do with it during sex. If you find it makes intercourse difficult, it's probably safest to remove it. Whether you do or not depends to

a large extent on the size of your vagina and the position in which you have intercourse. It's best to keep it in if possible, to avoid the risk of infection caused by removing it. If your partner enters you from behind, you may not need to remove the catheter. Taping the tube to your tummy with Elastoplast will keep it out of the way.

When you are newly paralysed, you will probably find that your periods stop. This is because of the great shock your body has received, and in the great majority of cases they start again quite normally after a few months. Once they are back to normal there should be no reason why you shouldn't be able to conceive and have children in the normal way.

During pregnancy you must keep an especially careful watch on your kidneys, bladder, and bowels, to make sure they are in the best possible working order, and have regular blood tests to ensure that you're not anaemic (that is, that your blood isn't short of red blood cells). Treatment for anaemia is very simple, but very necessary to ensure that you and your baby are strong and healthy. Apart from these safeguards, your pregnancy and childbirth will be no more complicated than anyone else's. You should be looked after by a doctor who realises that your baby might arrive up to two months early, will care for you in hospital, knows about your need for turning, bladder and bowel control and - possibly - blood transfusion. At delivery he may have to assist you, but operation (Caesarian section) is only very rarely needed. It's usually possible for paralysed women to breastfeed their babies, except in very rare cases.

If yours is a very high lesion, there is more risk involved, but if you feel strongly about having a child and have expert advice and attention, you will be able to find ways of coping. You may find that during labour you get a steep rise in blood pressure, which makes you feel sweaty and chilly. As long as you have skilled medical attention this is nothing to worry about.

BIRTH CONTROL

The decision to have a child is always a big one, and especially so in your case. You and your partner will have to bear in mind the extra work a child creates, and how you're both going to cope with it. It's not something to rush into.

If you decide not to have a child, or to delay having one, you must consider, if you have no objection to birth control, which method is best for you. Before starting to take contraceptive pills you must have a very thorough medical check-up, as they can affect your blood pressure and may produce side-effects that could be hard for you to cope with.

There are several other methods of birth control. One is the diaphragm (cap) which is put into the vagina to seal off the neck of the womb. If used with a jelly that kills sperm this is quite effective, but if you haven't the full use of your hands you may find it difficult to put in. Intra-uterine devices (IUDs) are put into the womb by a doctor and kept there all the time. These are quite effective but sometimes slip out, and can cause complications like excessively heavy periods which may be very inconvenient. Contraceptive foam, which is put into the vagina before intercourse, does not work very well if used on its own. Neither does the rhythm method (intercourse only at 'safe periods'), or withdrawal of the penis before ejaculation, which is not only unsafe but very frustrating for both partners.

BIRTH CONTROL

It may be most convenient for you to let your partner take care of the contraception by wearing a condom (sheath) - these are efficient if used properly.

If you are quite sure that you'll never want children, you or your partner may want to consider sterilization - an operation to block the tubes through which sperm or eggs move. These operations have no effect on sexual drive, responsiveness, or the periods. However, sterilization can't be undone, so it needs very careful consideration before it is done.

MEN

For men the question of sex is more complicated, because first of all you need to find out if you can still get an erection. When you are newly paralysed you'll probably find you can't get one at all, but in most cases this ability returns after a while.

There are two ways in which an erection is caused. One type of erection is called 'psychogenic' - that is, it starts in the mind through sexy sights, sounds, or smells, as well as through the imagination and memory. A message is sent from the brain down the spinal cord to its lower part (the sacral area), from which a signal is transmitted to the penis to cause it to become erect. If the spinal cord is interrupted somewhere between the brain and the area controlling sexual response, the message can't get through and usually stops just before the lesion (interruption). If yours is a complete lesion, it's unlikely that you'll be able to get this kind of erection. Some spinal cord injured men, however, can get a psychogenic erection if their autonomic nervous system⁽¹⁾ isn't affected, because then the message from the brain can bypass the injured portion of the cord via the autonomic nervous system.

The other type of erection is called 'reflexogenic'. This results from direct stimulation of the genital area (the area which includes the penis and scrotum). This type doesn't need a message from the brain

MEN

(1) see page 8

to operate it, as it is caused by a signal that goes from the genital area to the spinal cord and back. So even if the cord is interrupted it's possible that you can still get a reflexogenic erection. Generally speaking, it's men in whom the sacral part of the cord is damaged who have difficulty in getting an erection. In this respect, tetraplegics are usually better off than low lesion paraplegics.

You may get spontaneous spastic erections, that just happen and don't seem to be caused by anything. In general these are not very useful, as you can't control when or where they may happen.

If your lesion is complete, you probably won't be able to reach orgasm. As you can't feel anything below the level of injury you won't be able to feel that you have an erection, but you may nevertheless experience a 'phantom orgasm'. Just as an amputee might imagine he feels pain in a missing limb, you may feel as though you are having an orgasm. This may occur at the same time as your partner reaches orgasm, and produces the same after-effects of relaxation, slower heart-rate and drowsiness.

Even if you can get an erection, it's unlikely that you'll be able to ejaculate (emit semen). Ejaculation can't take place if the particular nerves and parts of the spinal cord controlling it are injured. The more incomplete your lesion, the better are your chances of being able to ejaculate, provided that nerve supplies in the sacral region are intact.

It's rare for paraplegic and tetraplegic men to father children. Even if you can ejaculate, the sperm count of paralysed men is usually low. A doctor can tell, by examining your semen under a microscope, how high your sperm count is and whether the sperm are viable (able to fertilize eggs). Until you know for certain, though, it's as well not to be too hopeful about having children.

Like paralysed women, you will need to experiment to find the positions which suit you best for intercourse. You may find that lying on your back with your partner on top is best, especially if you are tetraplegic. This gives your partner the freedom of movement necessary to position your penis. From this position you can roll over to either side.

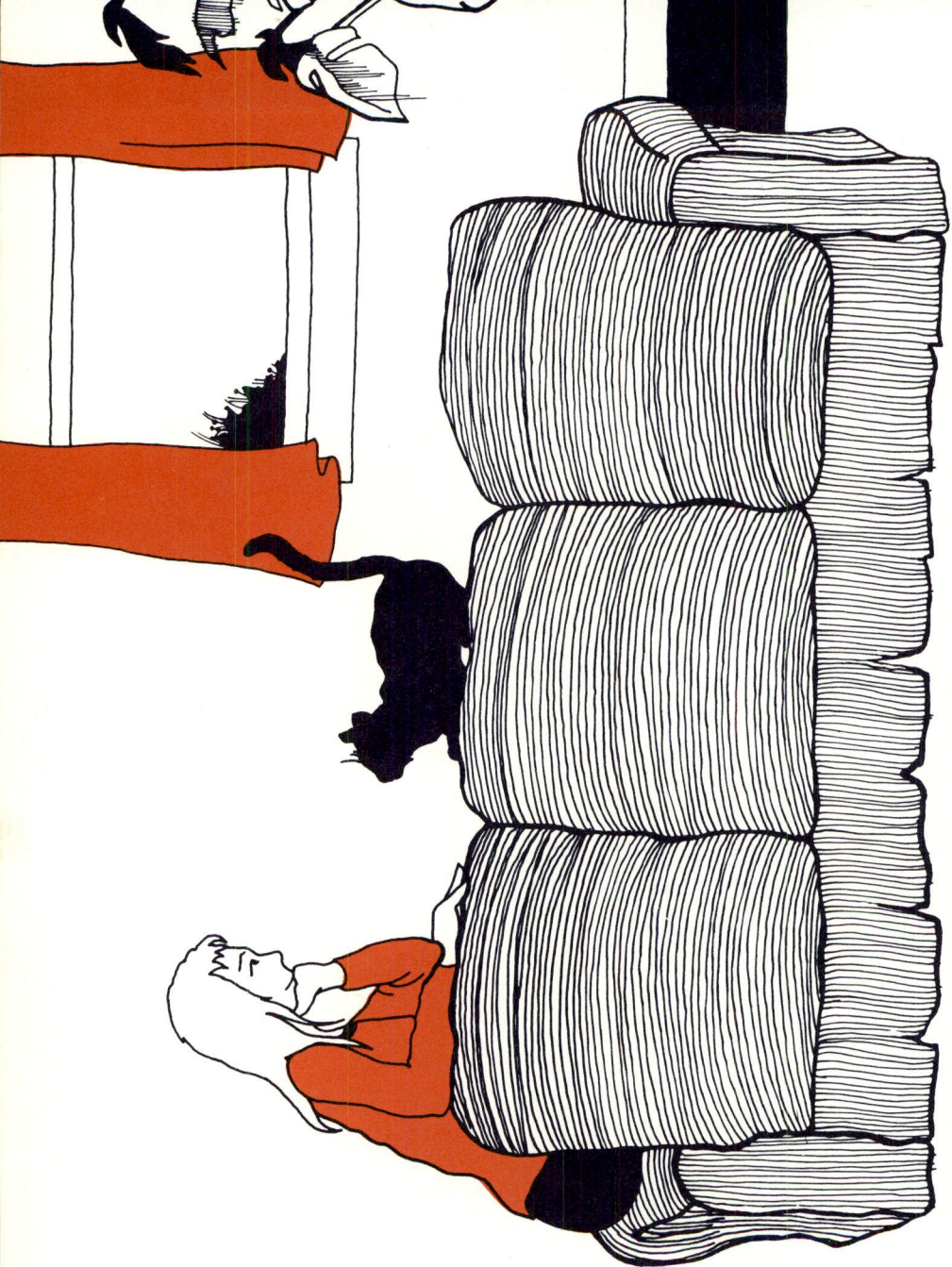
You must remember that the vagina itself isn't particularly sensitive, and if you aren't able to use your hands to stimulate your partner's clitoris and inner lips you may be unable to bring her to orgasm, so you will need to try other methods, such as using your mouth. If you have partial use of your hands you may be able to use a battery-operated vibrator to stimulate your partner.

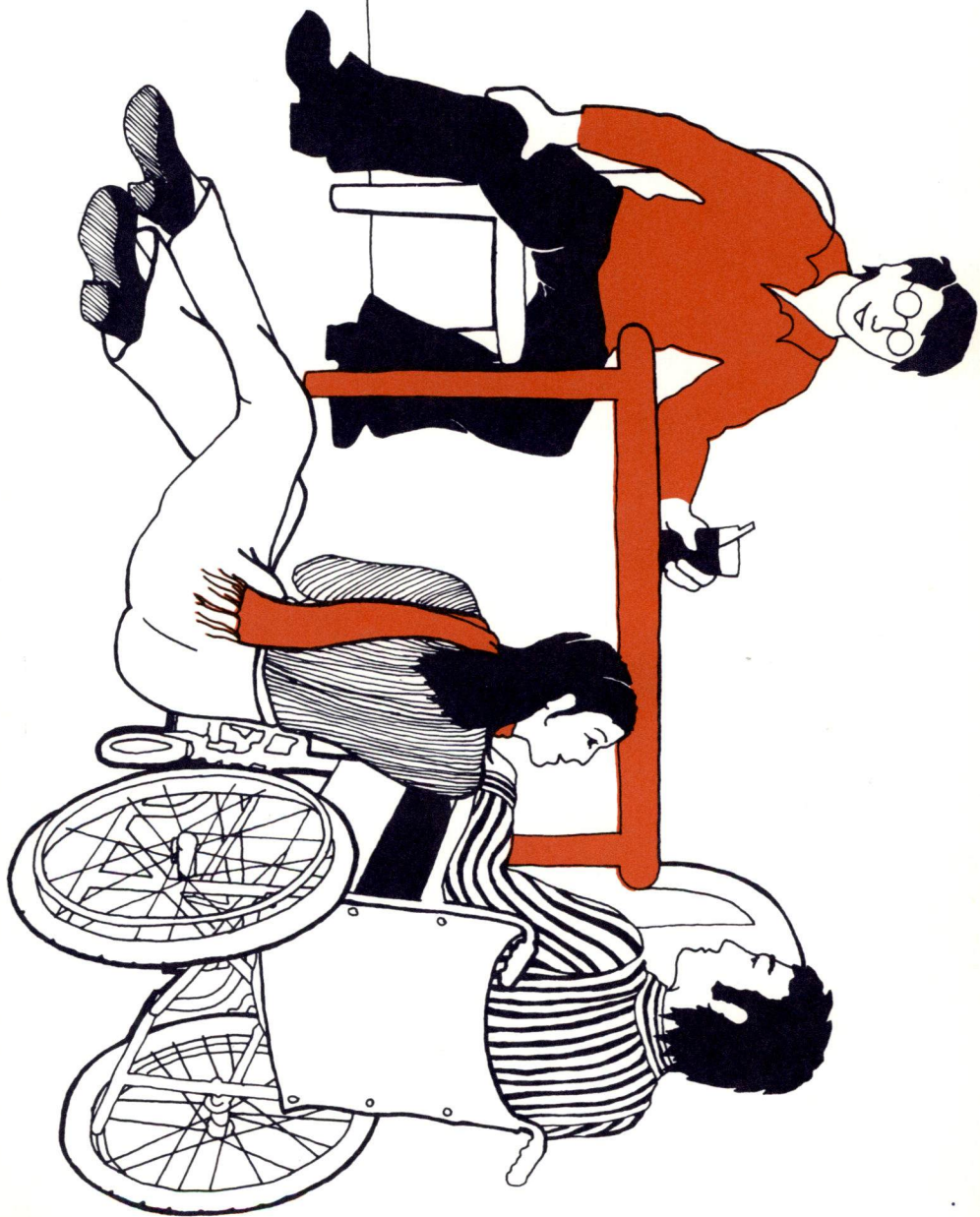
If you can't get an erection, what then? This does not mean at all that you can't have a sexual relationship. There are many ways of satisfying a partner other than straightforward intercourse, such as using your mouth, and your hands if you can. You may like to try

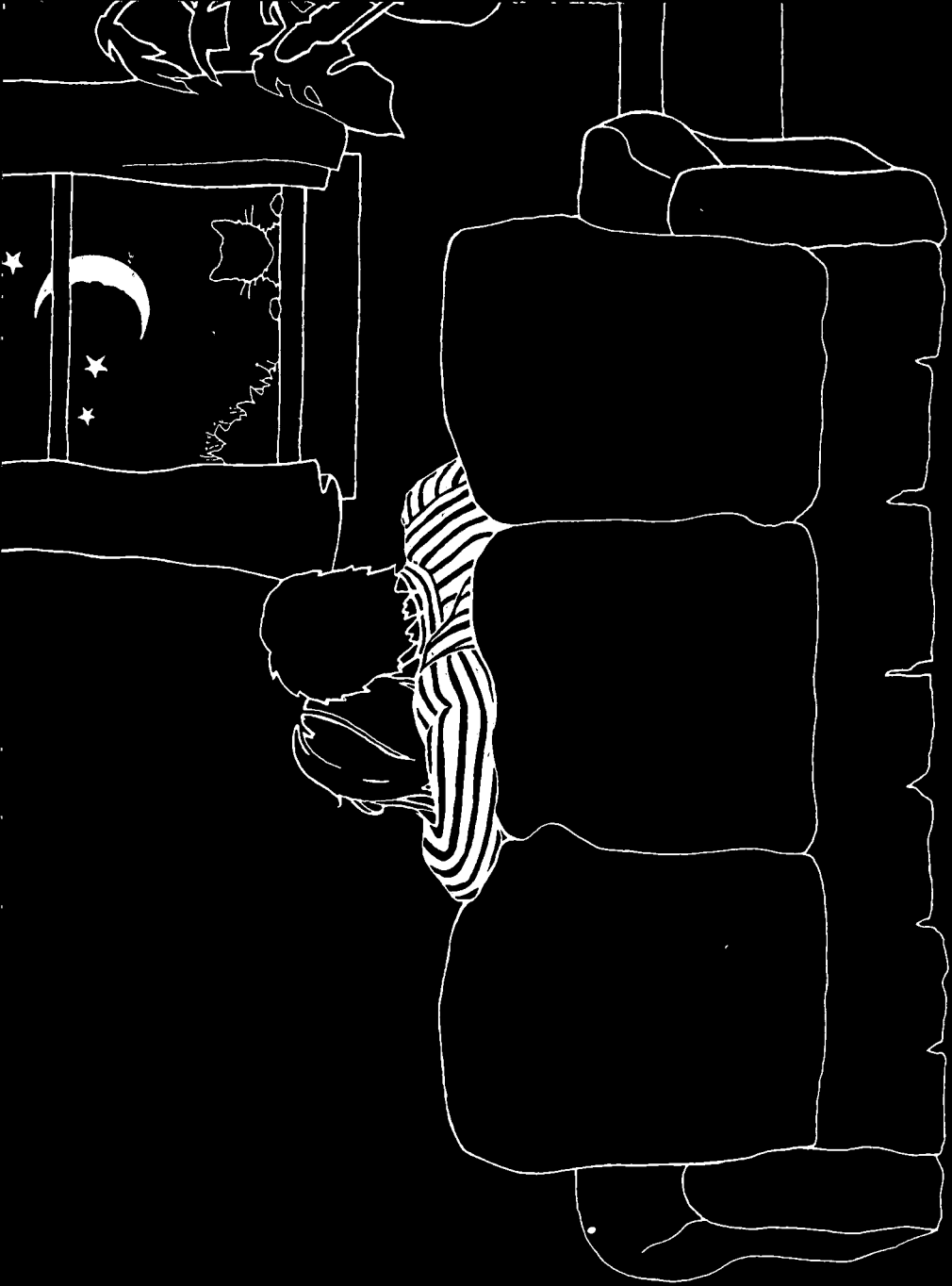
the 'stuffing' technique, in which your partner gently stuffs your soft penis into her vagina with her fingers, while working her vaginal muscles back and forth. Sometimes this friction will cause an erection, sometimes not - either way it is very satisfying for both partners. Or you may consider using a 'prosthetic device' - an artificial hollow penis which fits over your own.

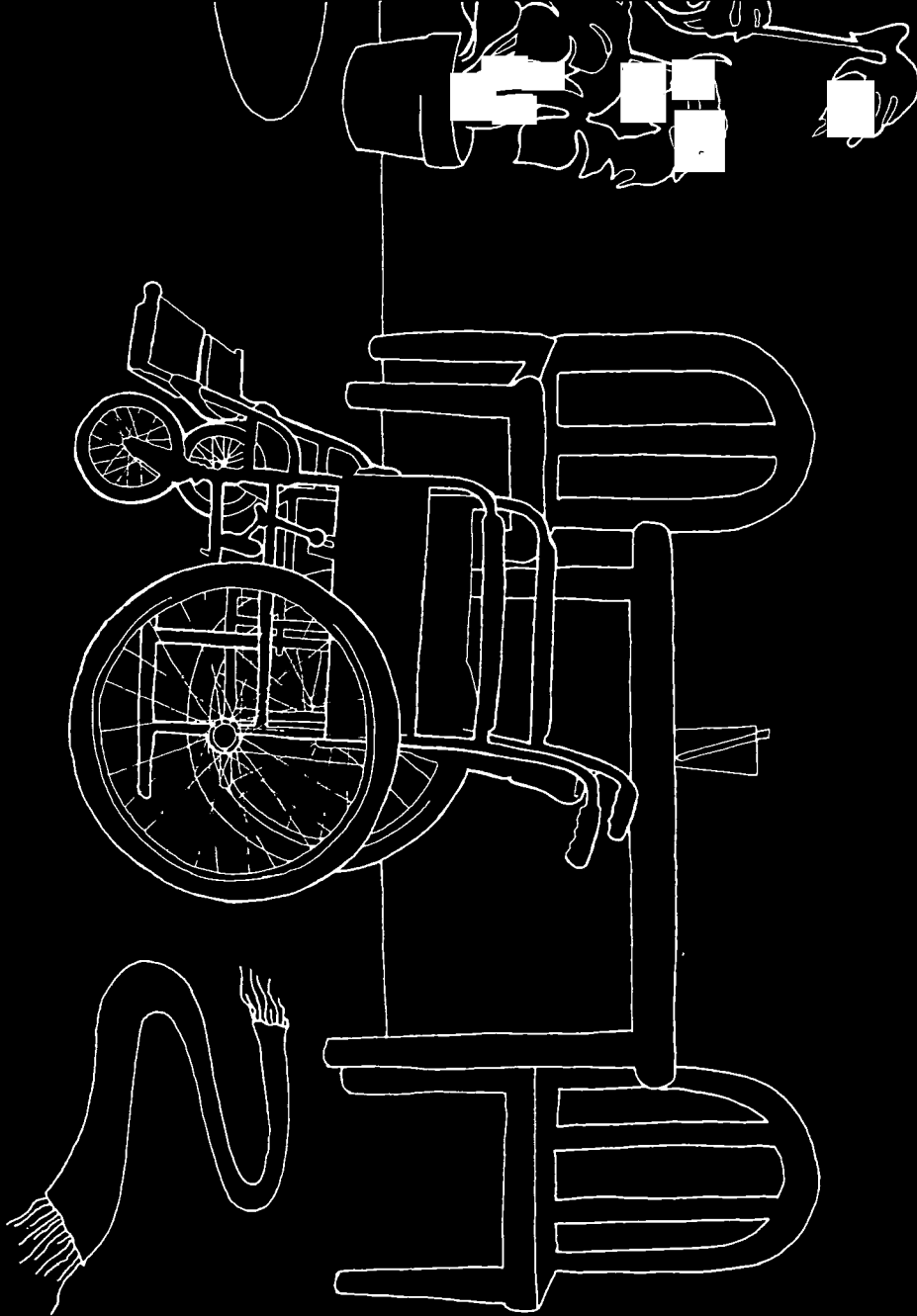
If you wear a condom urinal it is easy to slip this off before sex. If you have an in-dwelling (Foley) catheter you can either remove it or fold it back over your penis and lubricate it well with KY jelly - or slip a condom (sheath) over it to keep it out of the way.

You should take extra care with personal cleanliness when you are paralysed - for instance, washing your penis carefully before intercourse. This is not only considerate to your partner, but also helps to make you more attractive as a person.









SOME COMMON PROBLEMS

Is it possible for me to be accidentally hurt by my partner during sex?

This is highly unlikely if ordinary precautions are observed, including avoiding any unnecessarily rough or harsh handling. Also remember that prolonged pressure on any part of your body that has lost feeling can cause pressure sores. If your partner is concerned about hurting you, you should reassure him or her that injury is not likely. It's important to remember that sex can never be really satisfying if either of you is frightened - fear is very off-putting.

How can I best prepare myself for sex?

If at all possible, it is best to plan sexual activities for the time of day when you are least tired and have the fewest distractions - when children are out of the house or asleep; when bowel routines are finished; when you aren't exhausted from self-care, work, or household tasks. Since relaxation heightens sexuality, it's best to relax and unwind beforehand. You may find that taking a warm shower or bath (alone or together), listening to music, a gentle massage with or without a body oil or cream, or using a vibrator can help you to relax. Make sure you're not running the risk of an unwanted pregnancy, as fear of this can make you tense.

SOME COMMON PROBLEMS

Since I have been injured, my body has changed considerably. Will a partner be surprised when he or she sees me naked?

It's important to remember that if your relationship is a good one, your partner hasn't picked you just for your body. It will probably ease your mind and help to prepare your partner if you explain what happens to the body when the spinal cord is injured. Exploring each other's body before you undress or have intercourse would also lessen any surprise your partner might feel. You may feel a bit awkward and tense at first, but this feeling should soon wear off. As long as you can accept your body the way it is, your partner will be able to also.

What if I should urinate or have a bowel movement in bed?

This has happened to many paraplegics and tetraplegics at one time or another. You may find it embarrassing, but as long as you've explained your physical condition to your partner and hinted that this might happen, it shouldn't shock or upset your partner, and he or she is likely to understand.

There are some precautions you can take against this happening. You should empty your bladder and avoid drinking for a few hours before sex. For men; if you are very active during intercourse, you may lose your erection and need to urinate. Usually spasms will warn you of this so you can withdraw in time. This makes it especially important

for you not to drink before intercourse. If possible, you should also try to empty your bowels well in advance.

Can an ileostomy drainage bag be left in place during intercourse?

It's quite safe to leave an ileostomy bag in place. Empty it before intercourse to avoid the risk of spillage, and tape the bag to your tummy with Elastoplast to keep it out of the way.

Is it difficult for a handicapped person to adopt a child?

As a general rule, it is more difficult. This doesn't mean it's impossible. If, after fully considering the implications, you decide that it's really the right thing to do for you to adopt a child or children, and are sure that you can give it or them a good home, approach an adoption society. You may be lucky at your first try, or you may find that the adoption society presents you with all sorts of reasons why you wouldn't be a suitable parent. Sometimes these are the silliest of reasons - for instance, that a paralysed father can't play football with his son! Don't be put off by this. The important thing, for the child and for you, is that you can offer it a stable, secure home, and as long as you're sure in your own mind that you have this to give, press on. If necessary, try another adoption society.

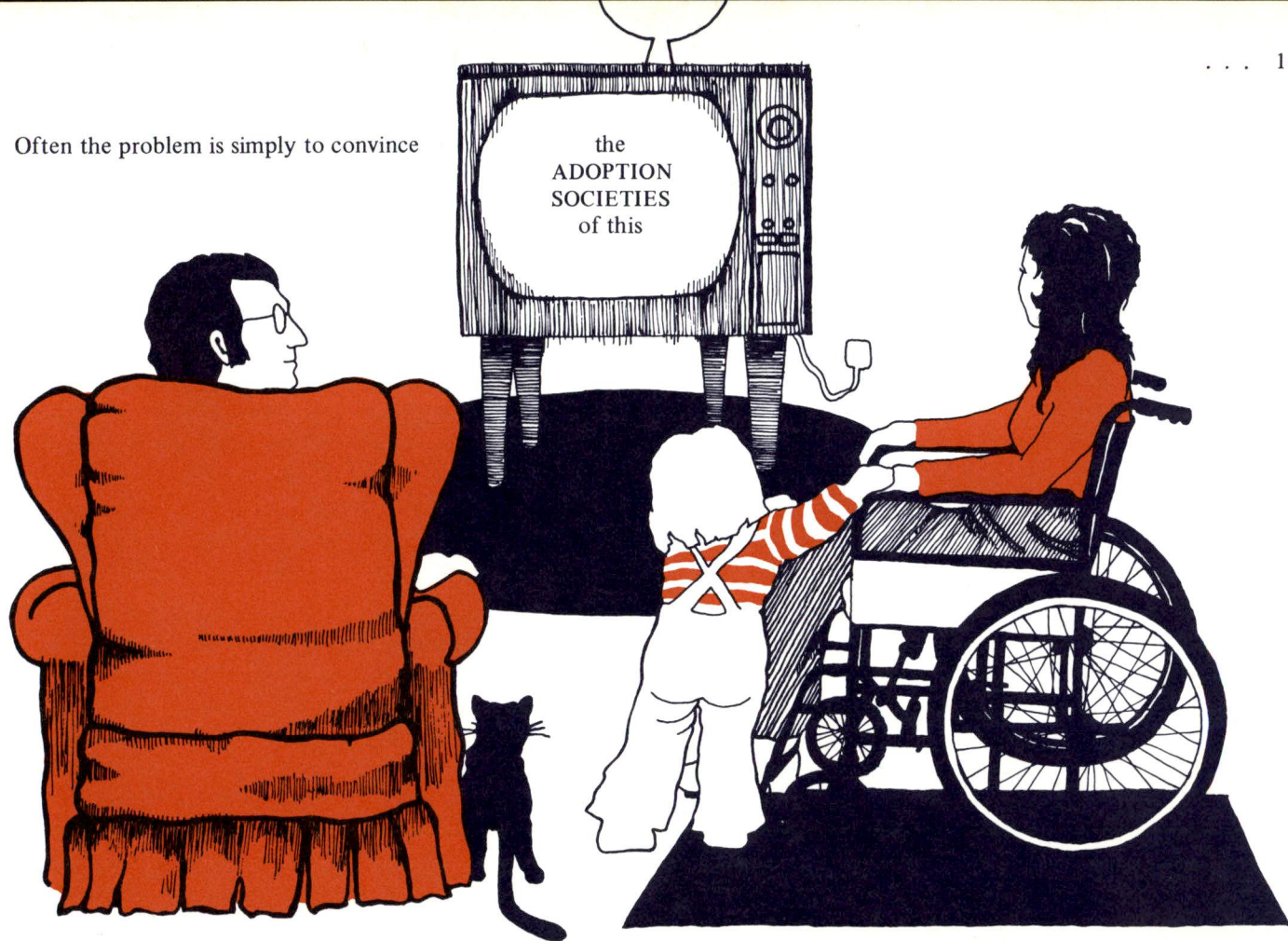
You'll need your doctor to sign a form saying that you are a fit person to adopt, so it's a great help if you are on good terms with your doctor and can get his support right from the start.

If all else fails, try to get in touch with other paraplegics or tetraplegics who have successfully adopted (through your spinal centre or the Spinal Injuries Association), and ask them how they went about it. If necessary use them as examples to your own adoption society.

Two things to remember. One is that, if you're continually in and out of hospital, it may not be wise for you to adopt. The other is that, since abortion became more easily available, there have been fewer babies and children in need of adoption. This makes it more difficult for anyone who wants to adopt - if you are prepared to take an older child, or one of mixed race, or perhaps one with a social, physical, or mental handicap, things may be easier. You may like to consider fostering children through your local authority.

Many paraplegics and even tetraplegics have adopted children very successfully. The important thing is what sort of person you are, not what physical disabilities you may have.

Often the problem is simply to convince



Before your accident or illness, as for everyone else, pain was the signal which warned you that you had hurt yourself or that something was going wrong inside you. Since your accident or illness, this signal no longer works wherever you are completely paralysed; in your legs and bladder if yours is a 'low' paraplegia, in your tummy and chest as well if yours is a 'high' paraplegia or tetraplegia. While you can still feel ill like everyone else, you may have no idea where this illness or upset comes from. But there are 'new' signals helping you - and your doctor - to find the cause, and it's important that you know about them.

Here are the most common signals and explanations of what they mean:

SYMPTOM

More or less sudden sweating in your face and the non-paralysed part of your body, face red, nose blocked, increasing pounding headache, sudden unconsciousness in tetraplegics. Often mistaken for 'flu.

Sudden change in colour of urine:

greenish

dark red

Sudden shivering, feeling hot and weak, vomiting. Temperature may be 103° or more.

COULD BE

Blockage of the bladder - either inability to pass urine or blockage of catheter.

Slight bleeding from kidneys or bladder.

Serious bleeding caused by stones (although some laxatives may stain urine red).

'Flare-up' of urinary infection.

WHAT TO DO

You need catheterisation or removal and replacement of indwelling catheter. Can be done at home if you or a member of your family are skilled in sterile catheterisation; if not call a doctor or go to nearest hospital immediately.

If you try to remove catheter and balloon won't deflate, don't try other methods of deflating it - pull it out gently and firmly.

Urgent admission to Spinal Centre.

Call doctor immediately. With right antibiotic, should go within three days. If temperature remains high, you must be admitted to a Centre, as a stone may block kidney or ureter.

SYMPTOM

(Mainly in cervical and high thoracic lesions) - a cold, sore throat, cough, rising temperature.

Fresh blood on faeces.

Blood or pus on faeces.

Faeces almost black, like tar.

Feeling weak and listless, often looking pale.

COULD BE

Dangerous as you can't breathe deeply or cough up properly.

Piles (haemorrhoids) - widened parts of veins at anus and rectum (lower part of bowel). Danger of infection by faeces.

Rectal fissure - split in lining of wall of rectum, due to damage.

Fistula or sinus of the anus - small hole in wall of rectum, caused by damage or infection. Danger of faeces getting into hole, causing abscess.

Bleeding from ulcer in stomach or bowel.

Probably anaemia - shortage of red blood cells.

WHAT TO DO

Urgent treatment with antibiotics and assisted breathing exercises necessary.

Ask doctor to examine you to find cause. Treated by injection. In a few cases, operation necessary.

See doctor.

Treated by minor operation.

Urgent admission to a Centre.

Tablets and injections of iron usually not enough - you need blood examination and transfusion, probably as outpatient.

SYMPTOM

(Mainly in high lesions) - sudden extreme weakness, feeling sick, pulse racing.

Sudden heavily swollen knee or ankle. You may have heard a crack and felt weak fifteen minutes later.

(In men) - swollen, hard, possibly red testicles (balls).

COULD BE

Sudden complications in chest or tummy.

Nearly always due to broken bone caused by fall.

Hydrocoele - a little bag of fluid attached to testicle.

Epididymo-orchitis - inflammation of one or both testicles caused by infected urine travelling up connecting tube. May produce abscess which destroys testicle.

WHAT TO DO

Immediate admission to hospital very urgent.

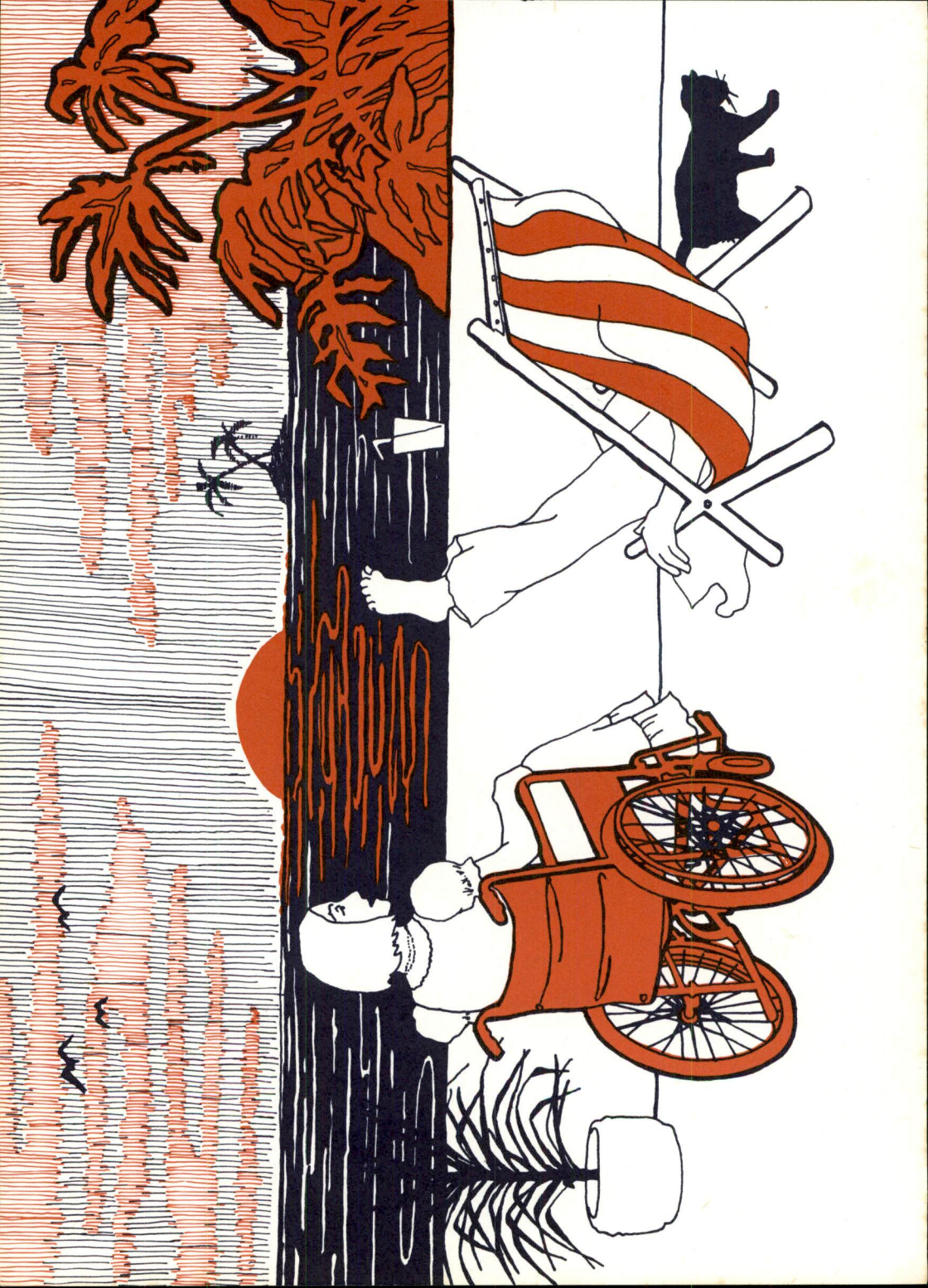
X-Rays and splinting urgent. Splints must be very thickly padded. Never allow closed plaster cast - will almost certainly cause pressure sores.

See doctor - not serious, but may need operation.

See doctor immediately. Check testicles regularly by looking and feeling.

When you are discharged from the Spinal Centre for the first time, your GP (family doctor) will get a detailed letter, describing your injury and suggesting further help he can give you. If you and your GP get on well, if he comes to see you at regular intervals, if he even knows something about para- and tetraplegia because he has attended one of the special courses, he will come at once should you have to call him. But you may not be so lucky. If you need a doctor, you or a member of your family should 'phone him. If he is not willing or able to see you the same day, 'phone your Centre. There they know all about you. Often they may advise you over the 'phone as to what you can do yourself, and all may be well. Or they have to suggest that you 'come in' at once. Unfortunately they will not always have a bed for you at once, and may have to suggest that you have yourself admitted to your local hospital. There they may or may not know about your special needs. For example, if they have no turning beds, if you can't turn yourself, and if the hospital is short of staff, particularly at night, you won't be turned, and will get pressure sores which develop much more quickly when you are ill. If you need catheterisation, this may not be done as cleanly or as gently as you know it ought to be done. If you have to have an operation or if you have broken a bone, you will need blood transfusions more urgently than the non-paralysed.

If you find yourself in a hospital without special facilities or experience, show this book to your doctor.



SPORT

If you are keen on sport, being paralysed need not prevent you from taking part in a variety of sports and games. While you are in hospital, you will be encouraged to take part in various sports, as these are an excellent way of keeping fit, learning to balance, and regaining independence. Not only this, but they are a source of real fun, recreation, and companionship. Among the most popular sports for paraplegics and tetraplegics are archery, swimming, table tennis, snooker, basketball, and javelin throwing. There are many sports organisations for the disabled (and even a Paraplegic Olympics!), but you can still compete on equal terms with able-bodied people in a number of sports. Many paralysed people join their local archery or snooker club or table tennis league, and swim in their local pool. Further details of your local sports organisations for the disabled can be obtained from the Spinal Injuries Association or the Disabled Living Foundation (346 Kensington High Street, London W14 8NS).

TRAVEL

Although getting around may now be more difficult, it's still possible for you to travel by a number of means, and to take holidays abroad. It's quite usual for people in wheelchairs to travel by air. If you let the airline know in advance, they will make special arrangements for you.

SPORT

TRAVEL

British Rail are introducing a new type of carriage in which a seat can be removed to make room for a wheelchair (first class, but you only pay second class fare). But if you travel in an older type of train you may have to ride in the guard's van.

There are no extra difficulties involved in taking a car with hand-operated controls on ferries or into other countries.

When it comes to choosing where to go for a holiday, there are special considerations you'll have to take into account, such as the accessibility of various places, the width of hotel doorways, and so on. You can always write to a place you think might be suitable and ask for details of this sort of thing, but probably the best way is to enlist the help of able-bodied friends who travel abroad. If they can check out the places they visit for accessibility and report back to you, this is a great help.

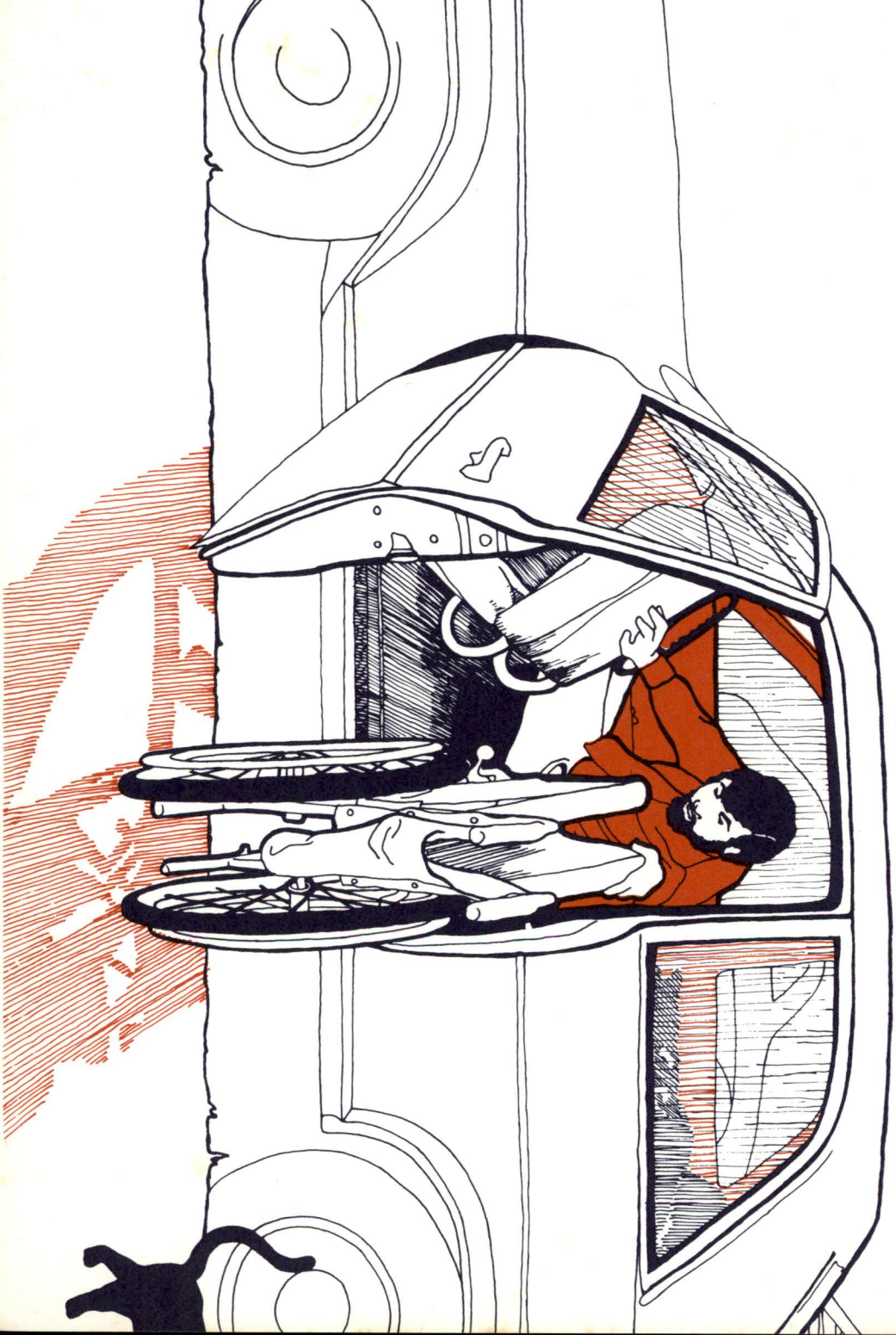
The Spinal Injuries Association can advise you on suitable places for holidays, and the Central Council for the Disabled (34 Eccleston Square, London SW1V 1PE) publishes a list of hotels in Great Britain accessible by wheelchair. Some local organisations for the disabled run their own organised holidays.

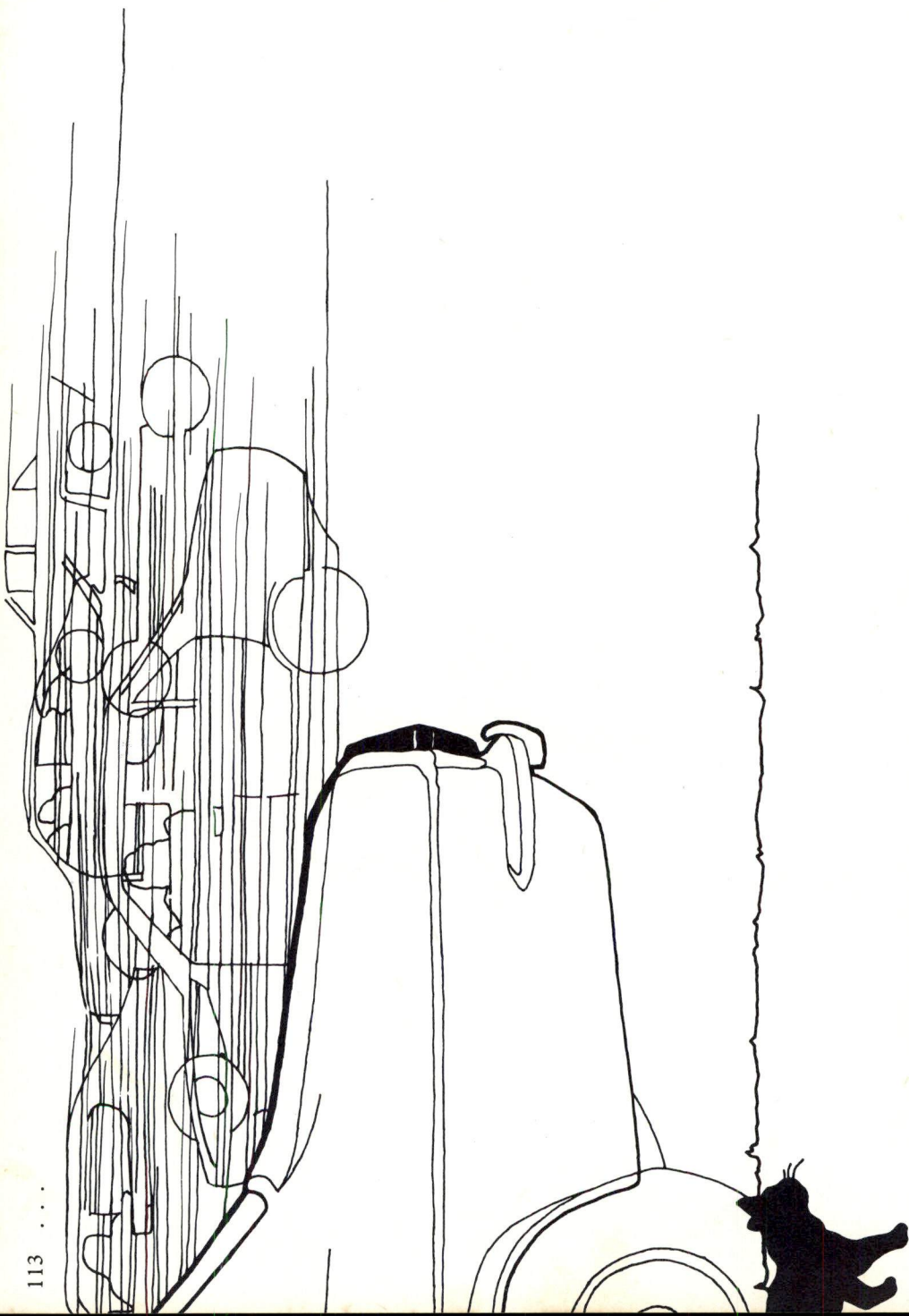
DRIVING A CAR

You may be surprised by the high level of disability at which it is still possible to drive a car. Even tetraplegics with very little movement in their hands and arms can drive specially adapted cars, and this is a tremendous benefit in regaining independence. With a car and a wheelchair, a paraplegic can be completely independent, although a tetraplegic may need help with getting the chair in and out of the car.

At present the Government provision for mobility for the disabled is either an invalid tricycle or an allowance towards the use of your own car (except in special circumstances, when they will provide you with a car). An increasing number of disabled people have their own cars.

The Spinal Injuries Association can put you in touch with organisations which will advise you on the most suitable adaptations to have made to your car.





All this book can do is give you information and advice. Whether or not you make use of it, and what happens to you for the rest of your life, depends on you. If you choose to spend your life sitting at home feeling sorry for yourself you are free to do so, but no one should feel this is the only choice they have. There are large numbers of paraplegics and tetraplegics in the world, and the great majority of them lead active, ordinary lives. Some achieve remarkable things in various walks of life, and there's nothing to stop you doing this if that's the sort of person you are. Most just get on with the everyday business of life, and find it's not much different from life before they became paralysed.

It's easy to let your wheelchair become a barrier between you and the rest of the world. Nobody's stopping you. But it's funny how nobody notices some people's wheelchairs - they notice the person instead.

If at any time you are in need of information, help, or advice, the Spinal Injuries Association exists to provide these. Write to Diana Irish, General Secretary, SIA, 24 Nutford Place, London W1H 6AN, or 'phone 01-262 2641.

There are also organisations to advise about aids and gadgets of various kinds, and generally to help with everyday life.

There are no organisations to live your life for you.

It's up to you . . .



ISBN 0 9504474 0 4

so you're paralysed . . .

A practical guide to coping with the everyday problems of paraplegia and tetraplegia, for paralysed people, their families and friends, and all who are involved in their care.