

THE SEXUAL FUNCTION AND ENJOYMENT OF SEXUALITY
AFTER SPINAL CORD INJURY

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INTRODUCTION

Not only are spinal cord injuries quite common, they also often lead to extensive restrictions and handicaps.

The rehabilitation of persons with spinal cord injuries has undergone significant evolution over the last fifty years; the survival period is almost that of non-injured persons, the chances of social participation have increased and there is increasing consideration of the quality of life.

Although a spinal cord injury can also have important consequences for the sexual function, which may often be very serious, rehabilitation and the provision of help in this field is nevertheless often limited. With this brochure we aim to give persons with spinal cord injuries, and their partners, basic information concerning this subject.

Those persons who are involved in the rehabilitation of paraplegia patients may also find this brochure a useful tool.

Possible positions during intercourse are illustrated with photographs of four "experienced" couples, which include both a paraplegic and a tetraplegic man and woman. Their open and honest co-operation has added to the value of this brochure. The photographic material does not pretend to be more than it is. It is varied but will certainly not show everything; it is also beautiful and hope-inspiring.

The sexual function after a spinal cord injury

A spinal cord injury changes the life of a well person in a very short time, to that of a person with a permanent handicap. Spinal cord injury may lead to complete or partial paralysis of the lower limbs or of all four limbs (paraplegia and tetraplegia). Due to this paralysis people with spinal cord injury are suddenly confronted with a considerable loss of function and physical limitation. They are no longer able to continue a number of activities which formed part of their normal life, and sometimes are in great pain. After a spinal cord injury one is therefore set the task of orientating oneself anew as regards one's own body. Together with this change in physical possibilities, one must also know how to access a new, and generally different, place in society.

This is not always easy. People around one always see the external picture: the paralysis, the wheelchair, the crutches. An external picture which calls up questions in them and sometimes also leads to prejudice. People with a spinal cord injury, and those close to them, also know that there may be plenty happening on the inside. Problems with the bladder and bowel function, and sexual dysfunction, are often a huge source of worry, as are also the feelings of uncertainty and of reduced self-esteem.

It is obvious that many of these problems are reflected in the experience of sexuality of people with a spinal cord injury. In the field of sexuality there are not only the problems with accepting one's own changed body, there is also the question of learning to accept this body which does not function so well, on the part of any partner.

Sexuality is regarded as a domain of life which can make an important contribution to a person's general feeling of well-being, a greater feeling of self-worth and an increase in individual happiness and happiness within a relationship. This is reason enough to give some consideration to sexuality after a spinal cord injury.

This brochure will provide information concerning the sexual function and the possibility of enjoying sexuality after a spinal cord injury. We are trying to fill a gap and answer the questions which arise from many of the parties concerned (patients, partners, carers, doctors, and so on).

In the first place we want to supply general information and offer a survey of the possibilities for sexual functioning after paralysis. One important consideration in all this, is that what is said is no more than a description of the possibilities, these are not norms or standards of how it has to be. What is possible and not possible within a relationship must be discussed between the two partners, then investigated and tried out.

Chapter 1: The physical aspects of sexuality

Since the instrument for any form of sexuality is our body, we want to begin with some concrete information about the physical aspects of sexuality. The internal and external sex organs and the physical reactions of men and women will be discussed briefly. The reason for this is that we have learned in practice that a lack of knowledge of these physical aspects of sexuality often stands in the way of a satisfactory experience of sexuality; this certainly applies to people with a spinal cord injury.

1. Men: the physical aspects of sexuality.

The male sex organs. (+ drawing)

The external male sex organs are the penis and the scrotum. The penis consists of the shaft of the penis and the glans, which is covered with the foreskin. The inner side of the foreskin and the outer side of the glans are coated with mucus membrane. The glans is the most sensitive part of the penis.

The male internal sex organs are the testicles or testes, the epididymis, the seminal duct, the seminal vesicles, the prostate and the urethra. Sperm are produced in the testicles and are carried by the seminal duct to the seminal vesicles. The sperm are stored in these seminal vesicles. In the prostate seminal fluid is produced. During ejaculation the sperm are forced out with the seminal fluid (semen), and this is accompanied by an intensely enjoyable feeling (orgasm).

Physical reactions during sexual activity in the man : erection and ejaculation.

During sexual excitement in the man the nipples swell slightly, there is an increase in muscle tension and in the frequency of respiration and heart beat. The first and most visible reaction to excitement in the man, however, is erection of the penis.

Obtaining an erection is absolutely essential if you want to achieve sexual (genital) intercourse during love making. Various mechanisms contribute to the production of an erection. We will discuss these briefly below.

The penis consists of three bodies which are capable of swelling (+ diagram). The inner (spongy) body lies around the urethra and forms the glans at the top of the penis. The two outer (cavernous) bodies are connected to each other and are necessary to obtain a good erection. Essential to getting an erection is a massive blood supply to these cavernous and spongy bodies.

Due to an increase in the blood supply to the penis, and at the same time a reduction in the blood flow from it, the penis increases in volume and gradually becomes firm and stiff. Thus it is clear that a good erection presupposes supple and patent blood vessels. These blood vessels and the cavernous and spongy bodies are also under the control of the nervous system, so the spinal cord and the brain also play a part.

An erection may occur on the basis of two mechanisms (see also below). An erection may, firstly, occur due to touching the penis or the skin around it; this is called a reflexogenic erection. A second possibility is that an erection occurs because one sees, hears, feels or smells sexually exciting things, and/or due to sexually coloured thoughts or dreams. This is called a psychogenic erection. A long-lasting, firm erection usually requires both reflexogenic and psychogenic stimulation. Persistent and stimulating excitement of a penis in erection may result in an orgasm with ejaculation. Due to the contraction of the seminal duct, the prostate gland and the seminal vesicles the semen is driven out to the urethra. This produces the feeling that one can no longer hold back the ejaculation. Then the semen (ejaculate: the sperm and the seminal fluid) is driven out by the contraction of the urethra and the muscles of the penis. After ejaculation (coming) the erection gradually diminishes.

2. The woman: the physical aspects of sexuality.

The female sex organs. (+ drawing)

The external female sex organs are the mount of Venus, the major and minor labia, the clitoris. The clitoris lies above the vulva (external female sex organs) and consists of a shaft and a top (glans). This glans is covered by a fold of skin which is attached to the minor labia (preputium).

The female internal sex organs are the vagina, the neck of the womb (cervix), the womb (uterus), the Fallopian tubes and the ovaries. The vagina is a long crevice with very elastic walls. The neck of the womb lies deep and high in the vagina and forms the connection between the vagina and the womb, which in turn is connected to the Fallopian tubes and the ovaries.

Physical reactions during sexual activity in the woman.

During sexual excitement the breasts swell, the nipples harden and there is an increase in muscle tension, the skin is flushed red (sexual flush) and the respiration and heart rate increase in frequency. The most noticeable reaction to excitement in the woman, however, is swelling of the labia and moistening of the vagina.

The vagina becomes moist due to an increase in the blood supply to the walls of the vagina, which causes secretion of mucus. This mucus is important as it allows the penis to glide more smoothly into the vagina. It is like a natural lubricant. The increased blood supply causes swelling of the major labia, so that they move slightly apart, and a dark red colouring of the minor labia. The clitoris also becomes larger and firmer. The vagina becomes deeper and wider. As with the man, after persistent and appropriate stimulation of the vagina and in particular the clitoris an orgasm is may be achieved. The orgasmic feeling of the woman begins with the contractions of the muscles in the foremost part of the vagina and may surge out over the rest of the body. Immediately after the orgasm the muscle contraction diminished and the heart rate and respiration return to normal.

3. The sexual response cycle. (+ text diagram)

Although men and women look physically very different, it has been possible to show by research that the physiological basis of the sexual reaction of men and women shows many similarities (physiology = the study of the way organs work). So although the outside looks very different, the process which takes place on the inside is very similar. It has been noticed that the sexual reaction of men and women is divided into different phases, which can be clearly differentiated.

One can differentiate between the wish to make love (libido, desire), excitement (outward signs: erection in the man, vagina becoming moist in the woman), orgasm (with ejaculation in the man) and relaxation. Each of these phases is characterised by specific physical changes and psychological experiences, which with sufficient stimulation increase in intensity, and which if the stimulation is reduced or stopped may be reduced or even disappear.

When someone has a sexual problem, those giving help usually try to find out in which specific phase this disturbance occurs. We speak of disturbed libido (no desire to make love, too little or too much desire), excitement disturbances (erection problems or problems with the vagina becoming moist), problems with orgasm (too early, too late or not coming at all), pain during love making (dyspareunia) and vaginismus (spasm of the outer part of the vagina so that penetration is not possible, the penis cannot come into the vagina). It is clear that a defect of one or more phases will always have important consequences for the sexual function and for the overall enjoyment of sexuality.

This sexual response cycle is made up of essentially physical, physiological reactions, which are accompanied by the accumulation of blood (vasocongestion), muscle tension and contractions (myotonia). Thus is it immediately clear that the sexual reaction is based on various physical processes upon which the hormones and the nervous system have an important effect.

4. The importance of the nervous system (the brain and spinal cord) to the sexual function. (+ schematic presentation of the spinal column giving the names of the different segments).

Everything that human beings do or don't do is under the control of the central nervous system. The central nervous system consists of the brain and the spinal cord. The spinal cord consists of two kinds of nerve paths. Firstly there are the downward paths which bring the nerve stimuli from the brain to the various parts of the body, and among other tasks conduct our movements. Secondly there are the upward sensory paths which send all the sensory stimuli from the various parts of the body to the brain. The spinal cord is divided into various segments by analogy with the spinal column. The location of paralysis resulting from a spinal cord injury is given by indicating the lowest intact level of the vertebral column. We speak of neck or cervical injuries (C1 to C8), thoracic or dorsal injuries (T1 to T12), lumbar injuries (L1 to L5) and sacral injuries (S1 to S5). The location of the injury is then indicated both as regards the level of the injury for the motor nerve paths and that for the sensory nerve paths.

There are two important nerve centres for the sexual functioning of both men and women. In the brain there are a number of important centres which process sexually coloured information and send these via spinal cord signals to the sex organs. The nerve supply to our sex organs is controlled via two important levels in the spinal cord, these are T11-L2 and S2-S4. The sexual drive systems, which are located respectively in the brain and in the spinal column, are as it were systems which supplement and intensify each other, and can bring our sex organs into action on the basis of two important mechanisms.

As already described above, we speak of psychogenic stimulation when our brains, while processing sexually stimulating thoughts (fantasies), send images or sound signals which give rise to physical excitement reactions. We speak of reflexogenic stimulation when these sexual excitement reactions are caused by touching and stimulating our sex organs or the area around them. These are in essence two important systems of sexual stimulation. In the first case the stimulation takes place in the brain, from where the signals are sent via the spinal column to the sex organs. In the second place the stimulation travels from the sex organs and goes via the spinal column back to the sex organs. Such a stimulation is similar to a reflex arc, which after a tap with a reflex hammer on the knee tendon, makes the lower leg shoot outwards.

(Schematic presentation of the psychogenic and reflexogenic erection).

Chapter 2: the effect of a spinal cord injury on the sexual function

1. Level and severity of the spinal cord injury

Based on the description of the manner in which the brain and the spinal cord are responsible for control of the sex organs, we will now discuss in more detail the consequences of a spinal cord injury upon the sexual function.

The spinal cord has a function in the transport of signals or messages to and from the brain. A spinal cord injury leads to partial or complete interruption of the connection between the brain and the organs and muscles and for these various bodily functions. A spinal cord injury is described on the basis of the lowest intact spinal cord level. The location of the injury and the

nature of the spinal cord injury (complete or incomplete) are thus of great significance to the loss of function. The severity and the nature of the consequences for the action upon the sex organs depends on the location and the nature of the injury. The realisation or enjoyment of sexual stimulation and the feeling of orgasm are not determined by the motor level of the injury but they are determined by whether or not the rising sensory nerve paths in the spinal are intact. In order to present this even more specifically, the particular influence of a spinal cord injury for men and women is described separately below.

2. The influence of a spinal cord injury on the sexual function of a man.

As already stated the most important sexual reactions in the man are: erection, ejaculation and orgasm. For this reason we will discuss what the influence of a spinal cord injury may be on each of these phases.

Erection : (+ text diagram)

An erection occurs due to a simultaneous increase in the blood supply to, and a reduction in the blood flow from, the cavernous and spongy bodies of the penis under the influence of psychogenic and/or reflexogenic stimuli (see above). For psychogenic stimulation, in particular segments T11 to L2 are of importance. For reflexogenic stimulation, in particular e segments S2 to S4 are of importance.

A spinal cord injury may lead to three different situations, with the result that failure of a reflexogenic or psychogenic erection may occur independently.

- When there is an injury above segment T10 the flow of information between the brain and the sex organs is interrupted above the centre which is responsible for the sexual reaction based on psychogenic stimulation. Erections based on psychogenic reactions are then in principle ruled out. In the case of an incomplete injury it is possible that the messages can still pass the damaged part of the spinal cord, so that a psychogenic erection is still possible. The nature and extent of the incomplete injury will determined what is and is not possible.
- When there is an injury between L3 and S1 then in principle both psychogenic and reflexogenic erections are possible. The nerve centre in the spinal cord which is important for psychogenic stimulation (T11-L2) remains in connection with the brain, the centre for reflexogenic stimulus (S2-S4) does not need this connection. Reflexogenic erections are not, after all, dependent on information from the brain. On the basis of stimulation of the sex organs or the area around them, information is passed to the spinal cord, which provides an erection via a reflex arc, thus without interaction with the brain.
- When there is a complete injury in segments S2 to S4 reflexogenic erections are no longer possible; psychogenic erections are possible in theory after such injuries, but are rather rare.

For each of these situations the quality of the erections may differ from those that one had before the injury; generally the quality of the erections is reduced both as regards stiffness and duration. Reflexogenic erections may trigger autonomic dysreflexia, chiefly in some men with high injuries (above T6). Autonomic dysreflexia is a reaction of the autonomous nervous system, chiefly to stimuli from the paralysed part of the body resulting in a severe increase in blood pressure, which may result in transitory cardiac arrhythmias, headache, sweating, nausea, tendency to vomit, etc. It is also important to the prevention of erectile dysfunction in someone with a spinal cord injury, not to forget that other reasons may give rise to erectile dysfunction (e.g. hardening of the arteries because of cholesterol and/or smoking; certain medication; stress; depression; fear of failing;

reduced libido). It is therefore important with any erectile dysfunction after a spinal cord injury, to always discuss this with a rehabilitation doctor or a urologist.

Ejaculation

Ejaculation is a motor function based on muscle contractions (see above) and dependent on nerve stimuli from segments T11 to L2 and S2 to S4. If there is an injury in these segments, the ability to ejaculate is generally affected.

Ejaculation itself is preceded by a phase of seminal congestion (see above) which in normal sensitivity is experienced as very stimulating. It is a phase of highly accumulated stimulation in the dorsal spinal cord region from which the ejaculation is put into operation.

Ejaculation requires an intact nerve supply to the base of the pelvis, seminal vesicles and prostate, which means that ejaculation may be affected by spinal cord injuries. Even if the ejaculation happens, for this reason the semen may not be expelled to the outside. Practice has shown that there are men who ejaculate their semen into the bladder (retrograde ejaculation). Ejaculation into the bladder occurs because the innermost sphincter muscle, which ensures that the semen does not go into the bladder, no longer closes completely. In men with a spinal cord injury, however, the cause is often not reduced function of this internal sphincter muscle; a spastic outer sphincter muscle is generally the reason why the semen is no longer driven outwards. The semen then takes the path of least resistance and that is towards the bladder. The fact the semen gets into the bladder is not a problem in itself, since at the next subsequent emptying of the bladder the semen will be passed. The urine is then rather cloudy. This situation only causes problems when there is a question regarding fertility (see below).

Whether there is an orgasmic feeling during ejaculation does not depend entirely on the patency of the sensory nerve paths of the spinal cord. An orgasmic feeling is observed in the brain and thus depends on the patency of the rising nerve paths. A normal orgasmic feeling is generally not present, or is less intense. Some men with a complete spinal cord injury nevertheless report the occurrence of an experience of pleasure, which is in itself felt to be positive, but which is usually different from a normal orgasm.

Especially in men with injuries high on the spinal cord, there may be dry ejaculation accompanied by the uncomfortable consequences of autonomic dysreflexia.

3. The influence of a spinal cord injury on the sexual function of the woman (+ text diagram).
As stated the most important sexual reactions in the woman are: secretion of vaginal fluid and orgasm. For this reason we will discuss what the influence of a spinal cord injury may be on each of these reactions.

Vaginal secretions.

Due to an increase in the blood supply to the vaginal walls, a process is started of mucus secretion into the vagina and of swelling of the major and minor labia and the clitoris. These physical excitement reactions are, just as in the man, under the influence of psychogenic and reflexogenic stimulation (see above). Here too, segments T11 to L2 are of particular importance in psychogenic stimulation, and S2 to S4 in reflexogenic stimulation. A spinal cord injury may give rise to three different situations, with the result that a reflexogenic or psychogenic swelling and secretion of fluid may occur independently.

- If there is a complete injury above segment T10, the flow of information between the brain and the sex organs is interrupted above the centre which is responsible for sexual reactions based on psychogenic stimulation. Vaginal excitement reactions on a psychogenic basis are then ruled out in principle. In the case of an incomplete injury it is possible that the messages can pass the damaged part of the spinal cord, so that a psychogenic excitement reaction is still possible.
- If there is an injury between L3 and S1, in principle both psychogenic and reflexogenic excitement reactions are possible. The nerve centre in the spinal cord which is important to psychogenic stimulus (T11-L2) remains in contact with the brain, the centre for reflexogenic stimulation does not need this connection. Reflexogenic fluid secretion is not dependent on information from the brain. As the result of stimulation from the sex organs or the area around them, information is passed to the spinal cord, which via a reflex arc, that is without mediation from the brain, produces an excitement reaction.
- If there is a complete injury in segments S2 to S4, no reflexogenic excitement reactions are possible, but psychogenic reactions are still possible.

For each of these situations, that the quality of the swelling and secretion reflex may differ from that before the injury. In the woman too, as in the man, other factors may play a role in the ability to be stimulated and the excitement reaction. Consultation with a rehabilitation doctor or gynaecologist is therefore still indicated.

Orgasm and the experience of pleasure

In a woman an orgasm occurs because of contractions of the pelvic floor muscles, the neck of the womb, the womb and the Fallopian tubes, contractions may also surge to other parts of the body (see above) and are dependent on nerve stimuli coming from segments T11 to L2 and S2 to S4. An orgasm occurs because of an explosive and rhythmic contraction of the pelvic floor muscles and as the result of a neurological discharge at the spinal column. The experience of an orgasm can only occur if the emotional stimuli of the external sex organs can be sent to the brain. Here too, the location and the nature of the spinal cord injury (complete or incomplete) determines the possibility of experiencing an orgasm.

Many people with a spinal cord injury, even those with a complete injury, nevertheless report that they too have orgasmic experiences, or experiences which are greatly similar. This is possible because an orgasm occurs in the brain. These orgasmic experiences may be triggered in many people with a spinal cord injury due to stimulation of sexually sensitive parts of the body (erogenous zones) other than the sex organs, such as for example the breasts or lips. This can be explained by the fact that above the level of the spinal cord injury there may be changed sensitivity of the skin so that other parts of the body become more sensitive to sexual stimulation (ears, neck etc.).

4. Men and women: are the problems the same as regards sexuality after a spinal cord injury?

This survey clearly shows that although the reproductive organs of men and women are very different, the nerve supply to the sex organs and the sexual reactions of men and women exhibit great similarities. Sexuality, however, is a domain to which much more is contributing than physiology alone. These physiological reactions are experienced in a certain manner, and the meaning that the enjoyment of sexuality has, is often different for men and women. These

differences are also often found between individual men and women, however. For every man and woman sexuality obtains its own importance and in his or her own life, a meaning which can change in the course of his or her own development. The consequences of a spinal cord injury upon the sexual possibilities are often of such a kind that a certain redefinition and different enjoyment of sexuality will develop.

Chapter 3 : The enjoyment of sexuality in general

In the second half of the last century there was a change in our thinking and behaviour as regards sexuality. This 'sexual revolution' has made a great difference to the way we deal with sexuality.

Sexuality was freed from the atmosphere of taboo under the pretext of 'free love', and was given a positive meaning: 'sexuality is something you can choose and something you can enjoy'. The forbidding atmosphere 'nothing permitted and nothing possible', made way for a new, almost equally oppressive attitude: 'everything is possible, and what is more, obligatory'. The consequences of this in daily life are clear. Sexuality is present always and everywhere. On advertisement hoardings washing powders, cars and clothing are acclaimed with a touch of nudity. In the media we are beaten about the ears with sexual stimuli and messages. Sexuality has emerged from the darkness of the marriage bed and now stands central to the media. Sexuality, however, has not just become more present in the media, but in a specific manner. It is not the value of sexuality as the sign and symbol of a relationship, or the meaning of sexuality for reproduction which is being demonstrated. The image of sexuality is often severely distorted and limited. We are setting up a number of misconceptions and myths here.

- In speaking about it, sexuality is often limited to sexual intercourse. This is too narrow a vision of sexuality, by which one could forget that cuddling, horseplay, warmth and offering comfort, provocation, caressing, are just as much at home in the healthy sexual repertoire.
- One often hears that a 'healthy couple' have intercourse on average 2 to 3 times a week. These figures are misleading, however, as this is a statistical average. In other words, this figure is the average which you get if you ask a very large number of couples with a very varied frequency of sexual activity. This general average may thus be impossibly regulating for a particular couple. The frequency of sexual activity is furthermore very variable within the sexual history of each couple.
- The presentation of sexuality in the media also gives the impression that sexuality is only an activity for young, healthy people with smooth, tanned bodies, who are lithe enough to stimulate each other sexually in acrobatic positions, in which they together reach an unknown sexual high point. Practice tells us, however, that this is not a representative picture of the experience of sexuality of the average man and woman.
- That in a good relationship the sex comes of itself, and that there is no need to talk about it, is a fourth misunderstanding. Generally we enter a relationship with someone for which we have the feeling that with him or her we click. Although people may get on well as regards sexuality, they still cannot read one another's thoughts. If you want the other to do or not do something, you have to ask for it, or say it.
- That the man is the one who should take the initiative as regards sexuality, is something that is also often heard. Although it is still the accepted male role, men also enjoy it if a woman lets them know that she also wants something in the way of sexuality. If the man and the woman in a relationship admit to their own wishes and feelings, there is a great chance that in the relationship each will meet the other's personal needs.

- The statement that coming at the same time is the high point of luck and happiness, has also led to a number of fruitless discussions. Trying to 'come at the same time' is only one possibility of enjoying sexuality. It presupposes that you know well how quickly the other becomes excited and comes, and that you can take account of that in the way you make love and in your own enjoyment. It is the case with most couples that one comes before the other. If the one who comes first does not leave the other in the lurch, there is still no problem, or is there?

Sexuality: A realistic presentation of the way things are

The picture of sexuality and the enjoyment of sexuality which is put over in the media, does not altogether tally with the meaning that people ascribe to sexuality. Sexuality in humans has a rich and varied meaning, which is not just limited to experiencing pleasure. Sexuality does have a lust or pleasure function, but it also has a natural meaning to the extent that sexuality is responsible for the continuation of the human species. Sexuality also has a meaning within a relationship as an expression of being glad to be together. The meaning that sexuality obtains in a person's life, is produced in the course of their relational and sexual history.

As every human being has their own life story, so everyone has their own personal sexual history.

Our sexual history grows in the course of our lives and is about different aspects of our life. Each human being has their own ideas and experiences at the sexual level through which they learn to recognise their own longings and possibilities. One gains experience in relationships with others. One learns to communicate about feeling and desires. The extent to which one learns how to make social contacts, build relationships, to like ones own body and enjoy it, forms an important basis for the enjoyment of sexuality.

If two people meet each other, they have the task before them of bringing together their personal sexual histories in a further or new sexual history of the couple. When looked at in this way, sexuality is not so self-evident: it presupposes that we know ourselves well, that we are open to the sexual history of the other partner and that we are capable of integrating well into a common sexual history. This presupposes that sexuality is based on being able to feel good, to be sensitive and able to communicate this well. When one or both partners have some sexual dysfunction, it will perhaps take a bit more trouble to find one another sexually.

Chapter 4: The enjoyment of sexuality in men with a spinal cord injury

Every man and woman is a sexual being who may or may not lead an active, or very active, sexual life. For men and women with a spinal cord injury this is just the same, they too are sexual beings with their own sexual desires, wishes, needs and possibilities. The desire for sexuality is not affected by a spinal cord injury. The first step in seeking a solution to the sexual problems which accompany a spinal cord injury, is the basic assumption by which one starts with what is still possible in spite of the paralysis. This assumption is more positive than continuing to concentrate on the limitations which one has due to a spinal cord injury.

In this respect it is important to differentiate between people who are and are not already sexually active before they suffer the spinal cord injury. Young people who were not yet sexually active before the injury, are faced with the challenge of building a sexual identity in which they immediately have to take account of the consequences of the injury. In other words they learn to deal directly with the possibilities that they have at the sexual level in spite of the limitations which the injury imposes. They have never been able to experience it otherwise and must build

up their sexual history from the beginning. That is clearly different from people who were already sexually active before the injury. They have already had experience with their own bodies and that of present or past partners, and know where they are sexually. For many people spinal cord injury overturns this certainty which has been built up, or is in process of being built up. You no longer know what you can do sexually, and it is also difficult to imagine a different enjoyment of sexuality than what one knew before. Many doubt their own sexual identity, and ask questions about their sexual future.

There is a sexual future for every man and woman with a spinal cord injury. Just as with the other problems that one has after suffering a spinal cord injury, sexual problems also require to be 'rehabilitated'. Just as one needs all kinds of information, knowledge, training and experience concerning the physical possibilities after a spinal cord injury (including posture, changing position, the use of wheel chairs, etc.) one also needs these as regards sexual function. Sexuality is also typically a field in which knowledge and insight are not sufficient. One must actively seek for solutions, for ways of giving form to a new, different experience of sexuality.

A number of functions of the body (including hormones, blood vessels, nerves, muscle activities) play a part in the sexual function of a human being. A disturbance in one or more of these functions may have very negative consequences for sexuality (see above). Luckily human beings have exceptional capabilities for adjustment. One example of this is the wheel chair patient who, in spite of the fact that he has lost the function of the lower half of his body, succeeds in gaining a new and valued place in society. This clearly shows that the loss of a physical function does not necessarily have to result in a permanent condition of immobility. The comparison with the sexual function is obvious. The loss of certain aspects of the sexual function does not have to mean the complete loss of all forms of sexual enjoyment. A striking example of this is that some patients are still able to experience an orgasm even in the absence of any feeling in the vagina or penis (see above). This is perhaps at first sight unusual, but earlier in the text we have already pointed out that the experience of sexuality is not just based on strictly physical observations, but that what is going on in the head certainly also plays an important part.

Chapter 5: Rehabilitation and sexuality after spinal cord injury

1. Rehabilitation (revaluation) of the enjoyment of sexuality

A spinal cord injury forces a person and/or couple to learn to deal with their sexual life with a changed locomotor system and with absent or changed skin and muscle sensitivity. A number of functions of the familiar body refuse to work, and the present physical image, with which one may or may not be satisfied, now has to be built up anew. This newly built up physical image is important to be able to enjoy physical contact once more, and again experience enjoyment in love making. The basis of relearning well how to deal with sexuality and the experience of pleasure thus has to do with learning how to deal with one's handicap, how to cope with the lost past, how to learn to value again the handicapped body which one has to train as an instrument of physical contact and the experience of pleasure.

We may call it a devaluation of one form, and a rehabilitation (revaluation) of other forms of enjoyment of sexuality.

It has already been demonstrated that serious changes occur in the sexual reaction of men and women with a spinal cord injury. The sex organs do not always react as they used to and this

requires adjustment. One important step in this adjustment is being able to let go of the way of enjoying sexuality that one was used to and to seek out again, and try out, what is possible. What can help in this search is the conviction that the whole of one's skin surface, with which we come into contact with others, is in fact one sexual organ in which one can experience pleasure to a greater or lesser degree (see above). The experience of pleasure during love making is much more than just enjoying an orgasm. Some people also speak of a "partial experience of pleasure" in which the person with a spinal cord injury experiences sufficient satisfaction during love making, in enjoyment of the pleasure of his or her partner. People who make love with the object of reaching an orgasm quickly, leave unused many of the possibilities of experiencing a more extensive physical and mental pleasure.

Practice has taught us that this adjustment does not always run smoothly for men and women. Differences in adjustment between men and women are not always concerned with the spinal cord injury itself, however, but are related to the differences in sexual enjoyment between men and women. Men are simply more often genitally orientated, often have a greater 'drive to achieve' at the sexual level and their sexuality is often rather more narrowly aimed at the physical. Women are by nature more in tune with a broad spectrum of the enjoyment of sexuality. This means that the enjoyment of sexuality of men is in a certain sense more vulnerable if there is a disturbance of the sexual function.

This perhaps also explains why more time and thought is usually devoted to discussing the sexual function in men with a spinal cord injury, than in women. Women with a spinal cord injury nevertheless also have the task of learning how to deal with their changed physical image, skin sensitivity, muscle control and experience of enjoyment. Women with a spinal cord injury thus have no fewer problems than men. The differences in the enjoyment of sexuality do mean, however, that the stimulation problems of men and women have a different impact. In the case of sexual intercourse an erection problem is often a big problem at the instrumental level since sexual intercourse is not so easily possible without a sufficiently long and firm erection. The aids available to help men obtain an erection are also much more drastic than those necessary to compensate for any reduction in vaginal secretion.

2. Aids

Under the influence of the changes which have occurred in our thinking and behaviour about sexuality, more and more people with a sexual problem now consult various helpers. This has led to various aids coming onto the market for dealing with sexual problems experienced by men and women. We will discuss these below briefly.

It is important to remember two things regarding these aids. The first is that these aids have as their objective to give the chance of having sexual intercourse in the familiar way. Most aids are aimed at helping with erection problems, so that the focus is again narrowed to sexual intercourse.

A second thing to remember is that the use of an aid should be discussed with the partner so that it will be successful, and so that it will earn a place in the sex life of the couple.

– Aids for erection problems

There are a number of aids available which one can use to obtain an erection. Which aid is most suitable, depends on one's own preference but also on possible medical contra-indications. It is

always very important in the choice and the use of aids to consult a rehabilitation doctor or urologist with experience in the treatment of sexual problems in people with a spinal cord injury. Below we will discuss a number of frequently used methods, namely the stuffing method, the vibrator, binding devices, injection therapy, Muse[®], oral medication, the vacuum pump and the penile prosthesis.

The stuffing method.

The stuffing method refers to a method by which the limp or only half-firm penis is placed in the vagina by hand. The woman takes the penis into the vagina by using the pelvic floor muscles and the muscles in the vagina, in a kind of drawing, sucking movement. In particular men with a reflexogenic erection can maintain their erection better by this method. The woman herself can learn to have more control over her pelvic floor muscles by training these using the Kegel exercises, in which she exercises the muscles which are also contracted to suppress the need to urinate.

Binding devices (+ drawing)

Men who have less problem with obtaining an erection, but do have problems with maintaining it, can often be helped by using binding devices. A rubber or silicone ring with the appropriate tension is placed over the base of the penis after erection and keeps the blood in the cavernous bodies; this maintains the swelling in the penis, if this does not remain erect. One does have to take necessary precautions not to damage the skin, and not to use the aid for longer than 30 minutes. The binding action may cause some oedema and progressive reduction of the skin temperature. The binding only keeps the penis stiff and not that part of the cavernous body which is attached below the pubis. This gives the impression of a less stable, rather 'wobbly' penis. Better protection of the skin of the penis can be achieved by use of a suitable lubricant.

The vibrator (+ drawing)

The vibrator is an elegant solution for persons who need a stronger stimulus in order to obtain a good erection.

By this we do not mean a vibrator in the form of a penis model but a small apparatus which is used by the physiotherapist for all kinds of purposes and has an optimal vibration frequency. The aid is simple to add to foreplay and may also be used by the partner.

Injection therapy (+ drawing)

Intracavernous injections (injections into the cavernous body) are a frequently used treatment for erectile dysfunction. Just as someone with diabetes can learn to inject themselves, the person learns to inject their own cavernous bodies with a chemical substance. Usually this technique leads to strong erections which may last for one to two hours, and this also makes it possible to carry out the injection in all discretion prior to the beginning of foreplay. It is important to make these injections with the correct amount according to the doctor's prescription, so that the erection does not last too long (priapism), which may result in tissue damage to the penis and even in permanent impotence. In prolonged erections (more than four hours) urgent medical assistance must be sought, and this prolonged erection can be counteracted by injecting an 'antidote'. A persistent erection becomes very painful in the long term, but people with loss of feeling in the penis will sometimes not be aware of this; some precision concerning the duration of the erection is thus advised when using injection therapy.

Muse®

Muse® stands for 'Medicated Urethral System Erection'. For this a suppository is placed in the urethra which contains a medicament (alprostadil) which may also be used in injection therapy.

This medicament relaxes the blood vessels and causes a supply of blood to the penis. There are still some side effects with this method, such as a risk of infection, hypotension and fainting fits. (NB: Muse® is not available in Belgium)

Oral medication (+ photo of blue tablet)

An important breakthrough in the treatment of erectile dysfunction is the use of Viagra® (sildenafil). Each time a pill is taken, after 30 minutes to one hour and after some stimulation, there is an erection. Viagra® works very well in persons with a spinal cord injury especially if they can have erections, but when for example these are unreliable or insufficiently maintained. The scientific pack leaflet for this medicine reports on clinical trials which have showed success percentages of 83 %. Viagra® is well tolerated by patients who do not use nitrates, and who can make the efforts related to sexual activity. Use is contra-indicated in men whose blood pressure is too high or too low, or those with certain cardiovascular disorders. Medical advice is necessary. Viagra® has in a short time become one of the preferred treatments for erectile dysfunction after spinal cord injury. New oral medications are in development.

The vacuum pump (+ drawing)

The vacuum pump is a mechanical aid with which most men can obtain a sufficiently strong erection. The vacuum pump works as follows. The pump is placed around the penis for a few minutes and a vacuum is created, which causes a swelling and stiffness which can then be maintained by placing a ring on the base of the penis. Once the penis is "in erection" the method is then comparable to the use of the elastic binding device (see above). There are both hand-operated and electric models.

Surgery (+ drawing of semi-rigid prosthesis and three-part prosthesis)

Surgery in erection problems consists chiefly of bridging the obstructed blood vessels and inserting an erection prosthesis. Bridging is only sensible in rather younger men with narrowing of the blood vessel, and is only indicated in exceptional cases.

As regards the implantation of penis prostheses we can report on the existence of various kinds of prosthesis including the semi-rigid prosthesis and inflatable prostheses. Inflatable prostheses are available as a system with one, two or three parts, depending on the pump mechanism. Inflatable prostheses all work according to the principle that a fluid can be pumped into or out of the cylinders of the prosthesis.

During implantation of a penile prosthesis the cylinders are implanted in the surgically opened and extended cavernous bodies of the penis.

Penile prostheses carry a high risk of infection of the prosthesis in persons with chronic urinary infections. If something goes wrong with the prosthesis due to infection, rejection or misplacement, injury may occur due to the absence of sensitivity of the penis. The penile prosthesis is certainly not a treatment of first choice.

– Aids for problems with vaginal secretions

Ejection problems in the man form a more severe hindrance to having sexual intercourse than problems with vaginal secretions in the woman.

If the reflex vaginal fluid secretion during excitement is disturbed in a woman with spinal cord injury, a lubricant should be used which is available in any pharmacy. The lubricant not only ensures that her partner can slide his penis in easily, it also has the advantage that during penetration and movement the penis does not irritate the vaginal wall.

3. Precautions during love making

Sexuality is an activity which is best enjoyed in an unhurried atmosphere, where one feels relaxed and without any worries. Certainly if one has not had much sexual experience, after a spinal cord injury all kinds of things can easily go wrong. Control of the bladder function, bowel function, spasticity, limitation of movement and pain are factors which sometimes cause problems and can disturb the sexual life.

In this respect it is best for persons with a spinal cord injury to take measures before love making in order not to encounter too many 'surprises' during love making.

For the most part it is best to begin with an empty bladder, but each individual must find out how their bladder and bowel behaves during love making.

Sexuality also has a lot to do with lust, longing and attractiveness. Luckily there are no general norms for these, but a groomed, pleasant-smelling skin is always important and stimulating. Urinary incontinence, sweating and poor skin ventilation due to urine being present for a long time, are things we can certainly do without. In brief, good skin hygiene is always beneficial and prevents bed sores as well as promoting attractiveness. We must also not forget that cushions which have not been washed for a long time, do not exactly act as a deodorant.

Transfers from wheelchair to bed and undressing may also be difficult in themselves, but with a bit of fantasy this can become part of the foreplay. These additional difficulties do not amount to much after some experience and familiarisation, so that the sexual and relational aspects of love making can again play the main part, and that is what is essential.

4. Positions

The paralysis in itself has important consequences for mobility and balance. Just as this is reflected in the activities of daily living, it will reflect on sexual activities. Patients with a spinal cord injury thus also ask themselves a lot of questions 'what in fact can I still do with this paralysed body?'

For a couple one or both of whom have a significant physical handicap it is often a case of seeking and trying out the easiest positions to make love. Some positions require more active movement and caressing, other positions will require more passive enjoyment. There are endless positions possible in which one can enjoy sexuality. In the end, you will have to search out with your partner which is the most pleasant for both of you.

Making the best of the overall functional possibilities and the general condition, also applies as regards the sexual possibilities.

What is and is not possible is a matter for each couple. Apart from the physical possibilities, personal convictions, relational possibilities and limitations as well as ethical considerations will also be determining factors here. Sexuality is and remains a very personal story. Yet we should like to make all this clear with pictorial information which four persons with a complete spinal cord injury have made available (complete motor injuries at levels C4, C7, T3 and T7). Pictures can often say it more clearly than a thousand words.

This brochure does not include any illustrative material of lesbian or homosexual couples in which one of the partners has a spinal cord injury. Nor has any use been made of illustrative material of couples of which both couples are handicapped, or of persons with an incomplete paralysis. The illustrative material is limited to four frequently occurring and typical cases. Nor is there material showing elderly persons with a spinal cord injury, although we do not in any way wish to give the impression that the enjoyment of sexuality only has a place in the lives of young people. Additional illustrative material would certainly be beneficial.

The illustrative material in this brochure is furthermore only a limited example of what is possible in the relationship of these people. It must certainly not be regarded as a norm for the enjoyment of sexuality for people with a spinal cord injury. It will, however, be proof that often much is possible and in this sense it may also be inspiring.

Chapter 6: Fertility and pregnancy

Fertility and reproductive techniques for the man with a spinal cord injury.

Obtaining a semen specimen (+ text diagram)

The possible influence of a spinal cord injury on ejaculation has already been described above (Chapter 2). Research has shown that only 3 to 20% of men with a spinal cord injury are able to have a reflexogenic ejaculation due to local stimulation (masturbation or by partner) and this without the use of an additional aid. If a man has questions concerning fertility and the possibility of begetting children, first of all the usual methods should be tried. If a spontaneous ejaculation appears impossible, however, there are at present various aids available.

In the first instance one can try to stimulate an ejaculation using a vibrator. Massage with a vibrator to the glans leads to ejaculation in 60 to 85% of men with a spinal cord injury. This treatment is not painful but it may trigger spasms. In patients with autonomic dysreflexia (i.e. an uncontrolled increase in the blood pressure which occurs in men with an injury higher than T6) medication may possibly be administered beforehand. The possibility of retrograde ejaculation in men with a spinal cord injury (in which the semen is ejaculated into the bladder) has already been mentioned. This means that if when using this vibrator technique no visible ejaculation occurs, it is best to check the bladder also after the session.

If no semen can be obtained by this method, the electro-ejaculation technique may be tried. A probe with electrodes is inserted via the anus into the lowermost part of the intestine (the rectum) and an electrical current is applied. This direct electrical stimulation leads to an ejaculation in 80 to 95% of patients, either to the outside or into the bladder. This means that here too, after the session the urine must always be checked also. This procedure may be painful in men with an incomplete injury, or with a very low injury, where the sensitivity in this region is retained. This

method may be carried out under short-term anaesthesia (5 to 10 minutes). Here too, with this method spasms may be triggered and to prevent autonomic dysreflexia the blood pressure must be monitored in men with an injury higher than T6.

In the third instance one can make use of microsurgical techniques. For this method a surgeon uses a small needle with which he aspirates the sperm directly from the seminal duct, the epididymis or the testis. If necessary a piece of testicular tissue is taken (biopsy) for further investigations. If semen is obtained in this way, this is examined under a microscope to ensure that there are sperm in the semen which can be used to fertilise an ovum.

The quality of the sperm

However a semen specimen is obtained, the quality will be reduced in comparison with that from a man without a spinal cord injury. Generally the volume is reduced to 0.5 to 2 ml (normal: 2 to 4 ml). The number of sperm per ml (concentration) is also often lower. The greatest problem, however, is the motility of the sperm, which in men with a spinal cord injury is on average only 10 to 30% (normal: > 60%) .

The cause of the quality of sperm which one obtains from men with a spinal cord injury, is not yet known. Perhaps there are various factors which play a part here. Since it has been observed that with repeated ejaculations the quality of the sperm sometimes improves, it may be assumed that stasis (accumulation) of the semen in the genital organs does not promote quality. Also urinary infections, certainly if these extend to the prostate, epididymis or testes, may affect the quality of the sperm. Certain antibiotics (nitrofuranes) which are used for these can also have a negative effect on the production of sperm in the testes (spermatogenesis). The manner of emptying the bladder obviously also plays a part. It has been observed that the sperm is generally better from persons with intermittent catheterisation, than from persons with an indwelling catheter or persons who urinate under high pressure (tapotement or abdominal pressure). Nor can it be ruled out that hormonal, vascular or neurogenic factors also play a part, but this has not yet been confirmed by research.

Reproductive techniques (+ text diagram)

If investigation shows that a usable semen specimen has been obtained, it is always advisable to freeze this. It is advisable to have an investigation carried out of the quality of the sperm as soon as possible after the spinal cord injury occurs, and to freeze any usable specimen. This advice is certainly important for people who as yet do not want children, but who would not rule this out in the future. Then when a child is wanted, there are various possibilities.

Men who can achieve spontaneous ejaculation, can of course try to bring about pregnancy naturally. If this does not succeed, which is what generally happens, the couple are advised to have "medically assisted fertilisation", in which there is a difference between the two methods of artificial insemination (AI) and test-tube babies or in-vitro fertilisation (IVF)

In artificial insemination a gynaecologist introduces a semen specimen via a thin tube into the womb of the partner. Provided the partner has a regular cycle, couples of which the man can easily have an ejaculation by means of a vibrator can, after the necessary training, themselves introduce the semen into the vagina.

If the quality of the semen specimen is too poor, it is often better to go straight over to in-vitro fertilisation (IVF). For this the female partner receives hormonal stimulation, so that more than one ovum matures during a menstrual cycle (normally only one ovum in each cycle is sufficiently mature to become fertilised). The large number of ripe ova are then surgically removed from the

ovaries and brought together in the laboratory with the man's semen. If the ovum becomes fertilised, this can be implanted once more in the womb. If the fertilised ovum embeds in the womb, then you have a pregnancy.

In some men, however, there are too few sperm in the semen specimen, so that just putting the spermatozoa and the ova together will never lead to fertilisation. In these cases one can try ICSI (intracytoplasmic sperm injection). In this technique one sperm is introduced directly into the ovum in the laboratory. This technique, although it has been used for years, is still to a certain extent experimental.

If the fertility problem is so great that after repeated attempts no semen specimen has been obtained, or if no pregnancy can be obtained by means of the above techniques, or if the couple feel that IVF or the ICSI procedure are too drastic, there is also the possibility of artificial insemination with the semen of an (anonymous) donor (AID). In this, in a similar manner as for AI the semen from a donor is placed deep in the womb. For couples for which none of these techniques has brought a solution to the fertility problems, or for people who do not choose these drastic medical treatments, there is of course still the possibility of adoption.

It is important to note here that a good solution of the fertility problems of men with spinal cord injuries, not infrequently require psychological assistance for the couple who are confronted with this problem. However, thanks to the spectacular progress in fertility technology made in the last 5 to 10 years enormous progress has been made, so that the chances of having a child have greatly increased for men with a spinal cord injury.

Fertility and pregnancy in the woman with a spinal cord injury

Fertility and contraceptive aids

Many women will ask about the possibility of still being able to have children after suffering a spinal cord injury, because they notice that menstruation has stopped. This absence of a normal menstrual cycle lasts on average 3 to 5 months, after which fertility generally recovers to the position before the spinal cord injury. So it is important that women who are still fertile use a safe contraceptive aid when they again become sexually active. The choice of a safe method of contraception should be seriously considered in women with a spinal cord injury. When using the pill account must be taken of the condition of the cardiovascular system and the increased risk of thrombosis (blood clot in the veins). The coil increases the risk of infection and due to reduced sensitivity in this region a woman may lose her coil, or complications may not be recognised.

Pregnancy and points to consider

If there were no problems with fertility before the spinal cord injury, the woman with a spinal cord injury can generally become pregnant just as women without an injury. The medical supervision of the pregnancy does need to be more precise, since the chance of a number of complications is indeed increased. This supervision is best done by an obstetrician in consultation with the rehabilitation doctor and the GP. The most important points for considerations during the pregnancy are the prevention of development of blood clots (deep vein thrombosis), to be treated by injection of anticoagulant medication. Wearing support stockings and regularly raising of the legs is necessary in order to prevent blood clots in the legs. Due to the change in metabolism, reduced mobility and the increase in weight, there is also an increased risk of bedsores. The

increase in the volume of the womb can make difficulties both with the bladder and the bowel. Just as with other pregnant women, urinary incontinence and infections may also occur more frequently and the risk of constipation is also increased. So it is advisable to take sufficient fluid and fibre. Urinary tract infections with high fever may cause a miscarriage. Furthermore all medication which the pregnant woman may use must be considered as regards possible risks to the baby. Since autonomic dysreflexia (uncontrolled increase in blood pressure due to reflex in injuries higher than T6) involves a danger for the baby, this must be avoided at all times. If this nevertheless occurs it must be treated as swiftly as possible. For this reason weekly check-ups from about the 32nd week of the pregnancy are indicated.

As the pregnancy proceeds the dependency for carrying out the activities of daily living (ADL) may increase. It is not impossible that more help from third parties will then be needed.

The delivery

The course of the delivery depends on the level of the spinal cord injury. The nerve supply to the womb is situated at the level of T10 to T11-L1.

- In women with an injury higher than T10 the womb contractions and the movements of the foetus will often not be felt. Thus the labour may be missed and delivery may occur quite suddenly. What is more, the rupture of the membrane with loss of the amniotic fluid may sometimes be confused with urine loss.
- If the injury is located at the level T10-T11, artificial delivery is more often needed (e.g. forceps) or the choice may be made for a Caesarean section because there are not sufficient uterine contractions.

The greatest risk during delivery both for the mother and the child is again autonomic dysreflexia. In order to prevent this in women with a spinal cord injury higher than T6 it is best to administer epidural anaesthesia or hypotensive medication. At the time of delivery it is very important to avoid bedsores by good positioning, whether or not in combination with the use of a special mattress.

In the period after delivery the risk of bladder infections or blood clots remains high. Women with a spinal cord injury may confidently choose to breast feed, provided sufficient account is taken of any use of medication.

After the birth sometimes extra supervision of the mother is indicated. The dependency on third parties when caring for a child may cause psychological problems for a number of women. This occurs more often in women with a high spinal cord injury, who are limited in the movement of their arms and hands. It is therefore important to discuss this before and during the pregnancy, and to prepare well for it. However, this generally works quite well and having a child can be an important element of her life and that of her partner for the woman with a spinal cord injury.

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