Sexuality and Spinal Cord Injury
Heterosexual Women

moving forward after paralysis
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Introduction

You may be reading this booklet with little experience of sexual activity as yet or you may have the benefit of experience behind you. This booklet has been written in a frank, open manner and is therefore explicit. Much of the information contained has come from spinal cord injured women themselves.

The lack of up to date relevant information on sexual matters is a real problem. Often, it is the sharing of women's experiences which helps to dispel myths, stir thoughts and provide the opportunity to grow in self-determination and confidence.

'Sex is an intimate pleasure, don't be afraid to experiment and most of all, don't forget to keep your sense of humour.'

If you would like contact with another spinal cord injured woman to talk about any sexual concerns you have, SIA could put you in touch with someone. If it is difficult for you to do this personally at present because you are in hospital, living with family or in residential care, a friend or partner could contact us on your behalf or for some support and information themselves.

The very fact that you are reading this will mean that you are seeking knowledge and clarification about many aspects of sex. Take from it what is relevant to you and adapt it to suit your needs and wants. Whatever your situation, age or sexual experience, we hope that this booklet will inform, reassure and encourage you to enjoy a fulfilling sex life.

'Sex was never mentioned to me in the Spinal Unit - until I returned to the Unit after a weekend at home. I was asked by the charge nurse how I had got on - so I replied 'left leg first'! It slowly registered with him what I meant and his first concern was contraception (I was offered condoms -I accepted) and the second was orgasm. I was told I wouldn't experience one - WRONG! The bits in between like positions were not discussed. Actions speak louder than words and practice makes perfect. Don't avoid the pleasures by building barriers in your mind, especially those put there by someone else.'
Your sexual identity

You may have been thinking that your sexuality has changed considerably because of your spinal cord injury and that now you have to feel, think and act differently to how you did before. Your sexuality is part of who you are. It is also unique to you and what you do with it is still within your control (taking any changes in function and living circumstances into account) as it was before your injury. You may experience a great sense of loss - loss of ability and a loss of the taken-for-granted life before your injury - a loss for what was. The changes to your body and to the way you do things may make you feel inadequate, insecure and confused about yourself, people and things around you. It takes time, thought and support to acknowledge the fundamental changes which have taken place and it is certainly OK to feel the loss and regret and acknowledge that these feelings exists.

"It's not me - this person I see in the mirror - it's all so different to how it was before."

The process of adjusting to the changes in body shape and functioning as well as your own attitude to your sexuality can depend on how you viewed yourself before injury. Naturally, you will make comparisons between yourself before and after injury. Many women feel that they lose their sexual identity when they are newly injured, but with time (and often circumstance), a more positive view can grow and develop. You need to feel good about yourself before you can risk being sexual and facing the possibility of rejection. Your attitude to yourself and other people will affect your sexual behaviour generally. These attitudes are as important as physical capabilities or limitations. Approaching sex with an open mind, a sense of fun and a positive attitude can mean that you reap rewards.

"In some ways my stay in hospital made me overcome my inhibitions. I don't feel so prudish about my body now as I did before my injury."

The ability to be sexual contributes towards our self esteem. With the absence of positive disabled sexual role models or even imaginary ones, you may feel invisible. For many women, the ability to see themselves as valuable human beings is the first step towards gaining some self respect and self esteem. Feelings of isolation are very common and these feelings can hinder you from growing and developing more confidence in yourself. You will find that you are not alone. When disabled women have the opportunity to get together in a safe environment they have much to say about who they are and what they want. Yet in searching for literature, there is very little to be found about disabled women's sexuality.

"I couldn't possibly see how anyone could want me sexually and it took me a long time to accept that I was still an attractive, intelligent woman with a lot to give. I think my husband would vouch for that."

If your partner has been constant in your life before, during and since your injury, he will be aware of your daily physical needs, although do not assume that he will automatically know your emotional or sexual needs or what you are feeling and thinking. You may find that he treats you like a china doll when you first come
home and doesn't quite know how to approach sex with you in case he hurts you in some way. It may take some time for you to get used to changes in sensation and function and you may feel uncomfortable at first. Therefore you must learn to decide how you want to be touched and handled. It is also very important to remember that your sexuality doesn't change or disappear, it is still part of who you are and you are still the sexual person that you were before your injury.

Sexual function

Before injury

Some things will obviously be different for you physically, such as degree of sensation and mobility because of the damage to the nerves in the spinal cord. So what happens to the body during sexual arousal? (you will be amazed at how many people don't know!). Sexual function is not purely physical as it is affected by psychological and emotional factors. Sexual arousal is a result of a complex combination of signals which stimulate one or more of the body's senses, such as smelling certain odours, hearing specific sounds, viewing something which is sexually exciting, and touch, especially in the erogenous zones (neck, ears, lips, nipples and genital area). Your body may respond to sexual stimulation in many ways. Breathing becomes deeper and more rapid, your heart beats faster, your blood pressure and perspiration rates increase, your muscles tense, your breasts may swell and nipples become harder.

Once aroused, the vagina begins to excrete a lubricant and expands. The clitoris which is extremely sensitive fills with blood and swells during stimulation as do the lips of the vagina. As an orgasm or sexual satisfaction approaches, the clitoris withdraws from its normal position, the muscles in the walls of the vagina and the rectal area contract strongly and involuntarily in a pattern that gradually tapers off. Other muscles including those in the face may also tense when orgasm occurs. Afterwards, breathing, heart rate and blood pressure slowly return to normal.

After injury

Essentially, the processes your body goes through will not have been altered by your spinal cord injury. The increase in your blood pressure, perspiration, heart rate, swelling of your breasts and the reflexes of your muscles are also essentially the same. What has been affected is your ability to feel sensation in your genital area and other parts of your body depending on whether or not your injury is complete or incomplete. If your injury is complete, you probably will not feel an orgasm in the 'normal' way and this is because the stimulation of your clitoris is controlled by the nerves in the lowest part of the spinal cord from T12 to L2 and S2,3 and 4. If you are incomplete a degree of sensation will be possible. You may also notice a decrease in lubrication in your vagina as a result of the damaged nerves. Your body may compensate for this loss by making you extra sensitive in areas above the level of your injury. For many women, the loss of not being able to experience an orgasm as they did before is very significant. Being touched in certain places may feel very unpleasant until you get used to being touched in those areas. Your nipples may be almost too sensitive to touch at times.
'Orgasm - the most written about sex letter word. Not everyone has them, not everyone has multiple orgasms. The medical people might scoff and say you can't possibly experience the big 'O' - so how do they know? Who cares? It's what you enjoy and feel that's important. Sex is not going to be the same every time - sometimes fantastic and sometimes you might wish you had never started! That's OK. That's normal! Don't become obsessed with the national average figures - do it when you both want to do it.'

The other main difference is the loss of movement in the use of your pelvic and hip muscles which may alter your ability to move during sexual activity. Whilst the traditional intercourse positions (Missionary) may still be comfortable and satisfying, there is nothing stopping you from experimenting (backwards, forwards or sideways) to discover positions which enable you and your partner comfort, freedom and fulfilment.

'Having tried out many new techniques and positions, our love making is actually better than before.'

With your existing or newly found erogenous zones, you will still be able to experience a heightened degree of arousal or a type of orgasm that many women describe as being 'as good but different'.

'My orgasms are very different to those I had before my injury, but the overwhelming feeling of pleasure and fulfilment is there, especially when I am stroked under my arms.'

Reclaiming your body

Your time in hospital may well have been quite traumatic with things going on around you over which you have little control. This loss of control is especially strong regarding the way in which your body is treated - bladder and bowel care are top priorities. For instance, your genital area becomes public property to any nurse who catheterises you and so you grow used to the invasion of your privacy which goes hand in hand with hospital life. On leaving hospital, you may find it very difficult to reclaim your body and feel it is your own again. Even if you still have help with your bladder and bowel care from your partner, district nurse or personal assistant, the reclaiming of your body and the control over it is very important to your emotional and sexual wellbeing.

'Before she became a disabled woman, American, DeVonna Cervantes liked to dye her pubic hair fun colours - turquoise, purple, jet black. After her injury, a beautician friend of hers came to the rehab unit and, as a Christmas present, dyed DeVonna’s pubic hair a hot pink. Soon the staff who’d seen her dye job when they were catheterising her, sent the psychiatrist around to see her. He said to her 'I know it is hard for you to accept that you have lost your sexuality but you don’t need to draw attention to it this way'. DeVonna spent the rest of the session convincing him that he was wrong - that this was normal behaviour for her and would continue to be so.' (New Internationalist July 1992)
Solo Sex

By 'reclaiming' your body and acknowledging your sexual needs (which may take some time to adjust to after being in hospital for several months) you will be able to take control of your whole self.

Discovering your body will become a new adventure. Take the time to get used to your body since its changes. Don't be afraid to touch and caress yourself, find out what you enjoy sexually about yourself, what turns you on, where you like touching yourself, what sex toys you may like to use. Try out all the things you liked before your injury, you may find that you are very disappointed because they now feel different. Acknowledge this loss, in whatever way you can and don't deny the effect this may have on you. By investigating and exploring yourself, you will find new ways of getting excited, of stimulating your sexual appetite and of giving yourself pleasure. Treat yourself to some tender loving care and sexual experimentation. Solo sex is a positive option with rewarding results both sexually and psychologically. Pleasurable, uncomplicated fantasies go a long way in enabling you to enjoy yourself by yourself and in getting to know your own body, your sexual needs and desires and ways of fulfilling yourself. Take pleasure in the knowledge of being a sexual being and of being sexually active in your own right.

Help! I haven't got a partner

You may be thinking this is all well and good for those who have already got partners but what about those of us who haven't? The fact that you are reading this booklet means that you have thought or are thinking about sex and this is a very positive move in itself. The whole business of dating, romance, attraction etc is a complex affair for anyone, regardless of disability. The opportunity to meet people is obviously important. If you don't ever go out of the house, the opportunity will be severely lacking. However, if you are working, have a social life, play a sport, attend evening classes, do activities with your children or get out and about generally then you are likely to meet many different and interesting people. You are more likely to meet and get along with other people the more you have in common. Take, for example, your hobbies, political and social activities, interests
etc you had before your injury. Have your politics changed? Have you stopped
supporting your favourite football team? Have you lost interest in the Theatre? If
you ask most women where they have met their partners, it is usually through a
hobby or interest they have in common. You must consider making a conscious
effort to place an emphasis on your leisure time, if you want to meet other people.
Obviously, your ability to meet people may also depend on you sorting out a few
basic problems such as transport, personal assistance etc.

'I wouldn't go anywhere for at least a year after my injury as I felt very
self-conscious. I started going to see some friends of my brothers and
found that I was attracted to one of them. I found out a few weeks later that
the attraction was mutual and we started seeing each other on our own.'

Unfortunately, this booklet will not help you to obtain a partner, but actively
seeking one can bring rewards. Obviously, it is much easier to get out and about,
if you are living in a city such as London or Manchester. If you are venturing out to
a club or bar, it is usually bravado that gets you there the first time. It takes a lot
of courage and confidence to venture into unknown territory or even to place an
advertisement or reply to one. Dating agencies and telephone dating lines can be
a good way of meeting new people and details of the many commercial agencies
can be found in popular magazines or by contacting The Association of British
Introduction Agencies (ABIA). There are also specialist agencies set up by and for
disabled and able-bodied people such as Handidate and DisDate which are also
members of ABIA. Social clubs can be a good way of mixing and meeting new
people and you can find out about one in your area by contacting your local
disability group or organisation. Finding out what is going on locally re clubs,
theatre events, hobbies and so on is a very positive way of getting involved in the
local community and of meeting a variety of different people. Personal columns
can be found in most newspapers, magazines, periodicals and disability magazines
such as Disability Now (the magazine of the Spastics Society). The New
Statesman has also been recommended for personal adverts. Obviously, if you
answer an ad, you will be sending a letter with your name and address and/or
telephone number on it and there is a risk involved in this. On the other hand, if
you place an ad (at a cost to you), your anonymity will be assured and you can
control the contact etc. It all depends on what you are looking for and where.

If you feel you would like to have contact with a dating agency, answer an
advert/place one or just go along to a social group, there is nothing stopping you
so don't be put off by other people's attitudes. Often things happen when you least
expect them. What is important is how you feel about yourself as this will be very
evident to other people. If you are relaxed and open, your signals and behaviour
will reflect this. People give off all sorts of signals which are easily detected even if
no words are spoken and first impressions, whilst not vitally important to a long
term relationship, are often the reason for people making the first move.

'I have such terrible fears of frightening the guy off or trying too hard. I just
can't be me because I don't know what he's thinking. So I try to cover up
my unconfidence by being noisy and totally extrovert when really I would just
like to be quiet and serene.'
Sometimes, overcoming the attitudes of non-disabled women is another hurdle which can be tough especially if you are lacking in confidence. Therefore, time spent with other disabled women will help your confidence, enable you to share ideas and worries and to feel a sense of strength and unity. The SIA Link Scheme is a good way of meeting and talking to other spinal cord injured women of all ages. SIA can put you in touch very easily and quickly. GLAD (Greater London Association for Disabled People) produces a Newsletter for women which contains contacts and information on women's issues. This new project hopes to build a strong network of disabled women. Also, you can contact your local disability organisation to see if any women's groups exist in your area.

'I was afraid of not being able to do anything. Grief-stricken that I might never feel that pleasure again. I was also embarrassed that I might ruin the situation with tears, anger, frustration, incontinence or whatever. At first I did realise my deepest fears, but with the right partner they were turned into beautiful moments of sharing when only the sharing mattered. Being single my main fears when forming new relationships were when to explain about the awful pants and pads, and possible bladder problems, and scars and (to me) my not so wonderful naked body, but it has always worked out alright for me.'

Fears and anxieties

You may be afraid of approaching someone for the first time, and getting to know them, or it may be that making friends with someone is OK, but how do you discover whether they are interested in you sexually. Are they just being 'nice'? Well, the surest way to know the answer is to ask the question. Of course, it is difficult to ask, and maybe he isn't interested. So what? Isn't it better to know early on rather than spend ages getting your hopes up, only to be dashed later on. Tell him you find him interesting, attractive etc. Ask him how he feels about you and see how he responds.

You may fear not being able to satisfy him sexually, that you might have difficulties. Have you considered he might too?! He might be doubting his ability to satisfy you. He is just as likely to be nervous. Explaining your anxieties in advance can help relax you both and free you for things you want to do later on and then, if you do run into difficulties, you are both at least a little prepared for them. If he's shallow enough only to be interested in high performance sex and is unconcerned about you, then you're probably better off saving your time and energy.

Taking the plunge

When you are ready to experiment either alone or with a partner, you could use the Sensual Touching Exercise (see further on) as a starting point. It is a useful guide to getting to know your body as well as your partner's. It is also a useful tool for communication between you both. You may have to do some talking early on in your relationship about positions, areas of sensation on your body, catheters and so on, and this will depend on how easy it is for you to talk about yourself and whether you think it is necessary. Talking early on in a relationship can help to minimise the embarrassment that might occur later on.
'My own experiences are that sex can be good, but it must be entered into with complete honesty and a sense of humour is essential. If one has a supportive partner, whether able-bodied or disabled, anything is possible and, with experimentation, it's amazing what you can achieve. It's essential to learn from each other how to give and take, to learn each other's sensitive areas so you can both get equal pleasure.'

China Doll Syndrome

For those that have a partner, it is important to let your partner know that when your injury stabilises, you can be handled (hugged, cuddled and caressed) not like a china doll but like an adult woman. Sex begins outside the bedroom with you both explaining your needs to each other, and you demonstrating your new physical condition (such as lack of muscle tone in parts of your body). Above all, communication is the key. A heart to heart talk about all areas of your lives together, now and in the future may need to happen at some point so why not start here?

Ways and Means

Talking can also turn into foreplay. If you start talking and this develops into the mood for sex including you being carried into the bedroom, it is a good start. You may have already discovered this!

'I prefer being carried - it's more romantic than transferring back and forth between bed and wheelchair.'

Being comfortable in pleasant surroundings, with no pressure on either partner to put on a performance, helps to lead to relaxed satisfying sex. Ordinary things of everyday life can sometimes be romantic and a turn on. If you both become turned on in the living room, on the sofa, or in the bath, there really is no need to transfer to the wheelchair and from there to the bed. Often though, a familiar setting may be less worrying for you initially, especially if you are only used to making love on the bed. Don't create problems for yourself or your partner if you are comfortable and happy in a familiar setting.

Certain times of the day find all of us more relaxed than at other times. (A heavy day at work is a real barrier to a relaxed evening). Sometimes, a warm bath with scented oils followed by a candlelit dinner with a nice bottle of wine or a few beers with soft lights and your favourite music playing can help you relax. This is just one scene which can be set to enable you to forget the stress and strain of
the day. Playing games (anything from Scrabble, Trivial Pursuits to strip poker); or watching TV for a while may help you relax and help set the mood.

If you need help in the loo, undressing and helping to bed by a personal assistant, it can be very embarrassing initially, especially when your partner is waiting in the other room. What this gives you though is a sense of keeping hold of yourself and your sexuality, your independence and your dignity.

'When I first started sleeping with my partner, my personal assistant would help me in the bathroom and then undress me and put me to bed. My partner would come in after I was in bed and so he wouldn't have to do any of my personal care - we could just be together.'

Once the atmosphere is conducive and the scene is set (remember you and your partner are co-directors), there are more than the traditional possibilities waiting to be discovered. Unlike the usual social stereotypes a woman isn't always passive (are you?) and a man not always dominant in sex.

'One of my favourite ways to spend an evening was and still is to go to bed early with a bottle of wine, the TV and my partner. The all important points to remember are contraception, a sense of fun and to remember that if you suffer occasional incontinence during sex, that's just another load of washing and not the end of the world.'

Some women highly recommend 'verbal sex', especially if the sense of touch is lacking. This involves you telling your partner and having him tell you what you are going to do, in language that turns both of you on. Sometimes this can be combined with description, in an erotic manner, of exactly what you're going to do to each other.

'Sex manuals, books and magazines are plentiful and freely available. Either read them by yourself and experiment in bed later, or read them together. Do whatever is right for you. You are having sex because you want to - don't just lie there and think of England!'

Erotic fantasy stories (or role playing a favourite fantasy) can enhance your lovemaking and can make sex more adventurous and fun. Erotic books (either novels or those with photographs or drawings), pre-recorded tapes (as advertised in sex magazines), or adult videos can be highly arousing. Vibrators, mirrors, sex toys, body paints can be used by both partners (alone or on each other), to good effect. Anne Summers shops provide the usual underwear and sex toys and also have a mail order service. If you have limited hand movement you may need a vibrator that is more sturdy and easier to grip and the Anne Summers variety may not be any good. A US mail order service has been recommended which offers help and advice to disabled women on sex aids such as vibrators (see address list).

'I was unsure which vibrator to order but when I explained my requirements and that I kept dropping and breaking them, they recommended the 'Magic Wand' which has two speeds. Having less sensation, the higher speed gives a much better vibration.'
Use your imagination to find out what turns you or your partner on and as time goes by, you will feel more confident at experimenting with different toys, games, videos etc. However, these methods are only effective if they appeal to you - if the thought of it turns you off, give it a miss but do take the time to find out what does turn you on.

'If you find your vagina very dry even after arousal, you can use a lubricant. It is best to use a jelly lubricant which is water soluble such as Joy Jelly (in different flavours and available from most Anne Summers shops and other sex shop outlets) or the old fashioned 'KY'. Don't use a petroleum jelly such as Vaseline as it can provide a culture medium for infection especially if you have an indwelling catheter. Lubrication can make finger or penis penetration a lot easier for both you and your partner. You can use it on yourself for more lubrication but you can also put it on his penis so that when he enters you, he will lubricate you at the same time. Whatever is fun, try it! Sexual activity does not have to lead to penetration. The ways in which you can enjoy each other have no bounds as long as you are both happy about what you do with each other and you are both safe.

We use nose, mouth and facial stroking and get very turned on by these things - penetration isn't everything.'

To help your balance, you may like to use a number of cushions, pillows, the head board of the bed (padded if possible), a monkey pole or place your bed against a wall. These will allow you to be more comfortable generally and also allow for more movement when needed. You may need the use of one hand to balance or
move yourself especially if you use a monkey pole. You could try balancing against your partner for certain positions or against the headboard so that you can have two hands free and still feel secure. A brass bed headboard is good for pulling on and using like a monkey pole. Another useful item which has been recommended is an adjustable double bed which gives security of balance and movement.

A View From The Other Side of the Bed

'As an able-bodied man, a lot of questions are raised in the mind most of which cannot really be answered until they are experienced first hand. Perhaps for the first few times, let your partner go to bed first, giving her time to get undressed and get into bed as she may be shy at removing her clothes in front of you. Let her warm the bed up - but don't leave her alone for too long! She might also be unsure of herself now from the point of view of wondering if she is still physically and sexually attractive to you.

Take your time, try to be relaxed and find your own quiet, peaceful surroundings when and where you know you will not be disturbed. Take the phone off the hook! Let her know that you still find her physically and sexually attractive - by looks, signs, words and actions! Don't forget to caress her body all over - just because she can no longer feel parts of her body - doesn't mean that a reaction cannot be provoked, nor does it mean that you shouldn't stroke her. It doesn't feel any different to you, does it. It will also reassure her that you still fancy all of her. Such caressing will go a long way towards reassuring her of her sexuality. Though there probably won't be any leg movement, there will be the occasional spasm - don't forget about this and don't be worried by any sudden spasm. If she 'gets you' - laugh it off. No harm is done. If she has an indwelling catheter, perhaps the best position is from the side so that there is less potential worry that the catheter will come out. You may be happy and satisfied making love in just one position to start off with so that you can form/renew a good strong bond of love and understanding with each other. It is important to gain confidence and be comfortable making love, and then gradually move on to explore other possibilities. Don't rush into too much variety too quickly.'
Oral sex

Oral sex can be as much part of sex as touching, caressing and intercourse and can be a fulfilling alternative if intercourse is difficult. The mouth is a very sensual organ and can arouse and stimulate with very little effort. You can both use your mouth and tongue instead of your hands and lick and suck wherever you please. Anything can be licked and sucked and in case you can’t think of anything, here’s a few reminders. Ears, penis, toes, back, breasts, nipples, neck, underarms, face, clitoris, vulva, backside, tummy and so on. If your sensation is weak in any of those areas, try to look and see (back yourself up with some cushions) what he is doing to you and how he is enjoying you. Many women find this a very fulfilling way of enjoying each other and of getting turned on. An orgasm can also be achieved by oral sex and you may like to have your partner ‘come’ in your mouth.

Alternatively, if this does not appeal to you, bring him very near orgasm and then he can ‘come’ on your body. Oral sex can be fun, sensual and exciting. Try as many different ways of turning each other on without using hands as you can so that you learn to discover the joys of oral sex. Again, it is important to check out things with your partner so that you are doing what you both enjoy. Giving and taking pleasure go hand in hand, mouth in mouth...

Intercourse positions

Here are some positions recommended by spinal cord injured women. Try those that appeal and functional movement allows. If you find your vagina very dry, try some jelly already mentioned.

* You are seated on your partner’s lap facing him. He could lift you onto his lap, Both rock back and forward. Can be done on a chair, bed or on the floor. A blanket or cushion can make it more comfortable.

* You on your back with bum on the edge of the bed or chair, he enters from the front.

* You in crawling position (‘doggy style’) supported by cushions or pillows under chest and knees and your partner kneels and enters from behind.

* You lie on your tummy and your partner enters from behind supporting himself with his hands or elbows.

* You lie on your back and support legs, bent at the knee, on pillows. He enters from above.

* You on your back (missionary) and variations on a theme:-

* Your hips supported by a pillow allowing deeper penetration at a comfortable angle.
* You can (if able) wrap legs around his back (some women with adequate movement recommend this as a way of controlling his thrusting rate and depth).

* You on top of your partner on your knees - (can be supported under arms by chairs with which you can effect a lift).

* . Side by side facing each other or side by side with him entering from behind.

'Right - you're in bed - now what! Turn the light off? Optional. If you're on an Edinburgh Simpson air mattress, then make sure it's pumped right up and then switched off. If you're on a normal mattress that's OK as you won't damage your skin in an evening. What about a change of scenery? Turn over on your stomach and hug 2/3 pillows lengthways into your chest and stomach; get your man to spread your legs and use your fingers to guide his penis in and relate to the moment of penetration - after a few weeks/months, you will know exactly where your man is. One of our favourite positions is to lie on my side - bring my top leg right over the bottom leg, keeping the leg underneath slightly bent. That's a great way for both partners to make love. Mmm... Cosy!!'

If a position is obviously impossible (is it really?) try something else. There's no need for uncomfortable gymnastics.

'As you make love he can move your hips up and down with his hands. He can also wrap his legs around you and give you more movement.'

'Position yourself kneeling and ask your partner to slip under and in, or he can move you from the missionary position. To do this, get him to help you move into a sitting position - with him still inside you - let him move your legs back under you, bending your knees of course, and then it's his turn to move his legs. Wow!'

Expectations

After sex comes more use of the mouth! Talking! Do talk. Talk about feelings. Talk about the good things (and the not so enjoyable things) that have taken place.

This often takes honesty and confidence and needs practice. You could put on another record (had you noticed the music stop?) and just lie there and talk and cuddle. Wind down together. Some people worry about how often they have sex but as in all things it's the quality not quantity that counts. Don't rush sex, take your time - before, during and after - and after is before, after all!

'I know that disabled people are supposed to develop an erogenous zone and mine is above my shoulder level, especially around my neck - the hypersensitivity is tremendous and I can feel extreme sexual pleasure by just stroking these parts. I am lucky, however, because I still have partial sensory feeling left and although sex before paralysis was 100% perfect, it is
only 50% perfect now, but at least I can and have experienced the pleasures of the sex act after paralysis.'

Be patient - don't expect miracles at first. Practise. Sex becomes better and better. It's a myth that if it's not right first time, it never will be. Don't expect your partner to know instinctively what you want (he may not) - tell him. Don't ask 'was it better for you?' instead tell your partner how it was for you and have him tell you! If you feel you can't directly come out and say what you would like more of, or what you really didn't like very much, you could write down five or ten good or not so good things and then talk about them afterwards. Also don't compare with your friends. Choices and tastes differ so much and some might tell little white lies to impress others anyway. Try not to be taken in by certain expectations of your sexual performance and don't be dissuaded from trying something new even if a friend has told you that there are only certain things you can now do. What you want to do sexually is between you and your partner and if you want to have sex every night or masturbate in front of the TV, do so. Trust yourself and your own instincts.

I might pee on him!

If your partner has been with you a while, he will probably know about possible bladder accidents but for those who are newly in a relationship, it is often the most worrying thing to have to tell someone that you may wet yourself or them. Don't be afraid, if you have got so far in the relationship as to want to have sex together, then just say that because you do not have total control over your bladder, you may have a little accident if you get very excited! If he wants you enough, that isn't going to put him off. Within a strong relationship, any difficulties which may occur can be worked on and an understanding developed between you both.

'Irrincontinence during love making can seem like a big issue. I empty my bladder by the intermittent catheterisation method and do so before and after making love. Several glasses of wine may impair my judgement but not my fun and don't despair if you wet the bed. Place an incontinence sheet or use a towel underneath to protect the mattress - remember - the bed is probably already wet with sweat! Don't worry about it but don't fall asleep on a wet bed.'

If you use intermittent catheterisation or "express" your bladder, you will be able to gauge by how much you have drunk as to when you need the loo. Reducing fluid intake before intercourse as well as emptying your bladder may make you more comfortable. Some women who use indwelling catheters may be worried about having intercourse. 'No problem - just tape it back' is one woman's answer. Some women find that what they do with catheters during sex is no problem at all and recommend leaving it in place whilst love making which allows more spontaneity. If you find it makes intercourse difficult, it may be better to remove it (you can use absorbent pads or towels to catch any leaking urine). 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. Some women tape the catheter to the abdomen to avoid it...
getting in the way. You can also spigot the end and take the bag off so that you can romp around without worrying about pulling the bag. You could teach your partner to put the catheter back in afterwards or do it yourself if able, but you always need to have a spare handy. Reducing fluid intake before intercourse as well as emptying your bladder may make you more comfortable.

‘In the beginning, incontinence is the biggest hurdle to overcome in one’s mind, but by being honest and with an understanding partner this can soon be overcome. The next hurdle, along the same lines, is when you have an appliance like a catheter. I, for one, was amazed at how little informed many people are about the biology of the opposite sex. For instance, one partner I had did not realise that a female has a urethral exit, vaginal exit and a bowel exit and thus thought that the catheter was in the vagina! One thing I would love to hear and learn more about is how one comes to love their body and how to express their sexuality. I get sick of wearing trousers everyday instead of long flowing skirts and alluring blouses’.

What about bowel accidents?

Most women find that they have to make no special arrangements if their bowel programme is followed. If you do not normally follow a bowel programme in the mornings, you may like to try emptying the bowel one or two hours before intercourse as this often aids comfort. If the possibility of an unexpected bowel movement worries you, tell your partner about this also so that it does not interfere with your enjoyment of being together. Obviously, for anal sex, your bowel needs to be as empty as possible.

It may be that your partner helps you with your bowel routine on a regular basis. Try to arrange sex so that it is many hours away from your routine. You can then start to enjoy each other without the thoughts of bowel movements getting in the way. Although this is often difficult, try to use a personal assistant or district nurse for your routine as this will help separate the role of personal assistant and lover. By being imaginative, thoughtful and setting a romantic theme, thoughts of anything but sex can be pushed a million miles away.

What about spasms?

If muscle spasms interfere with your sexual enjoyment discuss this with your physiotherapist or doctor to see what in the way of exercise, positioning or medication can be used to alleviate them. Also, standing for an hour each day is known to reduce spasms. It is probably most useful talking with other women as they will be able to provide helpful hints from their own experience. However, some women have said that certain spasms gave them extra movement which made sex more enjoyable.

Safe Sex!

No information about sex in the nineties would be complete without a few words about HIV and how to avoid it. It is often assumed that disabled women are asexual, inexperienced and not exposed to the dangers of HIV infection and other
sexual diseases. HIV is the virus that leads to AIDS and it is only passed on through bodily fluids such as blood or semen. Condoms are the safest form of intercourse. Experts believe the danger of being infected from oral sex is extremely slight. However, if you have ulcers or cuts in your mouth or around your vagina, it is probably best to be careful, in these situations, condoms (which now come in different flavours) and dental dams (squares of latex, also flavoured) will minimise the risk. Similarly if you are using dildos or sex toys which penetrate the body, either wash them before someone else uses them or put a fresh condom on the dildo each time. Obviously, using condoms is the safest form of intercourse.

These few simple precautions will ensure your safety. Remember, it is impossible to tell who has HIV and who has not. Even in a long term relationship, safe sex needs to be considered essential.

Contraception

Your nerves have been affected by your injury but beware, your fertility has not. Therefore pregnancy is very possible if you are having unprotected intercourse. During the first few months after your injury, your menstrual flow will be disrupted temporarily but this should sort itself out quite quickly which means that you will almost certainly be fertile. Your ovaries will also still produce the hormones oestrogen and progestogen which affect your fertility.

Your most fertile time is during ovulation, (mid way through your menstrual cycle) when a mature egg is released from one of your ovaries. The egg enters the fallopian tube where, if it meets with your partner's sperm, it will be fertilised. The egg moves into your uterus, where it is implanted and the baby begins to grow. If the egg remains unfertilised, it leaves the body and passes out in your menstrual flow.

Obviously, if you do not wish to be pregnant, you need to take contraceptive precautions and to get advice as to the most suitable one for you. Talk this over with your partner if you are going to share the responsibility of contraception so that you are both aware of the possibilities and consequences. Obviously, for most contraceptive devices you will have to talk to your GP, attend a Family Planning Clinic or refer back to your spinal unit consultant.

'I persuaded my GP to prescribe the Mini Pill for me, but this only lasted a year due to high blood pressure - mine not his! Prior to my accident I had enjoyed using the Cap but found this now totally impractical. Lastly I turned to the Coil, which was fitted for me at my Spinal Unit and this has been fine for two years. How soon after injury can you have sex? Well, it's preferable to wait until the Consultant has gone home and the other patients have fallen asleep...'
Here is a review of some of the contraceptive methods available.

The Male Condom - is made from thin, natural latex rubber which is soft and stretchy. It comes in a variety of types - plain, coloured, ribbed and lubricated and they are readily available at chemists over the counter - you do not need to go to a GP to obtain them. The condom should be put on before genital contact is made. Condoms are useful for unexpected and unplanned intercourse so you could keep them in your hand bag or purse. Although it has few side effects as opposed to the other contraceptive devices for women, it has been known to make the vagina sore if you become allergic to the rubber. Obviously, it is also a necessity for safe sex if you have a variety of partners.

'I found using a condom very uncomfortable as I have an indwelling catheter.'

'I prefer my partner to use condoms. I had a lot of trouble with mess after ejaculation and how to clean up afterwards.'

The Female Condom - called Femidom is a tube made of very thin polyurethane rubber. It is closed at one end and designed to form a loose lining to a woman's vagina with two flexible rings, one at each end, to keep it in place. The loose ring in the closed end fits inside the vagina, just behind the pubic bone. The fixed ring at the open end stays outside, lying flat against the area around the entrance to the woman's vagina. These are very new on the market. You insert the condom any time before having sex and it is important that you put it in before contact is made. The condom can be inserted when you are lying down or with one leg up on a chair. It may be easier for you to insert it on the bed, by half sitting up and splaying your legs apart to put it in. Your partner could also help with this.

'I found the Femidom a bit awkward to put in - having no feeling I could not be certain it was in the right place. Also during sex, there is a tendency for the outer ring to be pushed in, which means it does not do its job properly and is quite difficult to retrieve!'

The Combined Pill - is often the choice of contraception used by spinal cord injured women because they are unable to use many of the other devices. The Combined Pill is so called because it contains oestrogen and progestogen whose main action is to prevent ovulation, therefore it is said to be very reliable. It can come in low doses, so discuss this with your GP or spinal unit as to the most suitable one for you. The Pill can also regulate periods, if these are a problem for you. There are a number of risks involved and it is not thought to be suitable for long term birth control. This is due to the fact that the Pill aggravates any circulation problems and can increase the risks of thrombosis, cervical cancer and heart disease. Smokers should be encouraged to give up smoking if they use the Pill.

'I see no reason why SCI women shouldn't take The Pill the same way as the majority of women use this method of contraception. I think it's the safest, most reliable method of contraception on the market.'
'I thought the Pill gave me headaches so I tried alternative methods and decided that the condom suited me better.'

The Mini Pill - is for women for whom oestrogen-containing pills are unsuitable. This is a little less reliable than the Combined Pill and has to be taken strictly on time every day without a break. The progestogen-only pill does not always prevent ovulation but thickens the cervical mucus, making it difficult for sperm to enter the womb, and makes the lining of the womb un receptive to the egg if fertilised. You may also still experience irregular periods but the side effects, as with the Combined Pill, are not as great.

'The only problem I have experienced with the Mini Pill is occasional breakthrough bleeding.'

'I prefer the Mini Pill because I can't take the Combined Pill. However, its main downfall is that it must be taken at roughly the same time every day to be 100% effective.'

The Injection - Depo-Provera is a hormonal contraceptive which is given by injection. Progestogen is injected into a muscle and is released very slowly into the body. A single injection provides contraceptive protection for three months. Depo-Provera should only be offered to women for whom other methods are unsuitable. The GP should always explain fully the side effects to you. If not, ask.

Intrauterine Device (The Coil) - Some doctors use this as a short term measure but as it can become displaced (and become ineffective), women without tactile sense are often not advised to try this method. Although slightly less reliable than the Combined Pill, once in place it needs no further attention. The Coil is a small plastic device passed through the cervix into the uterine cavity. One effect of the Coil is thought to be to prevent a fertilised egg from settling in the womb. Once inserted, the woman may only need a yearly check-up and then replacement of the Coil every 2-5 years. The side effects include irregular bleeding, heavy periods and pelvic infection.

'The first two Coils I had seemed to cause a brownish discharge but with the third one, this problem disappeared. I like the convenience of the Coil though I do not like the idea of a permanently indwelling foreign body.'

'I have used the Coil but as I experience severe spasm I am worried that it may cause the Coil to dislodge.'

Diaphragm - is a thin dome of rubber which covers the cervix and so prevents the entry of sperm into the uterus. The correct size and type is determined by a medical examination and is initially fitted by your GP. You insert it before intercourse and leave it in position for about six hours afterwards. It must be used in conjunction with spermicidal cream, jelly, foam or pessary and its reliability depends on correct and conscientious use. The Cap is a smaller device which is designed to fit neatly over the cervix and is used for women who cannot use the Diaphragm. Thought by many women to be impractical both for insertion (if manual dexterity is impaired) and as it is hard to keep clean.
'As a paraplegic woman, I feel unsafe using the Cap as I am not sure when it is positioned properly. I am also allergic to Nonoxyl 9, a type of spermicide so do not use pessaries which are of this type.'

Postcoital Contraception - is a 'morning after' contraception and is available in the event of unprotected intercourse. This involves taking a special dose of the Combined Pill, within three days or insertion of a Coil within five days. This method should only be used in an emergency under medical supervision.

Sterilisation - involves the cutting or blocking of the fallopian tubes in a woman or of the vas deferens in a man (vasectomy). The operation in either sex must be regarded as irreversible although there have been successful attempts at reversing. Some people choose these methods but it must only be considered for long term contraception.

'My husband and I were in full agreement that after the birth of my two children I would be sterilised. It is permanent and allows us a full sex life.'

'I think if you can persuade your partner to have a vasectomy (or in my case, there was no persuasion needed), then this is a good idea for women who do not wish to practise contraception or have had all the children they want.'

Withdrawal Method - not very satisfactory as it requires an amazing amount of control and the male does not have to 'come' to release sperm which can 'leak' in his lubricating fluid.

'Although not completely reliable, I have found this to be successful as my partner is not keen to use a sheath and does not mind ejaculating outside the vagina.'

Rhythm Method - If your religious convictions dictate this, the Rhythm Method involves monitoring the female menstrual cycle to find the least (but still) fertile days of the month.

If you have any queries regarding family planning, either contact the Family Planning Association (see list) or your GP for information and advice. If you would like to talk to another spinal cord injured woman about aspects of contraception, please contact SIA.

For information and experiences of pregnancy and motherhood, get a copy of our Motherhood Factsheet.

Sensual Touching Exercise

Although this exercise is written for couples, there is no reason why you cannot adapt it to use when you are alone.

If you feel silly about following the exercise, perhaps read it through with your partner first and then improvise. The exercise may help you and your partner
relax, whether you are new to each other or have had a longer relationship but need to get to know each other again. Use what you want and adapt it to suit your needs. This exercise places the spinal cord injured partner in the active role and it is up to both of you to choose who goes first. If your partner is also disabled, adapt it accordingly.

Preparation

Try to pick a time when you won’t be disturbed. The important thing is to enjoy and explore yourself and each other. Make sure the room is warm enough for you without any clothes on - don’t let yourself get cold as you will not feel relaxed. Place a few blankets and pillows on the bed or sofa and both undress fully. Have some gentle music on in the background if you like. You should both be in comfortable positions where you can both be reached without stress or stretching for either partner. You may have difficulty with balance, if so, use some of the suggestions we’ve already mentioned under ‘Ways and Means’. If you have limited balance and arm movement, you can choose to stay in your wheelchair as you will be able to move around better. Your partner will be able to move towards you then if you have difficulty in reaching him. Baby oil, hand lotion or massage oils can be used if desired, to increase sensuous feelings and reduce friction on the skin.

The passive partner lies firstly on his front. The only responsibility he has is to relax, enjoy, respond and be communicative. Ask him to tell you how each touch feels or looks. Encourage him to use positive phrases such as, ‘I preferred the first type of touch to the second one’, ‘yes that is how I like it’, ‘could you do that again please? It was lovely!’ Or ‘could you try something else please?’, rather than negative phrases such as ‘stop it!’ or ‘don’t do that!’ This is so that you become encouraged by these communications.

Side I 'Warming up'

Start at the head and work downwards to the feet. Try different pressures and types of touches (stroking, tickling, scratching, rubbing etc) all over the back of the head. Then try different touches on the hands and wrists noticing the shape and size of the fingers etc. Caress from the shoulders down to the wrists on both sides and then from the head down the wrists. Is he beginning to relax?

Next starting with small movements at the shoulders work down the back stopping just before the buttocks. Now make long sensuous strokes down the full length of the back from the neck. You could be gently talking to your partner. Caress the buttocks in a circular motion (remember to check with your partner how he is feeling). Does he prefer a certain touch? Now caress downwards along the full length of the legs to the feet (avoiding the thighs for the moment). Pay attention to the feet and try to relax the toes. (If your partner is ticklish use more pressure). Stroke all the way down from the head to the feet. Remember which areas your partner preferred being touched and with which type of pressure.
Side II ‘Getting warmer’

Your partner should now turn over onto his back and be comfortable. Start from the head again and work down. Try exploring his face with different touches, notice the folds around the eyes and mouth (are his eyes closed or open?)

Now place your hands over the mound of his shoulders and make circular movements. When he has told you how this feels, stroke down and then back up each of the arms a few times. (Has he a favourite side?)

Now stroke all the way down the body (avoiding the groin and the inner thighs) a few times. (When it is your turn, you may want him to avoid your breasts and leave them till last if you are extra sensitive.) Now ask your partner to open his legs a little and stroke down the full length of the body but this time include the inner thighs. Then stroke up towards the genital area. Look at your partner’s genitals, see how they all fit together (this may be a little embarrassing the first time!) so it may help, (if you are on the bed as well) to place yourself between his legs or he could place his legs either side of your chair. Try all your best tickles, strokes and sensuous caresses to find out what effect they have. Touching around this area could bring your partner to an orgasm and if it does, let it and go along with the feelings you have created in him.

Now try all his favourite touches for a few minutes before changing places. Along with these touches, you can caress him by using your mouth, lips and tongue over his entire body (backs like it too!) A sensual massage often reveals new often unexpected sensitive erogenous zones. This exercise is a good guide (but not gospel) take your time, don’t rush. Being close skin against skin is loving at its best.

Vice Versa!

It’s your turn to take the passive role. Emphasise to your partner that you can be touched, caressed, fondled all over your body, not just in areas with more sensation. Your partner should try to remember what turned him on and try to apply the knowledge he has gained to pleasing you. Repeat the exercise but ask your partner to take into account certain things which may be different for you. If sensation disappears below a certain area, try to look at what he is doing or ask him to describe what he is doing to you by speaking gently and quietly. If your breasts are too sensitive to be touched at first, make sure you tell your partner about this so that he can avoid them until you are ready. Many women
have mentioned that, because of lack of sensation in their genital area, their breasts are their most erogenous zone!

After you have been both the active and passive partner you could tell each other why you like to be touched in certain places in certain ways and not in others. There is room for much improvisation in this exercise - don't treat it as a rule - see if you can improve it. If you feel embarrassed and are unable to tell each other straight away, perhaps write down a few things first and then go through your list, each saying why you have mentioned it. This is often more helpful than just coming straight out with it and can take away some of the funny feelings you may have about sharing your thoughts and feelings.

What to Read!

**So you're paralysed...** by Bernadette Fallon published by SIA. A practical guide to everyday life for spinal cord injured people and their families and friends, includes sections on independence, continence management and sex.

**Able Lives - Women's Experiences of Paralysis** edited by Jenny Morris published by The Women's Press, 34 Great Sutton Street, London EC1V ODX and also available from SIA. This book was written by a group of SIA women members, based on the lives of about 100 spinal cord injured women. It is about the reality of spinal cord injured women's lives in which there is pain as well as joy. The message is neither how awful life is for disabled women, nor how wonderful they are. Good section on sexuality.

**Sexuality after your Spinal Cord Injury** published by Harmarville Rehabilitation Center, PO Box 11386, Guys Run Road, Pittsburgh, PA 15238 USA. Tel: 412 828 1300. There are two of these informative guides to enjoying a sex life after injury, one for men and one for women. It covers all aspects of sexuality including attitudes, achieving a satisfying sex life, relationships and family planning.

**The Joy of Sex** and **More Joy of Sex** by Alex Comfort published by Quartet Books, 27-29 Goodge Street, London W1P 1FD. How to give and take sexual pleasure is now in two books. If you have read the first one, the second one carries on with more detail.

**Pride Against Prejudice - Transforming Attitudes to Disability** by Jenny Morris published by The Women's Press. This book challenges the reality of being different, covering current and historical debates on the quality of disabled people's lives.

**Disabled Lives** by Jenny Morris published by BBC Educational Developments and available from PO Box 7, London W3 6XJ. Over the last decade, disabled people throughout the world have highlighted how they are denied the very basic civil rights that non-disabled people take for granted. The booklet covers issues such as charities, independent living and the growth of a disability culture.
With Wings - An Anthology of Literature by Women with Disabilities edited by Marsha Saxton & Florence Howe, published by Virago, 20-23 Mandela Street, London NW1 OHQ. This paperback brings together the work of thirty writers who, individually and collectively, capture the day to day reality of life as disabled women.

Dating Agencies

The Association of British Introduction Agencies, London W8 6AL. Tel: 071 937 2800. Can provide a list of local commercial agencies nationwide.

Handidate, The Wellington Centre, 52 Chevalier Street, Ipswich, Suffolk IP1 2PB. Tel: 0473 226950. Open 2-4pm Monday to Thursday.

Disdate, 76 Springfield Road, Bromham, Bedford MK43 8NT. Tel: 0234 822598

Contact with Other Disabled Women

GLAD (Greater London Association of Disabled People), 336 Brixton Road, London SW9 7AA. Tel: 071 274 0107.

SIA Link Scheme, Newpoint House, 76 St James's Lane, London N10 3DF. Tel: 081 444 2121

Sex Shops and Mail Order

Anne Summers, GSP Ltd, 2 Godstone Road, Whyteleafe, Surrey CR3 0EA. Tel: 081 763 0122. To obtain a catalogue or place an order.

Good Vibrations, Open Enterprise Inc, 1210 Valencia Street, San Francisco, CA 94110, USA. Write and ask for a catalogue.

Well Sexy Women (video) is available from your local HMV Record and Video store or direct from HMV mail order on 071 631 3423.

Organisations which help with Personal Matters

Family Planning Association, 27-29 Mortimer Street, London W1N 7RJ. Tel: 071 636 7866. Can give details of a FPA near you. Provides information, support and advice on all aspects of family planning and health.

Brook Centres, 153a East Street, London SE17 2SD. Tel: 071 708 1234/1390. Have centres all over the country for advice and counselling on all matters of a personal nature.

DISCERN, 94 Mansfield Road, Nottingham NG1 3HD. Tel: 0602 588043. Can give advice, support and help on all aspects of disability and also have a counselling service.
SPOD (Sexual and Personal Relationships of Disabled People), 286 Camden Road, London N7 OJ. Tel: 071 607 8851. SPOD have a network of counsellors all over the country and they also provide information on sexual matters and training courses.

Relate: National Marriage Guidance, Herbert Gray College, Little Church Street, Rugby CV21 3AP. Tel: 0788 573241. Can give details of a Relate branch in your local area.

HIV and AIDS Organisations

Positively Women, 5 Sebastian Street, London EC1V OHE. Tel: 071 490 5515. Monday to Friday 12-2pm. Support service for women who are HIV Positive.

Terence Higgins Trust, 52 Grays Inn Road, London WC1X 8LT. Tel: 071 831 0330 - Helpline 071 242 1010. Services include counselling and support groups for people with HIV/AIDS, their families and friends.

BHAN (Black HIV/AIDS Network) Tel: 071 792 1200. This organisation offers support to black people affected by HIV and AIDS.

The Naz Project, Palingswick House, 241 Kings Street, London W6 9LP. Tel: 081 563 0191. HIV/AIDS service for the South Asian and Muslim communities.

Thanks!

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There are four booklets in the Sexuality and Spinal Cord Injury series: Heterosexual Women, Heterosexual Men, Lesbians and Gay Men.