



FACTSHEET







FATHERHOOD - IS IT POSSIBLE FOR ME?

Please note: This factsheet contains themes of a sexual nature.

Introduction

Spinal cord injury does not mean you cannot become a father.

Individual circumstances mean that some men will require the assistance of fertility experts, whilst some couples are able to achieve pregnancy in more conventional ways. New techniques developed now mean that the chances of a spinal cord injured man fathering a child have never been better. This factsheet gives you some ideas of how to make this possible.

There are four main causes of infertility:

- Failure of ejaculation
- Retrograde ejaculation instead of being ejaculated in the usual way the semen passes into the bladder. The semen may then become ineffective as its fertilising ability will be substantially reduced due to the acidity of the urine
- The testicles are affected due mainly to changes in the heat regulatory mechanisms. Raised scrotal temperature following prolonged wheelchair use also has a damaging effect on sperm
- Chronic infection of the prostate and seminal vesicles is also common in men after spinal cord injury.

Can semen be obtained from men who are unable to ejaculate?

Professor Brindley contributed an enormous amount to the understanding of the fertility of SCI men. He discovered semen can be obtained from two-thirds of men with complete lesions by a procedure called electro-ejaculation. The nervous pathways which initiate ejaculation are stimulated electrically by electrodes attached to a probe which is placed in the rectum. This is a very simple procedure and can be done under sedation or general anaesthesia, the latter only being required in a small percentage of cases. Electro-ejaculation does not necessarily result in erection, but emission of semen will occur in a large majority of cases. This semen can be used in the assisted conception procedure for the female partner.

What are the side effects of electro-ejaculation?

The most dangerous side effect is an increase in blood pressure (Autonomic Dysreflexia). This affects men with injuries at level T6 or above. Blood pressure usually falls again when the electrical stimulation is stopped. Other side effects which may occur include flushing of the face, sweating and severe headaches. (These effects are probably due to exaggerated reflex nervous activity through the isolated part of the spinal cord, i.e. the part below the injury.)

A Proctoscopy (examination of the rectal lining) should be performed both before and after the procedure to check for any damage to the rectum.





Is the semen obtained normal?

Semen of spinal cord injured men usually has a lower density and motility (strength of movement). Repeated electroejaculations can improve the percentage of motile sperm present. The sperm when collected can be frozen for future use provided the motility is reasonable. The sperm can be collected within six months of the original injury without risk to the patient.

Retrograde ejaculation sometimes occurs with electro-ejaculation and the sperm can be salvaged from the bladder using a special medium.

Are there other ways to obtain semen?

By applying a powerful vibrator to the glans (top part of the penis), semen can be obtained even in some cases where there has been failure to obtain semen by masturbation. The ejaculation seems to be roughly similar to normal ejaculation. The advantages of this method are first that it does not require a general anaesthetic and second that the semen is usually free from contamination by urine. Side effects reported in a few instances (with high lesions) are the same as for electro-ejaculation, i.e. rise in blood pressure, headaches, but more severe. Please note: This procedure will not work in men with complete lesion at L1 or lower.

Sex aids that are more powerful and have variable vibration strengths and speeds tend to work faster and are therefore safer to use for men who are susceptible to Autonomic Dysreflexia (AD).



All users must be aware of the risk of AD and may be given prophylactic (to prevent) nifedipine when necessary.

If you are under the care of a Spinal Cord Injury Centre, it would be worth contacting the outpatient department there as a number of centres now have a vibrator available to try before you consider purchase.

Electro-ejaculation is now used fairly widely in the U.K.





References

Electro-ejaculation and the Fertility of Paraplegic men G S Brindley (1980) Sexuality and Disability 3 (3) 223 - 229.

Electro-ejaculation: Its Technique, Neurological Implications and Uses G S Brindley (1981) Journal of Neurology, Neurosurgery and Psychiatry 44 (1) 9-18.

Reflex ejaculation under Vibratory Stimulation in Paraplegic Men G S Brindley (1981) "Paraplegia" 19 300 - 303.

Severe Hypertension in Patients with High Spinal Cord Lesions Undergoing Electro-Ejaculation - Management with Prostaglandin E2 H L Frankel and C J Mathias (1980) Paraplegia 18 293 -299.

The Treatment of Male Factor Infertility due to Sexual Dysfunction P A Rainsbury. A text book of In Vitro Fertilisation and Assisted Reproduction 345-359, Published by Parthenon ISBN No 1/ 85070/323/X.

ARTIFICIAL INSEMINATION (AI)

AI, as it is known, is used when the male partner is unable to impregnate the female in the usual manner, either because he cannot get an erection or ejaculate, or because he does not produce viable sperm, or requires electro-ejaculation. In some cases, it may be a combination of factors. AI is one way of overcoming these difficulties. There are two types of AI – artificial insemination by husband (AIH) and artificial insemination by donor (AID).

A sample of semen obtained from the husband or donor is placed high in the woman's vagina during ovulation, her most fertile time. The likely date is calculated using a calendar of her menstrual dates and a chart of temperature changes in the body; a study of changes in the cervical mucus can be used in the same way. Ovulation predictor kits are more accurate. They measure the level of luteinising hormone (released at the time of ovulation) in urine. Widely available at Boots, other chemists and supermarkets, as well as Amazon.

The insemination may be done with a special syringe, a cervical cap may be used to keep the sample in place or it may be done without any special equipment at all, other than a normal 5 or 10ml syringe. Conception usually takes place within one to six inseminations but can depend on other factors which have not been investigated. If it has not occurred within this time, it may be appropriate to investigate the woman's fertility.





Where do I go?

It is possible to have both AIH and AID on the NHS but the latter is much harder to obtain. SIA holds a list of 'sub fertility' clinics and can supply the address of your nearest one on request. However, not all these clinics are equipped for AI, so it is advisable to find out whether the local clinic will be able to help before you arrange an appointment. Very few NHS clinics carry out AID.

Is it legal?

Al is legal in Britain, clinics in this country are licensed to carry out AID by the Human Fertilisation and Embryology Authority (HFEA), which issue strict guidelines for the control of these clinics. The law states that the woman receiving treatment and her male partner being treated with her will be the legal parents of such a child.

Is it safe?

A pregnancy started by AI should be the same as any other, and the baby completely healthy. Of course, every pregnancy carries some risks and these would be the same following AI. Counselling about pregnancy may be indicated if one or both partners are anxious or concerned about anything.

Funding

The NHS does provide some infertility treatment but there are long waiting lists. However, following the NHS reforms, the purchaser/provider concept has opened up the possibility of District Health Authorities (DHAs) and GP fund holders purchasing assisted conception treatment from private specialist units. It is worth asking your GP if such an arrangement can be made for you.

Some fertility clinics will reduce the cost of treatments if the female partner is willing to donate some of her eggs.

Can the insemination technique be used at home?

Many women are also able to inseminate themselves using a syringe and cervical cap. If a partner is able to ejaculate but unable to have full sexual intercourse, then this process could be useful. The practicalities appear to be simple. Ejaculation should be done into a clean small glass or plastic container a short while before insemination. Sperm is best kept at just below body temperature. The sperm is drawn into the needle-less syringe and then, lying down, insert the syringe into the vagina. Before getting to this stage, knowledge of your body is very important so that you know when in the month is the best time and to ensure that the sperm is placed near the mouth of the cervix.





FERTILITY RESEARCH

Fertility units with research relating to spinal cord injury and which have provided information for this factsheet are:

BUPA

Roding Hospital Roding Lane South Ilford IG4 5PZ T: 020 8709 7882

Bourn Hall Clinic

Bourn Cambridge CB3 7TR T: 01954 717 210 W: <u>https://www.bournhall.co.uk/</u>

ASPIRE

Royal National Orthopaedic Hospital Trust Brockley Hill Stanmore Middlesex HA7 4LP T: 020 8954 2300

National Spinal Injuries Centre

Stoke Mandeville Hospital NHS Trust Mandeville Road Aylesbury Bucks HP21 8AL T: 01296 315000

You may want to contact the Human Fertilisation and Embryology Authority (HFEA) who license all fertilisation clinics throughout the UK on 020 7377 5077, <u>www.hfea.gov.uk</u>





Micro surgical techniques for retrieving sperm from spinal cord injured men

A technique has been developed called vas aspiration (VASAP). This involves the micro surgical aspiration of sperm from the vas deferens (a coiled duct that conveys sperm to the ejaculatory duct) under local anaesthesia. A small incision in the skin of the scrotum exposes the vas deferens, a small longitudinal incision is made in the vas area, a fine cannula is inserted and the sperm extracted. The sperm is used in the test tube baby procedure (IVF) to achieve fertilisation with the female partner's eggs. The technique is minimally invasive, takes less than an hour and has a very short recovery time

This procedure can be used with patients who have demonstrated severe dysreflexia following sperm collection using the vibrator or rectal electro-ejaculation.

Testicular Biopsy

Sperm can be obtained by testicular biopsy.

Intracytoplasmic sperm injection (ICSI)

ICSI is widely used for SCI clients and their partners. It is very useful in clients with sperm with low or no motility as a single sperm can be selected and injected directly into the egg to allow fertilisation to take place.

ERECTION ASSISTANCE

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The amount to be injected needs to be carefully established by trial and error under expert supervision.

Subsequently the injection can be self-administered. If the dose is correct, after a few minutes an erection will occur lasting between 30 minutes and 4 hours. The drug works by relaxing the smooth muscle and preventing blood leaving the penis. Ideally the erection should last no longer than one hour.



The technique is not without problems and must initially be closely supervised by experienced medical staff.

For example, if too much Prostaglandin is injected an erection lasting many hours may result which can damage the erectile mechanism. In these circumstances an antidote must be injected into the base of the penis. The long term effects of using the drug are as yet unknown. It is possible that injecting into the same area over a period of time may cause tissue damage. Currently only one injection a fortnight is recommended. You should contact your consultant or GP for more information and assistance.





ERECTION ASSISTANCE DEVICES

Active II

The Active II is a plastic cylinder with a gentle, battery-driven pump at one end. A rubber ring is loaded onto the cylinder, the open end placed over the penis and the pump activated, drawing out the air causing the penis to expand in the vacuum.

When the penis is erect, the rubber band is slipped onto the base of the penis to maintain the erection by slowing the blood circulation, and the cylinder removed. The band must be removed within 30 minutes to avoid damaging the penis. When used correctly, the Active II is a simple and safe alternative for people who want to avoid using a sheath and enjoy skin to skin contact. For longer sexual activity, its use would be limited to the point where intercourse is the next step.

Erec Aid

The Erec Aid works on the same principle as the Active II. The cylinder is placed over the penis with the tension ring on the open end. The pump like gun is attached to tubing attached to the cylinder and an erection obtained by pumping pressure into the cylinder. An erection is obtained and the tension ring is pulled back to the base of the penis slowing the blood circulation. Removing the tension ring returns the penis to its flaccid state. The system can only be used for up to 30 minutes at a time. Includes a video and explanatory booklet. It is now available on prescription for SCI men.

Available from Osbon Medical (UK) Ltd 91 Weston Park, London N8 9PR T: 0845 658 8877 or 0208 340 7311

Penile Prosthetic Implants

There are three types of prostheses currently available. All involve the surgical insertion of implants directly into the erectile bodies of the penis, producing sufficient stiffness for intercourse.

The semi-rigid or malleable rods are non-inflatable units. They are technically easy to implant, have the fewest complications and are the least expensive. However, the penis remains erect at all times and concealment is a problem.





The fully inflatable device is much more complicated. Consisting of two inflatable balloon cylinders surgically implanted within the penis, a small pumping mechanism placed inside the scrotum, a fluid reservoir located within the abdomen or scrotum and the connecting tubing. When the device is activated, fluid is pumped from the reservoir into the balloon cylinders which expand and harden. To deactivate, a valve on the pumping mechanism is pressed and the fluid returns to the reservoir, leaving the penis soft and flaccid. This closely mimics normal activity. There is a risk of mechanical breakdown or fluid leakage, and the balloon cylinders can buckle and break. Scar tissue can form around the reservoir, pump or cylinders restricting their function. The device is expensive and much more difficult to implant.

The self-contained unit implants are a new type of prostheses which contain the entire mechanism within a single rod-like unit that is completely implanted within the penis. There are no connections or tubing to leak or kink. The device becomes rigid when activated by squeezing or bending. The penis becomes soft and flaccid when the unit is deactivated. This prosthesis does not increase width or girth but fits entirely within the penis and requires less extensive surgery to implant. The cost is comparable to the fully inflatable devices. Seek advice from your spinal unit consultant.

Oral Medication

Viagra, Cialis and Levita

These are tablets taken between half and 1.5 hours before sexual activity. The man must be sexually aroused for the medication to work. They are not an aphrodisiac.

Possible side effects of these drugs include: headache, facial flushing, indigestion and disturbance of vision.



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Personal experiences

Below are examples of personal experiences of SIA members:

"I hope that the following account of my family's experiences of Artificial Insemination by Donor (AID) may be of interest to anyone who is contemplating it. There were two dilemmas which I faced when my wife and I discussed the idea of AID. Firstly, the moral question, - am I going to think of this child as that of my wife and another man, and is she going to think of me as the child's father? Secondly, the practical problems of just how does one arrange AID? I say that I faced these problems, as in our relationship we are both very open to each other about our feelings on all aspects of life and my wife had been considering the idea of AID for a while. However, I did not do much thinking on the subject since I felt that it was very important to allow my wife to come to her own decision, - she would, after all be the one who ultimately had to bear the child.

Having seen a good deal of the pleasant side of the world in which we live, I tend to be a rather amoral person and tend to only consider things on their effects on others and their workability. Since I was aware that my wife's instinct to bear a child was very strong, then I felt that AID was the only solution to the problem.

I also very strongly believe that we are products of our environment - that is to say, that a child turns out like the people who bring it up rather than its biological parents. I also felt that if one can share fully in the pregnancy and birth of the child then the feelings of detachment would not arise. My wife has always said that the idea of conception without sex was hard to get used to. However, this did not prove too much of a problem.

Having solved the moral problem, I moved onto the practical aspect. As so often in these situations, a lucky coincidence occurred. My GP told us that the waiting list on the NHS was about three years. However, he did know a doctor personally who was working privately in the field of AID/AIH. He said the words which struck terror in the area of my wallet - Harley Street!

The technique is basically very simple. We went away and took my wife's temperature every morning. After her period started we sent off the results to the doctor. On the basis of this information he then calculates the most likely day on which the woman will ovulate and arranges for the donor to come in on that day an hour or so before the woman is due to arrive. This ensures that the sperm can be checked and as it is totally fresh, the chances of fertilisation are much higher than with banked sperm. The sperm is introduced into the cervix with a special syringe and that's that. Nature does the rest."





Peter (T5) and Mary describe their experiences:

Peter:

"Well, we wanted a family for the usual reasons I suppose, and Mary didn't want to adopt."

Mary:

"No. It's so difficult nowadays and Peter didn't fancy AID, although we had talked about it."

Peter:

"I think I would have felt jealous. Anyway, I found out some two years after my injury, by chance whilst drying myself that I could ejaculate with a bit of stimulation although not through intercourse. After that I masturbated nearly everyday, then sometimes not for a week or so. I knew that to keep it coming was the best way of increasing my chances of becoming a father. I'd had tests done at Stoke Mandeville years ago but they were not positive; the sperm count was low and they were not swimming well.

Hormone therapy was tried but it didn't increase the sperm count significantly. However, it seemed like our only chance so I went back to Stoke for more tests and this time I was near normal despite the fact that I was masturbating more at the time of the first test. Apparently, the sperm count varies so it was perhaps strange that the tests were not done more carefully, e.g. ensuring that I had ejaculated at a given time before the test as, I was told, was normal practice at the Fertility Clinic. I don't know why it improved, possibly because when we started living together I stopped using an electric blanket. Anyway, they suggested that we go away for a month and keep a temperature chart to find Mary's date of ovulation, and then come back to have it 'done'."

Mary:

"I didn't really fancy going to the hospital that way. The next month I went to the Family Planning Clinic. They were really friendly; they didn't insist on seeing Peter, just took my details and gave me a kit to use. They said that if I went back the next month they would show me how to use it. Meanwhile, we were trying on our own. We tried all sorts of ways. In the end we used a standard piece of rubber connecting tube to introduce the semen into the vagina using an ordinary small plastic medicine container in which it was collected. I lay on my back with a pillow under my hips to make sure that the semen stayed down near the cervix. It worked! When we went back to the clinic the nurse said 'I won't show you how to use the kit because I think you are already pregnant'. And I was! It only took three months."

Peter:

"It seemed like much longer than three months that we were messing around taking temperatures and things but it has all been worth it."

Mary:

"But it was only the third month. It was incredibly easy."





The Experience of being a Father

Barry Cherryman, C6

"This is much harder work than I anticipated!! Everyone dreams of having the perfect child that sleeps and feeds well but in reality it doesn't always work out that way. I found it very frustrating not being able to do the things that a normal father would do, but you learn to accept that you have limitations and do the best you can in bringing up the child.

"We fully appreciate how precious Sarah is to us considering the chances of having a child were so remote to begin with. Because I am not in work I am able to spend a lot of time with my daughter. This has been of great benefit both to myself and to Sarah as she talks very well and appears extremely bright and secondly, as she gets older and I manage to do more for her, the bond between us gets closer. There's nothing quite like a hug from the child that you've brought into the world!"

Derek Stass, C6/7

"Due to the fact I had very close contact with two young nieces and two young nephews, I was under no illusions about the role of a father and my expectations were realistic. Although nothing prepares you (disabled or not) for the time and effort that needs to be invested in a family and the total change of lifestyle that comes with it, the rewards are immense. Given my time again, I would have no hesitation in doing the same.

"Due to my lesion at C6/7 and the resultant lack of dexterity, there have been many difficulties and frustrations. For instance, just picking up a baby from a cot requires two hands - one to support the head and the other supporting the body. I found this difficult as I use one arm to balance myself whilst lifting. This is less of a problem as children grow older - say, 18 months on as they learn to climb or adjust their positions to aid lifting and the hand supporting the head is no longer required.

I found changing nappies almost impossible, although I have managed when it proved absolutely necessary. It does help to give the baby something to play with as this reduces his wriggling and keeps him occupied as it can be a relatively lengthy process. Since my children were born I bought an outdoor electric wheelchair. This has proved to be invaluable. Before having children I never really considered this as I drive and am able to get my manual chair in and out of the car, as I still do.

"If you are prepared for a lot of hard work, and are capable of handling problems and frustrations and never want a lie-in in the morning again, go for it using any method possible. You won't regret it!"





Terence Panter, T5/6 Complete

"Using a pushchair I found difficult - Nathaniel just got used to sitting on my lap. Getting to the bed to help or change nappies etc. can be awkward - but one finds ways round this."

Simon Lovatt, C5/6 Complete

"Don't take NO for an answer. Life isn't easy - in fact, very frustrating - but always rewarding!"

USEFUL CONTACTS

Adoption UK

46 The Green South Bar Street Banbury Oxfordshire OX16 9AB T: 01295 752240 Helpline: 0300 6660006 @: info@adoptionuk.org.uk W: www.adoptionuk.org.uk

Operate an experiences resource bank, including members willing to share experiences.

Barnardos New Families Adoption Agency

43 Briggate Shipley West Yorkshire BD17 7BP T: 01274 532 852

Bourn Hall Clinic

Bourn Cambridge CB3 2TN T: 019754 717210 W: <u>https://www.bournhall.co.uk/</u>

Private clinic specialising in fertility treatment, and has helped a large number of men with spinal cord injury to become fathers.





British Association for Adoption and Fostering (BAFF)

CoramBAAF Coram Campus 31 Brunswick Square London WC1N1AZ T: 020 7520 0300 W: www.corambaaf.org.uk/

Umbrella association of local authorities and adoption societies.

Cotswold Cots

Grawins Rock Close Carterton Oxon OX18 3BP T: 01993–842885 W: www.cotswoldcots.co.uk

Manufacture adaptable cots and beds to suit a wheelchair-using parent (including concertina opening cot – particularly for wheelchair users). Demonstration video available on request.

Disability, Pregnancy and Parenthood International

National Centre for Disabled Parents Unit F9 89-93 Fonthill Road London N4 3JH Helpline: 0800 081 4730 Text: 0800 018 9949 Admin: 020 7263 3088 @: info@dppi.org.uk W: <u>www.dppi.org.uk</u>





Disabled Parents Network

National Centre for Disabled Parents 81 Melton Road West Bridgeford NG2 6EN T: 0870 241 0450 W: <u>www.disabledparentsnetwork.org.uk</u>

Disabled Parents Network is an organisation of and for disabled people who are parents or hope to become parents, their families, friends and supporters.

Family Care

21 Castle Street Edinburgh EH2 3DN T: 0131 225 6441 @: mail@birthlink.org.uk W: <u>www.birthlink.org.uk</u>

Provides a range of post-adoption services, for adopted people, birth parents and adoptive parents.

Human Fertilisation and Embriology Authority (HFEA)

T: 020 7291 8200 W: <u>www.hfea.gov.uk</u>

Licensed in all fertility clinics throughout the UK

Infertility Network UK

Charter House 43 St.Leonard's Road Bexhill-on-Sea E.Sussex TN40 1JA T: 0800 008 7464 @: admin@fertilitynetworkuk.com W: www.fertilitynetworkuk.org

Infertility Network is the largest national support organisation which offers general information (including factsheets on many related issues), advice and support to all those affected with infertility problems or undergoing treatment. The membership £20 per annum offers additional benefits including quarterly magazine.

Inter-country adoption (enquiries through the Department of Education and Skills)

T: 020 7972 4014





National Childbirth Trust

Alexandra House Oldham Terrace Acton London W3 6NH T: 0300 3300700 Breastfeeding Line: 0870 444 8708 @: enquiries@nct.org.uk W: www.nct.org.uk

REMAP (Technical Equipment for Disabled People)

D9 Chaucer Business Park Kemsing Sevenoaks Kent TN15 6YU T: 0845 1300 456(local rates) W: <u>www.remap.org.uk</u>

With more than 100 branches around the country, REMAP makes or adapts aids for disabled people when not commercially available at no charge to the client.

Women's Health

W: www.womenshealthlondon.org.uk

Deals with women's gynaecological and sexual health issues. Supports access to healthcare for women with disabilities. As of time of revision, the organisation has closed due to lack of funding; however the website still appears to be functional.

USEFUL RESOURCES

SIA Link Scheme

Parents and would-be parents have shared their experiences and sought advice and information from other members who have had children after injury. If you would like a link contact, please ring the SIA Advice Line on:

T: 0800 980 0501. W: <u>www.spinal.co.uk</u>

SIA Fact Sheets – free to download for members

W: https://www.spinal.co.uk/get-informed/knowledge-hub/





SEX TOYS

Sex aids / toys for people with disabilities are now more readily available, devoid of stigma and can add greatly to both sexual pleasure and assistance with reproduction.

Spokz

T: 01543899317 W: <u>https://www.spokz.co.uk/sex-aids.html</u>

Spokz provides services for people with physical disabilities and their partners. Their aim is to empower people, enhancing their lives, relationships, mental and sexual wellbeing.

Bigger Than the Sky: Disabled Women on Parenting

Published by Women's Press £8.99. 1999. T: 020 7636 3992.

For more information, contact us at:

Spinal Injuries Association, SIA House, 2 Trueman Place, Milton Keynes, MK19 6HY

0800 980 0501 (freephone support line open Mon-Fri 10.00am-4.30pm) sia@spinal.co.uk





About SIA

Spinal Injuries Association (SIA) is the leading national charity for anyone affected by spinal cord injury. We have specialist support available, for free, to support you through the mental and physical challenges you may face, both now and for the rest of your life.

Our support network is coordinated by a team of people, across the UK, who can put you in touch with our network of experts and trusted partners, covering all aspects of mind, body and life, to help you move forward with life. Our partners specialise in services such as legal, care, housing, finance, mental health and much more.

We are the voice of spinal cord injured people, through our expertise and we can connect you to the services and organisations you need through our network for all.

You can join the SIA community by signing up for free online at www.spinal.co.uk.

Disclaimer

This factsheet has been prepared by SIA and contains general advice that we hope will be useful. Nothing in this factsheet should be construed as giving specific advice, and it should not be relied on as a basis for any decision or action. SIA does not accept any liability arising from its use. We aim to ensure the information is as up-to-date and accurate as possible, but please be warned that certain areas are subject to change from time to time. Please note that the inclusion of named agencies, companies, products, services or publications in this factsheet does not constitute a recommendation or endorsement.

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