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Editorial

Merja Leppälä,
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The Different Needs and Fears of a Human Being

According to Maslow's hierarchy of needs, the most important need right after those involving physiological and safety needs is the need for belonging and love. One of the most profound fears related to becoming disabled or falling ill is that of becoming less attractive, and thus the fear of not being loved any more. We might be afraid that we will no longer be acceptable as women or men in our altered bodies. Even if aids, home alterations, car alterations and personal assistance have all been taken care of, a person needs love, respect and a relationship, and many also long for children and a family.

The statute for centralising the care of spinal cord injuries (SCIs) came into force on 1 May 2011, and the activities of the SCI centres are now well underway. Centralising the treatment opens up improved possibilities for receiving specialised help, even for matters related to relationships and fertility. Every spinal cord injured person has the right to be admitted to an SCI centre.

I find that peer support for spinal cord injured people is also fundamental in regard to relationship matters. Akson ry will continue with its peer support and information-sharing activities through club nights, seminars, the Akson Facebook page and the discussion forum at Selkäydinvamma.fi. This year,

Finland's Slot Machine Association RAY did not grant us funding for developing our peer support actions, but we will continue to look into the matter and seek partnerships (e.g. with the Finnish Association of People with Physical Disabilities). The SCI centres will increase the need for peer support, which is why it is important to get the current actors into the limelight and consider means to educate new supporters. Family peer groups, i.e. peer support for the spouses and family members of spinal cord injured people, would be needed, too.

I myself became a mother when I was 40 years old. Peer support and my husband's open-minded attitude were of great help as I considered starting a family. When I applied for assistance from the insurance company in order to hire an assistant, the decision was harsh. According to the insurance company, the need for assistance in taking care of the child was not related to the injury. I had 'caused' the pregnancy myself! Had I had the child when I got injured, I would have received help. The interpretations could use some improvement.

As the new chair of Akson ry I wish you all a busy year full of action! Come and join our activities!



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Treating Male SCI-related Infertility

Spinal Cord Injuries (SCIs) are most common among young men. On average, men are injured at the age of 33, and many have not yet started a family.

TEXT Seija Kaukoranta, M.D., Väestöliitto Fertility Clinics LTD
(Väestöliiton klinikat Oy Helsinki)
PHOTOS Väestöliiton klinikat Oy

Three factors contribute to infertility in men with SCI: erectile dysfunction, ejaculatory dysfunction, and semen abnormalities. The severity of these dysfunctions depends on the extent of the injury as well as its location on the spinal cord. In a partial SCI, the erectile dysfunction can be milder. However, the erection may be insufficient for intercourse, it might not last long enough or cannot be achieved at the right moment. Most men suffering from erectile dysfunction benefit from oral medication, such as phosphodiesterase inhibitors (Viagra, Levitra, Cialis). These drugs also increase the possibility of ejaculation. There are also other kinds of medications for erectile dysfunction. If ejaculation is not achieved through intercourse or masturbation, it can be useful to try a vibrator, when the patient has a partial injury or the sensory line is at navel level or higher.

If the injury is situated high up in the spinal cord, i.e. higher than the 6th thoracic vertebra (Th6), there is a risk of autonomic dysreflexia in connection with ejaculation, leading sometimes to dangerously high blood pressure. Because of this risk, the vibrator should be used first time under the supervision of health care professionals.

If ejaculation is not achieved with a vibrator, it is possible to use an electrostimulation device to stimulate the nerves via the rectum. Infertility clinics in Finland have not used these devices since the collection of sperm from the testicles became in use.

Semen

Research has shown that the quality of sperm of a spinal cord injured man rapidly

deteriorates after the injury. The sperm count is usually normal, but the motility is poor and most sperm are dead. No definitive reason for these changes has been found. It is useful to have the semen analysed when pregnancy is planned. Semen analysis can be done at private infertility clinics and in hospitals that treat infertility. A referral for semen analysis can also be requested at the local health centre. The sperm quality seems to improve if the spinal cord injured man has regular and frequent ejaculations. It is recommended to have a few ejaculations before the analysis.

Men often ask if there is something they can do themselves to improve the quality of their sperm. The same advice goes for spinal cord injured men as for other men. It is recommended to quit smoking and to avoid obesity. A healthy diet with enough vitamins is good for the production of sperm. When the sperm sample has been tested, it is useful to discuss with an expert whether it is sufficient for conception without infertility treatments.

Home insemination

If ejaculation is achieved through masturbation or with a vibrator, but not during intercourse, conception can be achieved by injecting semen into the partner's vagina. In home insemination, the semen is collected in a cup and then aspirated into a syringe, using which the semen is then transferred into the vagina. This is done at the time of ovulation. Pharmacies sell ovulation tests in order to determine the right moment. If the partner's menstrual cycle is irregular,

it is recommended that she consults a gynaecologist. Home insemination can be repeated several months, if the sperm quality has been confirmed to be good enough.

Insemination at the infertility clinic

If conception through home insemination has been unsuccessful, the assisted reproduction treatments can be started. At an infertility clinic the first choice of treatment is intrauterine insemination. During insemination the most mobile sperm, which have been separated from seminal plasma, will be taken into the uterine cavity. If necessary, hormonal treatment can be combined with the insemination.

In vitro fertilisation and microinjection

If the sperm quality is so poor that the possibility of conception at home is very low or the lighter treatments have failed, the option is in vitro fertilisation, IVF. This form of treatment is used also when the man cannot ejaculate even with the help of a vibrator. With in vitro fertilisation therapy the partner's ovaries are stimulated with hormone injections to produce several ovarian follicles. The treatment is started in the beginning of menstrual cycle, and the growth of the follicles is monitored with an ultrasound device at the infertility clinic. When the follicles are large enough, the eggs are retrieved from the ovaries with a needle via the vagina. The procedure is performed under sedation. If the man is able to ejaculate and



Microinjection: the sperm is transferred into the ovum using a glass needle.

his sperm is good enough, a conventional dish fertilisation can be chosen. The cells are in an incubator in the laboratory overnight and the fertilisation takes place without external assistance. The embryo is then transferred into the woman's uterus after two or three days.

If a man is unable to ejaculate, sperm can be collected with a needle from the testicle or epididymis. The same method is used, for example, when the man has azoospermia (no sperm in the semen) for unknown reason or after sterilisation. Another option would be the above-mentioned electroejaculation. However, there are so few spinal cord injured men in need of infertility treatment in Finland that it is demanding to sustain electroejaculation skills. Spinal cord injured men also tend to prefer testicle biopsy as the means for collecting sperm. If the sperm is collected from the testicle or the sperm motility is low, the IVF is combined with intracytoplasmic sperm injection, ICSI. A biologist selects the best-looking sperm and injects it into the egg with a thin needle.

With IVF, approximately one-third of embryo transfers result in a pregnancy per treatment cycle. The pregnancy rates are equal regardless of whether the man suffers from SCI or not. The woman's age is significant in regard to the possibility of conception, and it is recommended that couples seek assisted reproduction treatments at a young age.

In IVF, often more embryos have been obtained than can be transferred into the uterine cavity on a single occasion. These extra embryos can be frozen, and if a pregnancy does not start with the first attempt,

Research has shown that the quality of sperm of a spinal cord injured man rapidly deteriorates after the injury.

the frozen embryos can be used during a natural cycle without hormonal treatment. If a child is born after IVF treatment and there are still frozen embryos left, these embryos can be used to get a second child.

With the help of modern fertilisation technology, most spinal cord injured men can have a child using their own gametes. However, men can hesitate to seek help as the treatment may also involve their spouse. Luckily, assisted reproduction treatments are nowadays lighter, safer and less burdensome. Couples are thus encouraged to discuss treatment either at a private infertility clinic or through public health care

The ovum is transferred to the petri dish.



A Man, His Sexuality and Spinal Cord Injury

Our sexuality is an integral part of our identities. In some of us, it is more pronounced than in others, as we are all individuals. SCI usually affects sexuality and especially the experience of sexuality, the pleasure it gives and one's self-esteem, because SCI often causes genital dysfunction.

TEXT Aino-Maria Ilmanen, occupational therapy student, Turku University of Applied Sciences

It can be rough for a man to realise that he has lost sensation in his genitals and that touching them no longer gives the same pleasure than before, or that he is unable to get an erection or ejaculate, despite being sexually aroused. After becoming injured, sexual activity can lessen, and it might be more difficult to achieve sexual satisfaction than before the injury. The biggest reason behind this is lowered self-esteem and other psychosocial factors. Luckily, effective and easy treatments are available that can restore the experience of sexual pleasure, provide help with genital dysfunctions and strengthen sexual self-esteem, and thus also quality of life.

What causes genital dysfunctions?

SCI-related genital dysfunctions are caused by injuries in both the autonomic nervous system and the somatic nervous system. The symptoms depend on the severity and quality of the injury, i.e. at what vertebral level the injury is located and whether the injury is partial or total. The somatic motoric innervation needed for erection and ejaculation starts in the intervertebral space S2–S4. The innervation from these vertebrae innervates the muscles in the genital area, which generate an erection and ejaculation as they contract. Also, the sensory innervation of the genitals starts from the intervertebral space S2–S4. The sympathetic nerve strands that innervate the deferent ducts, the seminal vesicle and the prostate start from the intervertebral space Th11–L2. If the above-mentioned areas are stimulated, it causes the semen to rise from the epididymis to the urethra through the deferent ducts and further to the tip of the glans.

What treatments are available?

A spinal cord injury often causes infertility in men, as it may lead to sensory deficits in the genitals, problems in achieving or maintaining an erection, anejaculation and deterioration of semen quality. One kind of treatment that works well for erectile dysfunction are different drugs that are taken orally. If medical treatment fails, injection treatment can be chosen as the next step. The drug is injected directly into the erectile tissue of the penis, around 1cm deep. This treatment has given good results with people who have not found help from erection drugs. Also an erection ring placed at the base of the penis can be used to prolong the erection.

Anejaculation refers to the lack of ejaculation despite a possible orgasm. Even if it is possible to reach an orgasm, this usually does not provide the same satisfaction if no ejaculation is achieved. When treating anejaculation, the attempt to achieve ejaculation is usually started with the help of masturbation. If masturbation does not prove successful, a good option is the vibrator. Nowadays vibrators designed especially for people with SCI are available (e.g. Ferticare), and it is recommended that these are tried in treating anejaculation.

The vibrating part of the vibrator is placed against the fraenum, i.e. the part at the bottom of the glans where the nerve strands converge. The vibrator is pressed against the fraenum for three minutes maximum, after which a pause is necessary. The above-mentioned procedure can be repeated six times, at most. The blood pressure should be closely monitored during the process so that it does not rise too high. The vibrator has been especially successful with injuries in the Th10 vertebra or above. If needed, the effect of the vibrator can be accentuated with

the help of a drug called Midodrine. A physician should be consulted when using the vibrator for the first time, because of the risk of autonomic dysreflexia.

If the vibrator provides no help, electroejaculation can be an option. Electroejaculation involves electric stimulation through the rectum, which leads to ejaculation. If certain segments of the spinal cord, namely Th11–L2, have been completely destroyed, anejaculation cannot be treated. If semen is needed to conceive a child, in addition to the above-mentioned means, semen can also be collected directly from the testicle via a testicle biopsy using a needle.

Dreaming of having a child?

The benefit of using a vibrator for collecting semen compared to electroejaculation and testicle biopsy is that it can be used at home without clinical monitoring – not to mention the sexual pleasure which is possible at home. If a spinal cord injured man and his partner dream of having a child together, the vibrator may provide the opportunity to conceive at home, either through intercourse or through home insemination. Testicle biopsies and infertility treatment are common, even though researches have shown that around 80% of men with spinal cord injury at the Th10 vertebrae or above can achieve ejaculation with the help of a vibrator, and thus may be able to conceive at home with their partners.

140 spinal cord injured men and their partners took part in a study (Sonksen et al. 2012). The study followed their attempts at having a child with the help of a vibrator. All of the participating men were injured at vertebra Th10 or above. The research showed that 43% of the couples were able to conceive, and several couples had more than one child.

However, sometimes infertility treatments do need to be started due to the deterioration of the semen's quality. The quality gets poorer because of the decrease of sperm motility, but nothing more is known about the causes. It is, however, suspected to start to occur within a few months of the injury.

Source: Sonksen, J.; Fode, M.; Löchner-Ernst, D. & Ohl, D. 2012. Vibratory ejaculation in 140 spinal cord injured men and home insemination of their partners. International Spinal Cord Society.

Our Personal Experience of Infertility Treatment within Public Health Care

We are a couple from Turku who had been trying to conceive at home for about a year. Only in spring 2010, did Tiina, who has cerebral palsy (aged 36 at the time), and spinal cord injured Jukka (aged 32 at the time) learn that the sperm motility of spinal cord injured men is almost always weaker than normal. The news led Jukka to seek infertility treatment at the Women's Clinic at Turku University Hospital (TYKS).

TEXT Tiina and Jukka Kumpuvuori
PHOTO Shutterstock

The reception at the Women's Clinic was harsh. The physician asked about Tiina's ability to run, and we were asked several times whether we had a proper home, if our assistant resources were appropriate, etc. The doctor explained that the law obligated physicians to ask awkward questions. However, it remained unclear exactly which law posed such obligations. After the consultation we found out what this was about: the Act on Assisted Fertility Treatments § 8 Section 5. According to this particular section, fertility treatment is to be denied if it is obvious that the child cannot be granted a balanced development. The doctor requested additional reports, which we provided. These reports included statements of social worker, our personal physician and the physiotherapist that we initially do not endanger the balanced development of the child. After exchanging emails for the whole summer of 2010, we finally passed this screening and were admitted to a treatment programme. We refused to attend a programme at the TYKS Women's Clinic but demanded an appropriation for referral to a private clinic. We were granted this, and the

discrimination came to an immediate halt – even though the law is exactly the same for the public and private sector.

The Regional State Administrative Agency of South-west Finland: Disabled people must not be discriminated against in fertility treatment.

The unsatisfactory feeling of being discriminated against at TYKS did not leave us. We filed a complaint at the Regional State Administrative Agency (*aluehallintovirasto*, AVI) of South-west Finland. The agency investigated the matter thoroughly and issued its decision at the end of the year 2012. The decision was in our favour, and TYKS received a reprimand for the events of summer 2010. The AVI concluded that it was inappropriate to investigate whether our disability could endanger the safe developmental environment of the child. The AVI also concluded that requesting additional reports was not appropriate. As it was the AVI's opinion that the actions of TYKS were inappropriate, we filed a request for preliminary investigations

on the matter at the police department of Turku at the end of 2012. Offences in office expire in 5 years, so there is still time left to investigate this side of the matter.

Before Christmas 2012, Turun Sanomat published a large story on the AVI's decision. In the story, the Ministry of Social Affairs and Health (*sosiaali- ja terveystieteiden ministeriö*, STM) announced that it had a different opinion on the decision. The difference is related to whether physicians can require additional reports. According to the STM, they can, but not according to the AVI. The STM is preparing legislation regarding this matter, and the relevant associations are now striving to take part in this preparatory work in order to ensure that the rights of the disabled are sufficiently taken into account. Even though the STM's opinion somewhat watered down the joy of the AVI success, it is very good for matters to be brought up for discussion and taken forward. When a matter is this private and a social taboo, it just has to be debated in order for things to go forwards – or backwards. The disabled themselves and their associations need to be vocal for matters to go forwards!

Contact us if you encounter discrimination in infertility treatment; Akson ry will try to help you in every way we can!



Our Personal Experience of Fertility Treatment and Everything Related to it

When having a baby became an actual topic of discussion, Jukka happened to be at the neurology polyclinic of TYKS, where he was being inspected by a multi-professional group with the aim of drawing up a rehabilitation programme. Pee and pooh issues were discussed to the most thorough extent, as were matters related to general health and mental coping. All in all, very sensitive issues.

TEXT Tiina and Jukka Kumpuvuori
PHOTO Shutterstock

Jukka became injured at the age of twelve. Nobody had ever thought of mentioning that the sperm motility of spinal cord injured men often deteriorates to a level where fertility treatments are necessary for conceiving a child. This was not mentioned either at the examination at the neurology polyclinic.

Jukka registered a reprimand according to the Patient Act. His physician concluded that the matter is so personal that it is not brought up unless the patient does so themselves. The chief physician agreed with this statement. How on earth would the patient know to bring it up? The patient cannot bring up specific issues that require medical knowledge. Is it assumed that the patient is a medical professional? It is clear that clinical practices could use some improvement, but every spinal cord injured man has the right to know the status of his sperm motility, even if he does not have the intention to have a child at that very moment. It is a matter of human rights. Are you a spinal cord injured man? Ask for a referral for semen analysis!

Everyday life with infertility treatments

Once it was clear that we needed fertility treatments, we started on a programme at a private clinic after our issues with discrimination in the public sector. The first time is always nerve-wracking, regardless of the matter – this was also true when visiting the private clinic. Our nervousness, however, proved to be unnecessary: we were welcomed by a warm atmosphere as soon as we stepped through the door. The clinic had a different appearance to the public hospital. The staff were extraordinarily friendly and professional. It was interesting to see that even though the Act on Assisted Fertility Treatments applies to both the public sector and behind these doors, the atmosphere is completely different.

The programme began with micro fertility treatment. Tiina received injections on a daily basis, we both took drugs orally, and when it was time to collect the eggs, Jukka had to supply sperm at a precise time. As anyone who has spent time around spinal cord injured people knows, this is not an easy task. We became very familiar with the

Ferticare device, which proved to be helpful. TYKS refused to cover us for the device (worth roughly € 600), which is why the matter is pending in the administrative court of Turku. After the eggs had been collected, we waited to see how many of them would be fertilised, and the embryo was then transferred after a few days. This was followed by an agonising 14-day wait before we could take a pregnancy test. The result has thus far been negative, despite several rounds of treatment, and now, in spring 2013, we are yet again queuing for treatment.

An emotional rollercoaster

Infertility treatment is often necessary when a couple includes a spinal cord injured man. Our personal experiences of infertility treatments have been somewhat mixed. On the one hand, it is very burdensome to go through treatments, as the feelings of hope and despair change from day to day. Nothing happens in seconds, days, not even months. Usually it is a rough process lasting several years. On the other hand, infertility treatments are the only possible way to conceive a child. In this sense, it is a fabulous opportunity that only a small fraction of people in the world have the possibility to seize. From this point of view, we are privileged. In our own process, the discrimination based on disability was more pronounced at the beginning, which of course also affected our feelings. After the AVI decision, when we had, in a sense, beaten the arbitrary attitude of the public sector, more general feelings regarding involuntary childlessness have come to the surface. Sometimes it stings when other people have children. This is an irrational emotion that cannot be helped. The feeling partly fades away after the 'first shock', but involuntary childlessness inevitably involves a broad range of feelings. Despite everything, we do recommend infertility treatments to everyone who is dreaming of having a child of their own!





OF ADOPTION

Very little information is available on the possibility for a spinal cord injured to adopt a child. The matter was discussed, for example, on the TV programme A-talk in 2007, when a spinal cord injured man and his wife were denied adoption through the association Pelastakaa Lapset ry (Save the Children in Finland). Because of the husband's disability, the couple had not received a lawful adoption consultation, either. There is a small Facebook group called Vammaisille oikeus adoptioon (Adoptive Rights for the Disabled), and the matter has also been discussed to a certain extent elsewhere. Apart from this, there does not seem to be any discussion whatsoever. Is the issue a taboo?

TEXT Annukka Koskela PHOTO Shutterstock

A-talk brought up a problem that the couple featured on the show had encountered while seeking for adoption. Their adoption applications were rejected at the first stage based on the application papers – namely, because of the man's spinal cord injury. The couple was not admitted to a lawful adoption consultation. They then tried to make a personal appointment, which was not granted, either. The consulting physician at Save the Children concluded, without ever meeting the couple, that they did not meet the criteria for adoptive parents. The couple seeking adoption asked for the reason in writing, which was delivered by Jari Sinkkonen, Head Physician of Save the Children. According to the statement, the husband's spinal cord injury would, among other things, place the child in a position of double specificity (being adopted and having a disabled parent), which would be too burdensome and challenging for the child and would thus not be in the interest of the child.

On what does Save the Children base their assessment of physically disabled people as parents or their ability to raise a child? Have their staff met any physically disabled mothers or fathers? Is there research proving that a disabled parent burdens the child with their disability? Are the conceptions based on prejudice or the gut feeling of a few experts?

Head Physician Sinkkonen also noted in his statement that it would be too traumatic for the child to lose one of his adoptive parents. However, there are no medical

grounds for this notion, as a spinal cord injury does not affect life expectancy. The reporter asked on A-talk whether a disability was always and automatically a hindrance to adoption. Hanna Markkula-Kivisilta, General Secretary of Save the Children, who was on the show, replied that a disability in itself was not a hindrance, yet she concluded that the child had the right to receive physical care from both of its parents. However, it is possible for a lone woman to seek and be granted adoption, in which case there is only one parent giving physical care.

The A-talk reporter had asked a few psychologists about their opinion on the reasoning of Save the Children. The psychologist Vesa Nevalainen had concluded: “[Adoption consultation being denied on the grounds of disability] seems like a contrived reason. If the parent themselves are at peace with their disability, the child is more likely to grow up with the notion that one can lead a full and happy life even with such a problem.” The psychologist Riitta Niinivaara commented: “As a psychologist, I do not understand the reasoning of Save the Children. Such a physical disability does not measure the ability of parenthood”. Randy Barlow, an American adoption social worker, was also interviewed on the show. He concluded that it was “discrimination if a disabled person was denied adoption [due to their disability]”.

In January 2013 I emailed the Head Physician at Save the Children, Jari Sinkkonen, who had issued the statements presented in the programme, and asked for his possi-

bly updated opinions on the matter. It would have been interesting to know whether a spinal cord injured person had sought or been granted adoption through Save the Children after the TV programme. He claimed to be busy and did not comment himself, but in February 2013 I received an email from Riitta Hyytinen, Director of Child Protection Services at Save the Children, saying that there have not been any applicants with spinal cord injuries lately. Hyytinen also reported that after the A-talk show, other (in) equality issues in adoption consultation have also come to light, for example the adoptive rights of same-sex couples. Save the Children published a statement in 2009 concluding that nobody will be discriminated against in adoption consultation, but everybody will be given a consultation.

Conclusion

It is a fact that there are a lot of spinal cord injured parents in Finland, and even more parents with some sort of physical disability. Everyday life is the same in a disabled person's family as in every other family, with its joys and sorrows, successes and misfortunes. There are exceptions, of course, but these exceptions exist in other families, too. The children, however, lead a completely normal life in families with a disabled parent. A physical disability is but a quality, and a parent's relationship with parenthood does not depend on the disability. A physical disability poses physical challenges, that is obvious, but it does not affect the ability to be present, to take care, to love and to care. A physically disabled parent is completely able to raise a child, to encourage and to support, as much as any parent without a disability. Yet I dare say that children who have grown up in such families are a bit richer, have fewer prejudices and are more open-minded – and a shade more tolerant.

Becoming injured, as well as falling severely ill, the death of a loved one, or an accident, cause a crisis in a person's life, but unfortunately these issues are a part of life. Nobody knows what will be thrown into your path, and at what stage of your life. But it is possible to survive the crisis, to find a new balance and to continue with your life, stronger than ever. It is of course understandable that adoption consultation, with its meticulous interviews and meetings, aims at ruling out unsuitable applicants, but a spinal cord injury in itself cannot in today's world be a hindrance to adoption.

The Reformed Adoption Act



TEXT Elina Akaan-Penttilä
Lawyer, the Finnish Association
of People with Physical Disabilities

ILLUSTRATION Vainö Heinonen

The new **Adoption Act** came into force on 1 July 2012. The law revoked the previous Adoption Act. The general and primary cause behind the reform was to better ensure that the interest of the child is fulfilled in adoption matters. In addition, the law unified the national and international adoption processes, improved the related parties' legal security during the different stages of the adoption process, and developed the organisation of the authorities dealing with adoption matters in a more practical manner.

The interest of the child and the fulfilment of the child's rights are the leading thoughts behind the law. This means that adoption is about the child's right to adoption, not the adoption-seeker's subjective right to the adoptive child.

The reform aimed at improving the legal security of those seeking adoption. It is an important matter, because the different stages of the adoption process include making decisions which in some cases could also mean the interruption of the process. Along with the reform, the applicant has the right of appeal in such cases. Usually the adoption process is interrupted due to uncertainty as to whether the applicant is fit and suitable to become a parent, and whether continuing the adoption process is in the interest of the child.

People seeking adoption have the right to adoption consultation. In addition to clarifying the prerequisites for adoption to the applicants, the adoption counsellor must evaluate whether these prerequisites have been fulfilled. The adoption counsellor issues a written report on the adoption consultation for the permit for adoption and the confirmation of adoption. The report must include all relevant information on the related parties and their circumstances. The report must also include, to the extent possible and necessary, information on, for example,

the applicant's and their families' state of health and factors affecting their health. In their report, the adoption counsellor must also take into account the other members of the adoptive family. The adoption counsellor must provide their evaluation as to whether the applicant is fit and suitable to become an adoptive parent. The permit authority (the adoption committee) performs an evaluation of the applicant's suitability based on the adoption counsellor's report.

The evaluation must always be made on an individual basis, complying with the requirements set out in the law. Adoption consultation is provided as a free service under the Social Welfare Act. Thus the procedural rules of the Act on the Status and Rights of Social Welfare Clients as well as other legislation regulating the activity of the authorities are also applied in the case of adoption counselling. The adoption counsellor must attend to the child's interest in all adoption-related issues, and also give counselling, support and help not only to the child, but also to the applicants.

When evaluating the effects of the Adoption Act's effects on applicants with spinal cord injuries, the injury cannot in itself automatically imply that the candidate should be placed in a different position in the adoption process due to their disability. This would be regarded as discrimination on the basis of disability.

The adoption process, however, does require evaluation of the applicant's state of health and other matters related to taking care of the child and the adoption itself. According to the decree on adoption, the statement must include information on the applicant's identity, the reasons why they seek to adopt a child, the applicant's background, family relations and general social environment, the applicant's financial situation, and the applicant's and their family members' state of health and factors related to their health. The information must be given to the extent possible and necessary. It is in this context that the impact of the disability can indirectly be clarified.

However, the equal position of the applicants during the whole process must be taken into account in the reporting, including the method, extent and evaluation of the report itself.

According to § 6 of the Finnish Constitution, all people are equal before the law.

Nobody must without adequate reason be placed in a different position based on, for example, a disability, their state of health or any other person-related reason. According to the Act on the Status and Rights of Social Welfare Clients, the client has the right to receive a good quality social welfare service as well as good treatment without discrimination. In addition, the authorities must act in an unbiased manner, solely in accordance with their jurisdiction and closely abiding by the law.

Finland has ratified the UN Convention on the Rights of Persons with Disabilities. The convention prohibits discrimination on the basis of disability and requires states to equally secure all basic and human rights for disabled people. For instance, the convention's Article 23 requires that states eliminate discrimination against disabled people, for example in matters related to family relationships and parenthood. States are also required to implement efficient and appropriate measures equally with other people. This also includes ensuring adoptive rights for disabled people.

Thus it is clear that a disability cannot affect the adoption process or the granting of an adoption permit as a single factor. Several cases have come to the knowledge of the Finnish Association of People with Physical Disabilities in which, according to our understanding, severely physically disabled adoption-seekers have been placed in an unequal position compared to the other applicants without adequate reason. In other words, the disabled applicants have been discriminated against on the grounds of their disability. New methods of appeal as well as the strengthening of the adoption process will hopefully increase the clarity and transparency of the adoption processes, as well as preventing discriminating adoption customs from emerging. The Ministry of Social Affairs and Health is preparing instructions to support the implementation of the Adoption Act. The Finnish Association of People with Physical Disabilities aims to influence this work as much as possible in order to improve the situation of disabled adoption-seekers.

The most important matter is to make decisions and measure options which serve the best interest of the child while taking into account all factors related to each individual case, along with securing equal rights for all adoption-seekers



A SPINAL CORD INJURED WOMAN AND PREGNANCY

A spinal cord injured woman can get pregnant and give birth just like any non-injured woman, as a spinal cord injury does not, as such, affect fertility. However, the pregnancy should be more closely monitored, as an expecting spinal cord injured woman can encounter more challenges. It is also useful for the mother herself to be aware of these risks, because physicians change often at prenatal clinics and women's clinics, and the staff at a specific hospital might not be well enough aware of the special needs of a spinal cord injured woman who is expecting a child.

As the uterus grows, naturally the girth of the stomach also grows. This could make moving around more difficult. As the pregnancy progresses, new aids or solutions might become necessary in everyday life. The wheelchair might, for example, become too small or otherwise unsuitable, or it might become necessary to adjust the wheelchair due to the woman's different sitting position. As the sitting position changes and the weight increases, it is important to monitor pressure wounds more closely.

Infections in the urinary tracts are in general more common during pregnancy, especially for spinal cord injured women. The best way to prevent infections is to empty the bladder well. Repeated one-time catheterisations must be done more frequently as the pregnancy proceeds. Preventive medication is often used during pregnancy to prevent infections, because the presence of *e coli* bacteria in the urine increases the risk of preterm birth, even if it is asymptomatic. Some medication used for urinary tract infections cannot be used during pregnancy, which is why the medication must always be discussed with a physician.

As the pregnancy progresses, the uterus presses against the veins, and the feet tend to swell, especially in a sitting position. It is recommended to use support socks during the entire pregnancy. The swelling of the feet can be decreased by lifting up the feet and moving them, and by lying on the side. The risk of phlebothrombosis increases as the pregnancy proceeds. If necessary, preventive medication can be used.

Preterm birth was previously considered to be a risk for spinal cord injured women, but nowadays it is not perceived as a particular danger. A non-monitored birth, on the other hand, could be dangerous. The contractions of the uterus are pain-free if the injury is above the Th10 vertebra. Most women, however, do feel the contractions in some way: as a tightening sensation, as the noticeable hardening of the uterus or as back pain. It is still recommended that the uterine orifice is clinically examined on a weekly basis as of the 30th pregnancy week. It is also good if the woman herself learns to recognise and follow her contractions.

Some spinal cord injured women suffer from such severe spasticity that childbirth and even pregnancy is considered impossible. Orally-taken baclofen moderately re-

lieves the symptoms. If the drug is dosed into the spinal canal with a pump, this allows for larger doses without the risk of side effects.

Autonomic dysreflexia

The most important risk for spinal cord injured women is autonomic dysreflexia, and the treating staff absolutely need to be aware of this. Autonomic dysreflexia occurs in about 85% of people with a spinal cord injury at vertebra Th6 or above. Autonomic dysreflexia refers to an involuntary nervous dysfunction below the injury level which is triggered by a stimulus. The triggering factors are most often a full bladder, an infection, constipation, a pressure wound or a pain stimulus below the injury level.

Symptoms include a powerful, throbbing headache, increased blood pressure, redness of the skin and perspiration above the injury level, and sometimes nausea, cardiac arrhythmia, shortness of breath and vision problems. Blood pressure can rise to a very high level – it has even been reported to cause life-threatening cerebral haemorrhage. The symptoms of dysreflexia are best prevented by avoiding or removing the trigger factor, if possible. Sometimes medication is also necessary.

During pregnancy, the contractions of the uterus can suddenly and without warning trigger a dysreflexic reaction. During labour, the risk of dysreflexia is considered to be so significant that experts find it necessary to prevent this condition if the injury is at vertebra Th6 or above. Epidural anaesthesia prevents dysreflexia effectively, and women with the above-mentioned injury should be given the anaesthetic as soon as it is decided that the delivery has begun. The epidural must be given even if the mother does not experience any pain during the contractions.

Choosing the method of delivery

A spinal cord injured woman can choose from the same methods of delivery as a non-injured woman, i.e. the choice depends on the position of the foetus and the measurements of the pelvis. A vaginal birth is often possible. A spinal cord injured woman does not have normal strength in her abdominal muscles (except if the injury is at a

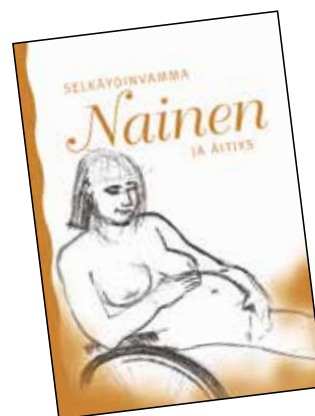
low level), which is why the expulsion stage often requires additional help. According to medical literature, the method of delivery can be chosen on obstetric grounds. However, caesarean sections are apparently more common among spinal cord injured women than non-injured women. The necessity for a caesarean section is evaluated on an individual basis, depending on the situation. Naturally, the mother who is about to give birth must be consulted.

Breathing must be monitored in the case of tetraplegia

For the most part, childbirth literature does not mention any specific breathing problems during delivery. However, sometimes the breathing musculature may become overstrained for women with a high-level injury and tetraplegia. In these cases, the staff in the delivery room should be prepared to monitor and, if necessary, assist the mother's breathing.

Conclusion

A spinal cord injured woman does not have any particular reason to avoid pregnancy and motherhood. All in all, it is useful to discuss all matters related to pregnancy and childbirth with experts as soon as the pregnancy is being planned, as well as letting a physician review the current medication. There are already several spinal cord injured mothers in Finland, and it is also recommended to discuss experiences of pregnancy and childbirth with those who have already gained experience in the matter.



The Finnish Association of People with Physical Disabilities has published the guidebook SELKÄYDINVAMMA, nainen ja äitiys (Eng. Spinal Cord Injury, Woman and Motherhood). For more information on the publication, contact: Akson ry/Anni Täckman.

“The best thing in my life is to be a mother”

This is what one of the women who participated in my survey said. The purpose of this story is to share the pregnancy-related experiences of mothers with a spinal cord injury, and use my doctoral thesis as a means to spread the general view of the availability of maternity services to women with a spinal cord injury in Switzerland. My study focuses on how women with a spinal cord injury use health services in Switzerland during pregnancy, childbirth and puerperium.



TEXT Sue Bertschy, original text translated from German into Finnish: Kaisa Ruoranen
PHOTOS Sue Bertschy

Many also wish to have their own family after becoming disabled. The extra work caused by having their own children is not seen as a burden. On the contrary, a child is considered to enrich life. Since pregnancy is based on hormonal action, natural fertilisation and childbirth is also possible for women with a spinal cord injury. All of the women who participated in my study got pregnant in the usual way.

“I wanted to have children of my own. I thought then that it could take a while before I become pregnant. On the contrary: Whoops and I was already pregnant. What a great feeling, I was ever so happy.” (Sara)

For many women with a spinal cord injury who want to become a mother, getting information about the possibilities proved to be difficult. Since there are only few pregnant women with a spinal cord injury, there also are only few experienced professionals available who are familiar with both pregnancy and spinal cord injuries. Even health care professionals who could show the path forward are rare. Few gynaecologists have experience regarding pregnant women with a spinal cord injury, and they are often not aware of the consequential complications related to the injury. Possible complications related to pregnancy are, for example, an increased risk of thrombosis, pressure sores and dangerous autonomous dysreflexia, in particular when the injury is situated high on the spine. The progress of the pregnancy is different for every woman. Some suffer from morning sickness, others cannot find a comfortable sleeping position with their growing belly. As different as the wor-

ries and needs of pregnant women are, they would like to reduce them and get answers to their questions

Will I miss the childbirth?

Does the future mom feel the fists and kicks once the baby starts moving in the womb? It is hard to estimate in advance what and how much a woman with a spinal cord injury will feel in her belly.

“I am a partial paraplegic, so we did not know in advance how and in which week I could feel the movements of the baby. Then when I felt movement in my belly I started wondering if I would also later feel contractions.” (Lilly)

During the first trimester of the pregnancy, the women in my study had suffered from nausea and vomiting, which they, however, considered normal in the early phase of pregnancy. The subsequent months when the belly began to round were described as ‘the time of enjoyment’ with the spouse. The women obtained information about the physiological changes that take place during pregnancy, childbirth and after it from other women with a spinal injury, from the Internet and from their own doctors. The women who participated in my study explained that they knew their body well and were aware of what they could demand from it and what they could endure. Intensive preparation for childbirth and motherhood helped, in addition to its practical benefits, to strengthen them mentally, which was useful in their new situation in life as a mother.

Most of the complications occurred during the last two months of pregnancy. They

Sue Bertschy:

- doctoral student of health care (Health Service Research), Swiss Paraplegic Research, Nottwil and Luzern University, Switzerland
- injured 13 years ago
- lives in Fribourg in Switzerland
- an avid athlete (tennis, hand-biking, downhill skiing and diving)
- in her free time Sue likes to travel

included, among others, breathing difficulties, swelling of the feet, increased fatigue and spasticity. The most common complication during pregnancy was more frequent urinary tract infections – these often go unnoticed and/or are treated incorrectly. In such a case it is worth seeing a urologist or trusting one's own knowledge about spinal cord injury and, based on one's own experience, place reliance on the form of treatment best suited. Indigestion was also common during pregnancy and this became worse because of the lack of exercise. One of the women who took part in my study said that she alleviated the condition by drinking tea, which is mildly laxative.

If the pregnancy allows the expectant mother to stay at home until the expected date of delivery, regular and precise control are fundamental. However, most women with a spinal cord injury give birth two to six weeks prior to the full term. A smooth childbirth requires good and functioning cooperation between the midwife, gynaecologists and the future mother. The women participating in my study had given birth by Caesarean section more often than women without a spinal cord injury. Health care professionals often recommend epidural anaesthesia and a Caesarean section because they are afraid that they would not recognise the signs of an approaching birth. The recommendation for a Caesarean section and reasons for it are understandable as such, and not unfounded. Expectant mothers with a spinal cord injury should be aware, however, that natural childbirth is perfectly possible. The participants in my study considered it a benefit of the Caesarean section that there is no risk of potential episiotomy, the consequences of which would be longer recovery and hospitalisation time, as well as pressure sores.

None of the women participating in my study had to make any changes to their wheelchair or its seat cushion during their pregnancy. Some purchased support stockings and others needed a more comfortable night cushion. There was little need for other changes at home and in the vicinity of home. However, in hospital and care environments the situation was different: the beds used for childbirth were too hard, rooms were too confined, and there was no wheelchair access to toilets and bathrooms:

“At the hospital I lacked everything. In practice, my husband had to bring our whole house into the hospital for me.” (Emma)

What is needed for good and functioning maternity care?

Expectant mothers may have very different viewpoints as to what the best possible maternity care should include. Some miss intensive monitoring of the progress of the pregnancy and support from professionals, whereas others – such as Saskia, for example – hope for as simple care as possible:

“I passed up prenatal classes because I had decided to give birth with a Caesarean section, meaning that I did not have to learn the correct breathing technique. I figured that I would surely learn everything else, like changing nappies, at the hospital and that it cannot be all that difficult.” (Saskia)

A reliable and open relationship with health care and support persons is highly significant, in any case. Since health care professionals do not possess sufficient information about the possible complications or what the treatment of a spinal cord injury requires, one must and should speak up about one's own wishes and needs in advance. It is a big favour to the little one in the belly and to yourself, to take responsibility and think of things beforehand.



Cot and pram custom ordered

There are not a lot of childcare accessories that would be useful for a mother with a spinal cord injury. Mothers and often also fathers come up with a lot of ideas and inventiveness; a low cabinet that is open in front can serve as a baby care table. The cot may still have to be ordered (or made) to order, so that a woman can sit by it in a wheelchair. No wonder that certain cots travel through dozens of years from one mother with a spinal cord injury to another. For example, using a baby car seat shown in the photo, which the mother can install herself on top of the Freewheel attached to the wheelchair, even a mother with a high degree of injury or others for whom, for example, a baby sling is not a suitable solution, can take the baby for a walk with no help.

For parents with a spinal cord injury, the only sources of information regarding solutions related to taking care of a baby or a toddler are the Internet and other parents with a spinal cord injury. Discussion and exchange of information with other mothers or pregnant women with a spinal injury is important to the future mother. After talking to the women, my own impression was that discussing with other expectant mothers is a good opportunity to improve your self-confidence and thus gain more courage to express your own opinions and make decisions. After conversing with others, they no longer felt that they were alone with their questions and the related worries and fears:

“The woman who I chatted with just reassured me, saying thing would go just okay, nothing to worry about.” (Lina)

Sue Bertschy:

The use of health care services during pregnancy, childbirth and childbed by women with SCI – A qualitative study. 2012. Fin. A qualitative study of the use of health care services by women with a spinal cord injury during pregnancy and after puerperium. 2012.

In Switzerland, 13 mothers with a spinal cord injury, who had given birth after their paralysis and during the past 15 years, participated in the study. The women were recruited through spinal cord injury centres and spinal cord injury communities. The research method was recorded, semi-structured group interviews (3) and individual interviews (3).

The Käpylä Rehabilitation Centre of the Finnish Association of People with Mobility Disabilities has conducted a survey of women who have given birth after a spinal cord injury. The survey was started at the end of 2012 and its purpose was to find out the impact of a spinal cord injury on pregnancy, childbirth and motherhood, and how the mothers themselves have experienced these. The summary of the study was not available for this issue of our journal.

Personal Experiences from My Pregnancy

A little over a year ago, my life changed and I became the mother of a little baby boy. What was the journey like for me, a 26-year-old paraplegic woman? One could say that it was quite a roller-coaster journey through a world of strange attitudes!

TEXT and PHOTOS Reeta Peltola

I have been a paraplegic since birth – the cause is not known. To me it was such a normal situation that once I learned I was pregnant, the type of assumptions and attitudes I would encounter as the pregnancy progressed did not even occur to me.

All in all, my pregnancy went well. That said, in the first trimester of my pregnancy I was already faced with a problem, because my hips began to widen and my wheelchair did not. I began the process of applying for a new wheelchair from the City of Espoo; the old one had become too small and unusable because of a quite natural event. Things did not go too smoothly. The case dragged on and on. I received mumbled excuses as to why it took so long to handle the matter, but nothing happened. Finally my contact person managed to tell me – embarrassed – that the senior medial officer was hesitant to grant permission to order a new wheelchair, because there was no way of knowing how much my weight would increase during the pregnancy, and the new wheelchair might be unsuitable after the pregnancy. I found the argument very odd, and also a bit insulting. I felt that the lucky rounding of my abdomen (and my behind) was only seen as a big expense. Should I have lain in bed for the rest of the pregnancy? And how can anybody know their future weight changes, anyhow? Finally I was allowed to get my chair, I just had to make a bit of a fuss.

During my pregnancy, I felt that I was well received at the maternity clinic. Our maternity nurse did not make any fuss over the physical handicap of the future mom, but



still asked pertinent questions, when necessary. The main thing was that the baby was doing well and that I was doing well. The atmosphere was different at the neonatal clinic. In the final straight, in the birth method evaluation, I met a doctor who was clearly very perplexed by my pregnancy. I was indeed pretty exhausted physically at the time; my back was on fire and breathing with the big belly was difficult, but all in all, things were going quite well. I was at the doctor with my husband, and the doctor kept asking my husband how he was still able to move me. At this point it is impor-

tant to clarify that I did not need help with moving from one place to another, and the most I weighed towards the end of the pregnancy was under 60 kilos. “So, do you have a forklift to help move her around?” asked the doctor. I was amused when my husband replied by saying that we move around by car. My smile soured when the doctor stated while doing the ultrasound: “So, your family will be complete after this one. You will have taken care of your duty, so to speak”. I was flabbergasted and confused, and spluttered something vague. My husband was also stunned. The doctor still continued: “I mean, this must be hard.” Is it? For whom? I would have understood the comment if a subsequent pregnancy would have been life-threatening. But thrown at us without any warning and for no reason, the comment was impertinent. I was appalled. Was this the kind of attitude one is likely to encounter in specialised health care?

My son was born with a planned Caesarean section in Week 37 at the Jorvi hospital, and everything went well for that part. We spent six days on the ward in a family room. The staff of the ward were excellent. The Caesarean was brought forward because the baby was ready and my breathing was getting increasingly difficult because of the pressure from my big belly. All in all, I have wonderful memories from the time I was pregnant, even if there were also some strange and unpleasant attitudes. And to the doctor at the neonatal clinic I can now send a message that it is unlikely that our ‘duties’ have been taken care of!



PROFILE:

Miia Ylimäki

TEXT Miia Ylimäki, Annukka Koskela
PHOTOS Miia Ylimäki

When Miia Ylimäki had a bad fall and became injured in 1990, she was sixteen years old. As the result of the accident, she fractured her C5–C6 vertebrae and became tetraplegic. Miia had dreamt of children of her own already before the accident: of three children, to be exact. As she lay in the hospital, tetraplegic and under head traction after the accident, one of the first questions that came into her mind was “Will I ever have children of my own?”.

The answer to Miia’s question is that there is no medical hindrance to getting pregnant. She still remembers when she heard the news, took a deep breath and thought: “It’ll be alright”. Being able to walk was already a secondary consideration at that time. Of course, the future felt very unsecure at that point, and Miia’s faith in her future family life was not very strong.

Miia met her future husband five years after becoming injured. After spending a few wild years at the start of adult life, the couple realised that they wanted the same things from life. It was not long before they lived under the same roof. Miia was 21 years old at that time. A life with three children was more of a daydream at this stage. Still she did not question for a moment that she could cope with a baby. She did not perceive her wheelchair or her disability as a hindrance to having children. She was more worried in advance about life with a teenager. Would she have enough authority over an adolescent from a wheelchair?

Miia had presumed that it possibly would be difficult to get pregnant and that the risk of miscarriage might be greater than average. Therefore she did not think of pregnancy when she started feeling nauseous and weak. Miia went to the doctor, and she got a prescription for heartburn medication in addition to being referred for a blood test. The medicine did not help, and Miia had lain in bed half-dead for a couple of weeks when she finally received the results of the blood test. The pregnancy test was positive!

When Miia visited the prenatal clinic for the first time, she found out that she was the first spinal cord injured woman to visit that clinic. The atmosphere was still very friendly, and the staff were more curious than

at all negative. The examination table of the prenatal clinic was so old that its height could not be adjusted. Miia could thus not be transferred onto the examination table, and a gynaecological examination could not be performed. There was no sitting scale for weighing, either. Miia was therefore referred to Tampere University Hospital (TAYS), and she was also placed under risky pregnancy monitoring. Her reception was also appropriate at TAYS, but the staff had no knowledge of the dangers and special needs involved in a spinal cord injured woman giving birth. Nor did Miia at that point. It was only at the TAYS maternity clinic, at the end of her pregnancy, that Miia encountered an obstetrician who had read an article on spinal cord injured women giving birth. Miia learned that a vaginal birth was possible, because the uterus does the job, so to speak; but because of Miia’s high-set injury and the accompanying risk of dysreflexia, an epidural would be necessary. Miia herself wanted a vaginal birth, and so an induced labour was scheduled.

The first birth

When Miia went to the hospital on the scheduled day, she was already feeling very emotional, and in addition to that, the staff were anything but friendly. They made it very clear that they had no time to help out. Miia was given a bed which was too high for somebody using a wheelchair. There was no toilet for the disabled in the whole department. When Miia asked for a lower bed, she was told that she could lie in the bed and that the nurses would bring her a bedpan when necessary! A spinal cord injured person can absolutely not use a bedpan. Miia was already about to head home with her husband, when they fetched her a lower bed from another department and showed her the

way to a larger bathroom in a neighbouring department. The labour was induced the next morning as scheduled, and Miia started to have contractions. When Miia was transferred to the delivery room, the midwife on call had not been informed of the pre-agreed epidural. Miia told the staff that she needed the epidural in order to prevent dysreflexia. The anaesthesiologist who had arrived in the delivery room wondered why the epidural was necessary, as Miia did not feel anything in any case. Miia tried to explain the situation and only felt like she was a burdensome mother going into labour. Finally she received the epidural, but the delivery had already begun.

Miia was covered in sweat, her fingers felt like they were in ice, and then the arrhythmia began – and an intolerable headache. On a scale from one to ten, the headache was an eleven. The obstetrician had not looked at Miia's charts and did not understand her symptoms. The doctor offered Miia ibuprofen for the pain! Miia's legs were tied to the stirrups and a ventouse (a suction cap) was placed against the baby's head. Nobody spoke to Miia, nor was her opinion asked about anything. Miia was bewildered and asked whether she could try to push. The obstetrician answered: "If you feel like it". Miia pushed as well as she could for a couple of times, and a three-kilo baby girl was born. The girl was hypothermic because of the dysreflexia, and she was put in a foil wrapper to warm up. Otherwise the baby was healthy and in good condition.

Miia told the staff about the blistering headache, but nobody took much notice. During the next months, Miia suffered from terrible spells of headaches and could do nothing but hold her head in her hands. She also saw blind spots. The spells made it very difficult to spend the time to take care of the baby in the first months. Thank goodness Miia's husband was at home for the first weeks.

Miia fed the baby and changed her nappies holding the baby in her lap or on the sofa, because when she tried to move the baby to the changing table or sink, she had trouble keeping her balance. For the most part Miia held the



baby in her lap and solved the nappy-changing problem with sanitary towels – and the baby appeared to be just fine. As the baby grew older, Miia had to just solve problems using her common sense, as she did not know any peer mothers from whom she could seek advice. Peer support would have come in handy from time to time. Miia has poor strength in her fingers because of her injury, which is why she preferred baby clothes that did not have buttons or poppers, but, for example, jumpsuits with zippers. Trousers with braces and harnesses were practical, as Miia could easily lift the child onto her lap and place her back on the floor safely. Bathing was primarily taken care of by the father, and both grandmothers were eager to help with taking care of the baby. The young family did not even think about hiring an assistant.

The second child

Miia soon became pregnant again, and this time she looked into all kinds of related information. She met with a physician specialising in spinal cord injuries





Miia was shocked to hear that she could even had died of dysreflexia.

and told the doctor what had happened during the delivery. She found out that she had received the epidural way too late and possibly it was not strong enough. Miia was shocked to hear that she could even had died of dysreflexia. At that point she started to get very frightened about the upcoming birth. Then again, now Miia knew what was required in order for the delivery to be successful.

The second pregnancy differed from the first one in that she now already had a child under one year at home. It was difficult to take care of a small child with a big belly, when it was impossible to bend forward, for example. If something fell on the floor during the day, it stayed there until somebody else came home and picked it up. However, with the first-born, it was a relief that she stood up against support at a very young age, and started walking when she was ten months old. Miia would not have been able to transport the child in her lap because of her large belly.

This second labour was also induced, precisely on Week 38. Despite the previous delivery report, Miia's own feelings and opinions were again disregarded. This time Miia was alert and demanded the epidural immediately that the delivery was about to begin. According to the midwife that could still take some time. Yet, even before the midwife had left the room, Miia felt the labour starting. Miia and her husband insisted on getting the epidural immediately, but the matter was belittled. Miia's husband stayed strong and said: "If you repeat the mistake of giving the anaesthetic too late and Miia dies, so will you". The anaesthesiologist was then fetched amazingly quickly. As soon as Miia had received the epidural, the midwife suggested that she tried to rest and let the staff know when she was about to start giving birth. A three-kilo baby girl was born shortly later – without ventouse, with-

out stirrups, and, best of all, without the dangerous dysreflexic symptoms.

The third child

Miia's third child was born without induced labour. This was because when Miia visited the maternity clinic at Week 36+3, Miia felt that the baby was not going to stay inside for long. This time, again, Miia's own sentiments were disregarded, but the labour was scheduled to be induced in a few days. The contractions started the night before the due date, and when Miia went to the toilet she noticed that her waters had broken. Miia was quickly driven to the hospital – luckily the children were taken care of. The cat, however, escaped into the freezing weather. Miia's husband galloped into the cold after the cat, and Miia was left sitting in the car with her contractions. Because of her previous speedy deliveries, Miia was starting to get nervous. Once at the hospital, Miia was admitted directly to the delivery room and the anaesthesiologist was called. Miia received the epidural and the delivery progressed at a quick pace. Miia again avoided dysreflexic symptoms, and the labour left her with pleasant memories. The third child was a boy, also over three kilos.

So in the end, Miia had no problems becoming pregnant, and all in all the pregnancies proceeded well. Catheterising did become more difficult during pregnancy, though, and there was a fair amount of constipation as well. Also the swelling of her feet was significant: Miia's legs were like logs.

Everyday life in a family with children

Everyday life in a family with three small children was stressful and challenging from time to time. The baby period progressed with a better routine with the second and

third children, though. Miia was no longer afraid that she would do something wrong, and she let herself off the hook and allowed herself to occasionally take the path of least resistance. With three children, you just had to try and take it easy, because when you're sitting breast-feeding one child, the second is standing on the table and the third one yells for help in the toilet, losing your nerve would do absolutely no good. So, just lay the baby down, head towards the toilet and on your way lift the second child down from the table to the toys, and after having wiped the third child's bottom, it's back to the business of breast-feeding again.

When Miia had three children, she tried to get a personal assistant from the city of Tampere, but she was not granted this. She was offered the option of putting the children into day care. That was not an option for Miia, however, so she continued her work as a stay-at-home mother. There were several children of roughly the same age in the neighbourhood, and Miia indeed tapped into the neighbourhood relationships. The neighbourhood mothers and their children used to spend an hour or two with the neighbours before the children took their afternoon nap. The children's play yard was right in front of the door, which made keeping an eye on the children easy. Also the big, fenced back yard of the house was a saviour through several summers. The neighbours usually took the children with them to hobby clubs, and Miia organised Christmas parties, bakery evenings and other fun activities inside the house. Often the mothers gathered in the yard to have a cup of coffee and run a yard picnic for the children. Miia finds that she has got most peer support from other mothers, as all families with children have the same problems and troubles, and of course also the same joys and experiences.

Miia does not feel, and has never felt, that she is any different as a mother from anybody else. Several parents left their children with Miia when her own children were small, which is a clear sign that she was trusted as a care-taker. According to Miia, children are genuine and come to terms with things very quickly. When a new play buddy came over to their house for the first time, the wheelchair was naturally at first a matter of astonishment, but in no time they

had completely lost interest. Miia also sought actively to be present at every possible club, school and hobby, so that the wheelchair would not become some odd thing in the eyes of the children. And when the children got to know Miia, the wheelchair was an aid comparable to glasses. Adults, on the other hand, seem to have had more trouble with their attitudes.

As a mother in a wheelchair, Miia of course has had to act differently in certain situations from mothers who are able to walk. The most challenging period was when the daredevil preschoolers did not yet understand all the dangers of the world, and speed was high and constant. Being able to keep up with that tempo in three different directions required some forward planning. Day-to-day routines were of great help in managing things and situations. However, the fact that Miia was not pampering and serving the children every second of the day led the children to be self-sufficient from a young age. Sometimes the children's friends were surprised to hear that Miia simply suggested they do a thing themselves. For example, when the friends stood waiting for someone to put their overalls on, Miia's son did it all by himself – and was very proud of that.

Even a small child does understand if their mother cannot reach something or is unable to perform some task. Also at Miia's home the children made use of the upper beds and the area behind the couch. The notion that mother could not reach them was enough. Sometimes Miia had to resolve to the golden triangle of parenthood, namely bullying, bribery, blackmail – although sometimes it was futile. Yet all in all, the children were obedient.

Now the children are already teenagers; 16, 15 and 13 years old. They all have their own personalities. The oldest is attending a vocational school, the one in the middle is heading for high school, and the youngest has a strong interest in sports and manual skills. Miia says that she is a good friend to her children, but primarily she is their mother. And it is not impossible to cope with teenagers – she does have enough authority, even from a wheelchair.

Miia does not feel, and has never felt, that she is any different as a mother from anybody else.





My Personal Experiences On The Use Of a Personal Assistant in the Care of an Infant Under 3 Years Old

When I was pregnant I gave a lot of thought to the possibility of using a personal assistant. I had not used an assistant before, so the thought of using one felt like a small defeat at first, or even a bit humiliating.

TEXT and PHOTOS Annukka Koskela

On the other hand, when I was expecting my first child, I was not sure how I would organise everything so that I could manage everyday life in the way that I wanted. And since the level of my injury is fairly high (T2), I considered the possible challenges related to lifting the baby up from the floor or into the car when my balance was rather poor. My old unwanted friend, syringomyelia, reminded me of its existence every now and then and I was wondering how much the back pains could affect my physical ability to lift a growing infant. After such contemplation, I finally filled in the social services assistant application form during the last trimester of my pregnancy. I applied for an assistant for the first year (6h/weekday, in total 30h/week). I received an affirmative answer without delay. Later I requested a continuation to the assistant decision with a lower amount of hours.

The baby phase

Looking for – or rather, finding – a suitable assistant was challenging. Since I was not able to offer a full-time job, this limited the number of applicants for financial reasons. I wanted to find one assistant, because I considered it to be in the best interests of the infant to have one and the same, familiar person participate in everyday life at home. Before finding an assistant I liked by chance, I had already met and even interviewed some candidates.

As a new mother I was adamant to do everything related to caring for the baby myself, like clothing and nursing the baby, talking to the baby and putting the baby to sleep. I absolutely did not want the assis-

tant to enter my own turf regarding these activities. While the baby was small I managed things at home independently, but outside the home the situation was different. When the baby was small, the assistant's tasks included, for example, lifting the baby into and out of the car when we visited the maternity clinic, went shopping or ran errands. And as it often happened, when the baby's nappy and beyond was full of poo, the assistant's hands were truly needed. Since almost all of the parent and baby rooms have been implemented to fit the height of walking mothers, I had no chance, for example, to change the nappy on a changing table when outside my own home. Naturally, in such situations I did not go to a cafeteria to wait for a clean baby to appear, but participated in all of the care situations as much as I could. Naturally, my need for an assistant was greater in the winter, when a unploughed route had to be crossed with a pram and a wheelchair to my car covered with snow. However, at first the number of assistant hours I had applied for felt perhaps too high, and indeed, I did not use all the hours granted to me every month. I wanted to spend as much time as possible alone with my baby. Had the child been more inclined to being unwell, there would have been more visits to the doctor, for instance. That is why it was good that the number of hours was estimated a bit too high.

Growing baby

As the baby grew, the tasks of the assistant increased somewhat. When the tiny bundle became a crawling one, the assistant was

needed to lift the child onto and off the floor. And when the weight and size of my child increased, I used the assistant for physical lifting, generally for lifting the baby into and out of the baby bouncer, onto and off the floor, into and out of the pram, etc. during the assistant's working hours. Using an assistant helped me to save my tired shoulders and upper back, which inevitably get overstressed in case of a mother in a wheelchair. Outside my assistant's working hours, I replaced crawling on the floor with lolling around and playing on the bed and lifted and moved my baby myself at home.

Toddler

The next phase for which I needed an assistant was that of a toddler learning to walk.

Assistant walking the toddler outdoors.





Assistant acting as a high chair.

From a wheelchair, one can help a child walk for a limited distance indoors, but the short time of a couple of months when the child finds its feet and the joys of moving was wonderful, and I was happy that my assistant was able to walk the toddler. Walking a tiny toddler outdoors while sitting in a wheelchair is quite awkward, so when we were practicing walking outdoors, the assistant held the toddler's hands and cheered her on while

Assistant helping with walking.



facing her. My toddler soon learned to stand up against the wheelchair so that we were face to face. The wheelchair served as an excellent pushcart indoors, and I could adjust the speed myself. Not many months passed before the toddler was able to climb into my lap with a little help. I managed to lift the package of some ten kilos into my lap myself, but my assistant eased the stress on my back by helping the lifting by supporting the toddler from behind. I find that this work by the assistant helped immensely in maintaining my ability to function. Functioning shoulders and upper back are invaluable for a wheelchair user, who depends on them.

The assistant was also needed when the toddler discovered the joys of climbing frames right before turning two, when the toddler wanted to visit the not-so-accessible play area next to the supermarket or when the toddler's shoe got caught in a pile of snow in the middle of our back garden. We encountered many such situations and it was good that the assistant was with us when we were outside our home. The assistant also enabled our participation in musical playschool, visits to our friends and small excursions in the immediate surroundings by offering light physical assistance in inaccessible places.

The role of an assistant

In short, the assistant who was suitable for me and my life quickly learned to see the situations where help was needed and after the assistance knew how to withdraw and be 'invisible' – for instance, by going to the laundry room to hang up cloth nappies to dry. I was present in all situations and close to the child, even when it was the assistant's hands that physically moved the child from one place to another. Naturally, my assistant also became a close and safe adult in my child's life, what with having been part of our lives for three years already. Now that my child is over 3 years old there is not that much need for an assistant, although the official decision is still valid. I mostly use the assistant only when we are going to a new place and I'm not sure how accessible it is, and sometimes when I take my child to leisure activities in a location that is not fully accessible.

Using an Assistant as a Parenthood Resource



TEXT Jarmo Tiri, Henkilökohtaisten Avustajien Työnantajien Liitto, Heta (The Employers of Personal Assistants) – Chair of Heta, father of a 17-year-old daughter
ILLUSTRATION Väinö Heinonen

Iremember well how we planned with my wife how our family would cope with parenthood and how I, with my severe disability, would also be able to be a father who is physically present. One of the core values of our family is to be independent and self-sufficient. Gender equality is also a value very dear to our family, especially in dividing house chores. My wife wanted to return to work life after her maternity leave; a stay-at-home-mum arrangement was not our choice. But above everything was, of course, the aim to give the child a good and safe childhood.

It was also important to plan the functionality of the whole situation. We had to reassess how we would cope with a situation where there was more need for assistance in the family. Of course, the baby needed a lot of physical time and a lot of hands. I also wanted to make sure that I myself was present in taking care of the baby as well as the growing child, that I could show her physical affection and be part of the activities involved in the different age periods. It was also obvious that I would often need the assistance of another person as a resource to support my own fatherhood. Parenthood involves all activities with and care of the child, but also being present and doing the background tasks – buying and cooking food, doing the laundry and cleaning the house. I, of course, had my share of these tasks to take care of. Depending on

the task, it was either my hands or the assistant's hands that performed it, but from the perspective of the family community, it was all done by Dad.

For me, using an assistant for tasks related to parenting was similar to using an assistant in any other sphere of life: at work, in my spare time, at the summer cottage or just everyday tasks. Already from the start it was clear that the presence of an assistant would not diminish my own role as a parent. I made the parenting decisions, and the communication and relationship between the parent and the child was undivided. I was the parent to the full extent. It was never unclear to my child who her father was and who her mother was. The young assistant sometimes found it awkward when people assumed that a young man, a young woman and a child formed a family. We had a laugh at these situations together.

Families differ from each other as any people do – we are not off-the-shelf standard products. It is thus useless to try to lead a standard life. We can all build our lives on our own strengths and resources. For those of us who are severely disabled, we luckily have the chance to rely on personal help. With the help of an assistant we can reduce the constraints that our disability puts on our activity. The assistant might just as well be the person who lifts the small human being into the parent's lap or the feeding chair, or changes the nappy as the parent makes parental contact with the child. This method raises as strong and balanced children as the kid next door. My own daddy's girl, almost grown-up now, has already proven this.

Granny in the wheelchair



TEXT Miia Häkkinen
ILLUSTRATION Väinö Heinonen

I have taken care of my four grandchildren since they were small. I have not needed any special assistance or aids with them, as I have a low-level (L1) spinal cord injury and my balance is good.

When my grandchildren were babies, they were in my lap, lying on their stomachs on my legs, so I was able to move fairly freely from one place to another. When they grew a bit older, they sat in my lap, and everything continued to go well. Taking them outside was a bit challenging when they were still in their prams, but that was manageable, too. When they were smaller, I fastened them to my lap with a belt, so that I could propel my wheelchair with both hands. Later, when the children were already walking, taking them outside posed no problems. For some reason, none of the children have ever objected to sitting in my lap. Cleaning their bottoms has never been difficult, and I have always fed them in my lap.

The best comment I can remember came from three-year-old Jere's mouth. When the children next door came to fetch him out and play, they looked at my wheelchair with doubt and wonder. Jere asked the kids: "Doesn't my grandma have a cool chair?" At the time I had colourful spoke guards: maybe the comment had something to do with them. But after that, the kids in the neighbourhood thought of me as any other granny. Now the babies I took care of are already 17, 12, 8 and 4 years old.

At the moment, I'm starting as a 'village granny' at a family café organised by the Mannerheim League for Child Welfare. I'm also starting to run a story club on the children's ward at Oulu University Hospital, meaning that I read stories to the children and play with them.

Single parent with tetraplegia



Antti “Moiski” Moilanen was injured in a diving accident in 1976 and became a tetraplegic. In practice, the high injury means the need for another person in all daily activities.

TEXT Annukka Koskela PHOTOS Antti Moilanen

Moiski graduated from Res-su upper secondary school and returned home from the Vaasa Coastal Battery as a Reserve Second Lieutenant prior to his injury in 1976. After the injury, Moiski attained a Vocational Qualification in Business and Administration and familiarised himself with studies in mathematics in the University of Helsinki, but then transferred to ATK Instituutti and gained a Vocational Qualification in Business Information Technology. His career began at the OP Bank Group Central Cooperative as a full-time analyst in 1987, and his most recent title in the same company is full-time Database Specialist.

Moiski got married in 1989 and the couple's son was conceived with the help of homeopathy. During the first years of their son's life the couple had no external assistant. This was a hard time for his wife. Moiski participated in taking care of the baby as much as he could, and pushed the pram with an electric wheelchair, for example around the park at Herttoniemi Manor. The biggest moment of those first years was when the son climbed into his father's lap in the wheelchair. According to Moiski, many practical things became much easier after this. Moiski took care of his son in the evenings after the work day as soon as the boy was big enough to move around himself.

His wife, who had played the roles of both mother and assistant, was tired and often overstressed; she also had other medical problems. The couple received help from Red Cross volunteers, who put in assistants to support the wife. The couple divorced when their son was 4.5 years old. At the time of the divorce it was clear that Moiski would become a single parent.

Everyday life of a single parent

After the divorce, Moiski lived alone with his son, and routines had to be arranged in the best way possible. On weekday mornings the boy woke up at time that Moiski's morning assistant arrived. The assistant helped with the morning chores for two hours every day – helping Moiski and, together with him, also his son. After the morning chores, Moiski took a wheelchair taxi to work and dropped his son off at the nursery on the way. At the end of the working day, Moiski picked up his son from the nursery, and in the evening had help from his personal assistant, who was available the whole evening (6 pm to 12 am). Since Moiski's son had already been diagnosed with a specific language impairment (SLI) by the age of four, he had taxi transportation throughout elementary school. The son went through elementary school at the Konala SLI class, although they lived in Kamppi.

Managing everyday life was sometimes tough and challenging. For example, it was sometimes difficult to stretch the personal assistant's time for both of them, because

Moiski himself needed a lot of help in his daily routines. In such situations they had to – unfortunately – consider whether to use the personal assistant's time for the son's activities or for helping Moiski with the toilet and shower. Moiski's assistants have primarily been employed for long periods (10 years), and Moiski is very aware that in such a situation, a long-term assistant has a major impact on the growth of a child and youngster.

In everyday life, the resources have come, for example, from Red Cross voluntary activity, to which Moiski has contributed a lot as a planner and implementer. The activity involving the Red Cross has made many trips and camps possible for Moiski and his son: meaningful activity and new human relationships. Partly thanks to this international activity, Moiski's son has excellent language skills.

Rough times

At 14, Moiski's son was diagnosed with leukaemia. The battle against this disease was tough – for the first six-month period the boy practically lived at the Children's Hospital. If it was not cancer treatment, he was being treated for infections. The leukaemia treatment worked well, however, and after a difficult beginning the boy managed with medical care for the next few years, and the leukaemia was declared to have been beaten a little over five years after he fell ill. During the time in the hospital, good assistants and the boy's mother, who had spent many years abroad and had travelled back to help, were most helpful in a difficult situation. On the other hand, something good came out of what had happened, too, because during the intensive period of hospi-

At Children's Hospital.





Red Cross Activities.

talisation, the son received a renewed diagnosis for SLI and thus got to take part in occupational therapy, which was very important for him. Moiski and his son had always been very close, and the boy's illness brought them even closer.

Adult son

Today Moiski's son is a 22-year-old young man who – for the time being – still lives at home with his father. The son describes his father as helpful and sometimes bossy. Moiski and his son are both interested in computers, and assemble, build and fix hardware together. Both also have some training in the industry. They also have other interests in common, and in addition, they talk a lot about everything and go to different events.

Moiski's son thinks that the presence of an assistant at home is quite usual and sees nothing strange in it. He practically regards the assistant as a family member. When an assistant resigns, it feels as if a family member is leaving. However, his father is what remains with him in life, and after 22 years of experience it can be said that fatherhood is anything but functioning hands and legs. Fatherhood is about travelling at your side, being present and looking after you – and sometimes about building computers together.

Tips and Tricks

Life for a spinal cord injured person gets easier once you learn a few everyday tips and tricks. In this column we publish handy tips our readers have sent in. You can send in your tip for any sphere of life, with or without a picture, to the email address: toimisto@aksonry.fi. This issue is dedicated to the care-taking of babies and toddlers.

Several child care accessories and pieces of equipment may be suitable for a parent in a wheelchair, even as such or then with a bit of tweaking. A low changing table, for example, may be hard to find as an off-the-shelf product, but it is easy to make one yourself. You could use separate legs of the right height and a table top, or saw the legs of a store-bought table to the right height. Every mum and dad figures out their own ways of transporting a small child, but different cushions, harnesses and slings often come in handy. It is possible, to some extent, to modify the pram afterwards (e.g. a hand brake, a pusher shaft). You can find almost endless amounts of information and pictures online, mostly outside the borders of Finland.

The association Parents with Disabilities estimates on their website that there are over 8 million families with at least one disabled parent in the United States only. The association has gathered a large amount of information on the subject, and the site presents, among others things, different adaptive parenting aids developed by parents themselves

Parents with Disabilities

www.disabledparents.net

See also:

Disabled Parents Network.

www.disabledparentsnetwork.org.uk



It is easy and even sturdier to hold a small baby in your lap with the help of pillows, which also helps to avoid overburdening your upper body.

A hand brake installed afterwards on the pram.





As the child grows a bit older, it is nicer to transport the child in a seated position, facing forward. This is a so-called 'stripped-down version' of a baby carrier. All unnecessary straps were cut off, and the strap which is meant to go around the parent's waist has been folded under the legs. This way the hands are free, for example, for propelling while you are outside. Later, as the child's balance improves, a regular belt or a scarf around the child and the wheelchair's back works perfectly well.



A small step has been installed on the wheelchair so that a small child can itself climb into the parent's lap. It also works with an older child, if they want to press the elevator's button or peek out of the window and are not tall enough.



PHOTO www.lauranlastentarvike.fi

Of the abundance of feeding chairs available, the one best suited for our household was the one you attach at the edge of the table. The feeding chair is easy to detach and take with you, when necessary. The feeding chair can be reached from beneath with a wheelchair, so it is easy to slide the child from the chair to your lap.



A low changing table A changing table lowered to the height of the mother. Next to the table is everything you need at arm's reach.



Vaavi bed The rentable (www.vaavi.fi) or loanable (from some hospitals) baby bed on wheels makes it easier to move the baby around the house. Here, a safety through from a car has been placed in the bed, which makes it easy to feed the child and move it to the changing table.



PHOTO www.vaavi.fi

The rentable/loanable **Vaavi bed** proved to be an excellent aid during the first months. It was easy to transport at home, and you could, for example, move the baby to be next to the changing table.

Annu



Harnesses It can be useful to use a harness with a toddler – it makes outdoor activities easier and safer.

Eeva



A pushing gadget A device fastened to the wheelchair with a quick fix for pushing the pram. It has a ball-and-socket joint for turning. The device is custom-made in an aid store. With the help of the pushing device, hands are left free for propelling, which makes it possible also to push the pram uphill and to slow down while moving downhill. The gadget is handy both when taking a turn outside as well as in shopping centres.



A bath tub Child care equipment stores sell racks, bath tubs and bathing supports for small babies. The legs of the rack can be sawn to a suitable height in order to improve the bathing position. The basket of the rack has an anti-skid rug on which the bath tub can be placed safely. The bathing support is installed on the bath tub and makes bathing a small baby much easier, especially if the person giving the bath has a poor sense of balance.



A cot The wheels from an office chair have been added to the cot, which makes it easier to move the bed from one place to another. This way you can move the child to be directly next to the changing table, for example. The opposite side of the bed can be lowered in order to lift out the child more easily. The sides can also take some leaning, in case your balance is a bit poor. The sides have a safety locking mechanism.



A baby carrier A practical baby carrier which is fairly easy to put on. An easy way to transport a baby. Not all babies, however, like this method of travelling.

Juha-Pekka



Being a father

I have almost six years of fatherhood behind me now, and for the last two years I have had the pleasure of being the father of two boys. My days are filled with all the things day-to-day life in a family with children involves. Especially after the day at work, my evenings are pretty much filled with spending time with the boys. It was for this article that I actually sat down for the first time to think about the past six years from the perspective of a father sitting in a wheelchair, me and fatherhood, a disabled father... Well, let's give it a go.

TEXT and PHOTO Ville Vuosara

When our first child was on his way, my own wheelchair and fatherhood did not feel like an odd combination, and I did not even give the matter much thought. We waited for the birth of our child just as in any other family; the home was prepared for welcoming the newcomer, and the parents were as ready as they could be. However, I do remember that January night when I sat and pondered, and came to realise that my wheelchair could actually give my fatherhood some special characteristics. Our home would not work with a baby after all. Or our flat was fully functional, but an old block, sixth floor, a small lift with its heavy door... I would not be able to take my child outside in a pram, because the wheelchair and the pram would not fit in the lift at the same time. So, off we went to look for a new home. Luckily, they were building single-level terrace houses nearby, and we even got our say on the floor design. The location of our new home, where we still live, is brilliant: the day care centre, the playground and the school are all just a few hundred metres away. The car had to be changed, too, of course. The new car could no longer be chosen (solely) on the grounds of looks and the size of the aluminium rims, but based on practicality and a transport capacity that was as big as possible.



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In order to make everyday life smooth, I had to hand over some of the 'man' and 'dad' jobs to my wife, and tasks needed to be thought through in a practical manner. Especially in wintertime, it is obviously my wife who takes the children skiing and ice skating. It is a tad easier for her. I could of course sit by the ice skating rink or by the skiing tracks, which I do occasionally, but it is kind of challenging to teach your children to ski or ice skate from a sitting position, or

to pick up children who are tumbling over in the snow in every direction. I prefer fulfilling my role as a father by, for example, cooking my family a delicious feast while they are outside.

For my children, a father in a wheelchair is a self-evident matter – they have no experience of a father of other sort. It does sound harsh when you put it that way, but that is how it is. And there is nothing special, odd or even different about that for the children. A wheel chair and fatherhood do not exclude one another, and there is no reason to highlight the wheelchair or the disability. The matters I pondered earlier were very tangible, and relatively easily dealt with. The wheelchair is something hard, physical; fatherhood, on the other hand, is everything but.

Now that I have somewhat concluded this self-reflection on my own fatherhood, I am very much of the opinion that my wheelchair does not affect my parenthood,

and that's that. At most, my physical disability may force me to do some tasks a bit differently from the way in which people usually do them. But fatherhood is mostly everything but solely performing some physical task. I now understand that that is exactly the reason why I have not pondered on fatherhood and the wheelchair in the same context. Just being a father is already quite enough for one man.

Sean and Rachel from Australia

TEXT Rachel Vickers and Sean McGugan, Annukka Koskela
PHOTOS Rachel Vickers and Sean McGugan

Rachel Vickers and Sean McGugan have been together since their school days. Sean was injured in a surfing accident when he was 22, and as a result he has a level C5/C6 spinal cord injury. The couple has travelled together all around the globe – they have even visited the Arctic Circle! They also share active hobbies such as cycling, paddling and camping. After they had built their own house, Sean and Rachel started to plan a family of their own.

Now the couple in their thirties have a son, Maxwell, almost two, and a daughter, Adele, who is a couple of months old. Rachel says that all of their healthcare professionals have met them with a great attitude; they have received lots of support and encouragement in the different stages of raising a family. She also tells us that it is very common in Australia for spinal cord injured people to start families just like anybody else. Communities respect spinal cord injured parents, and they are considered to be just as capable and loving as every other parent.

Sean has not sought any child care aids for disabled people, because he has not felt that he needed any. He has developed some tricks and aids himself, though. Because the dad of the family moves in a wheelchair, the couple has noticed that it is safest to keep things in their proper places and the floor clear from toys: even the smallest toy under the wheelchair's front wheel can be dangerous when dad is transporting tiny Adele in his lap. Because Sean's injury is situated high on the spine, he cannot bathe the children: he is not able to lift the small bather to and from the tub. Instead, he takes showers with them.

When Sean transports the small baby, he uses a baby carrier in order to have his hands free. Now that the family includes two children, when they move outside the house, Maxwell likes to sit in his father's lap. He particularly enjoys this method of trans-

portation, and he already knows how to sit nice and still. Sean himself likes cycling, and being the handyman he is, he has built a children's seat on the back of his hand-bike. This way, the 'guys of the family' can take trips just the two of them.



"It is common for a sci mum or dad to raise a family and sci parents are viewed by others as very capable and loving parents in the community."
–Rachel Vickers



Maureen and Michael from the United States

Maureen and Michael Frogley live in the United States with their three children. Seven-year-old Macy is their biological child, and Jayvon and Devin, six and five, are adopted. Michael has a spinal cord injury.

TEXT Maureen and Michael Frogley, Annukka Koskela
PHOTOS Maureen Frogley

Maureen and Michael started their international adoption process over a decade ago. If you wish to adopt a newborn in the United States, the child's biological mother has, in practice, the biggest say on who is chosen as the adoptive parents. In some cases, the adoptive parent's disability can be a quality that leads them to not being chosen. Similarly, the candidate's other qualities can also become a hindrance, such as their age, location or ethnic background. Maureen and Michael knew that in international adoption, some countries do not give children to adoptive families in which one of the parents is disabled. However, the couple proceeded quite far along in their adoption process, and they were about to receive an adoptive child from China.

At the same time, the couple had acted as a foster family for two boys, Jayvon and Devin. The foster father's physical disability did not affect the process of becoming a foster parent or acting as one. There is a shortage of foster parents in the United States, and those who seek to become foster par-

ents can apply for a kind of foster parenting licence. The authorities decide on who has the right to become a foster parent, and the rights of the biological parents are limited.

Michael and Maureen had already been acting as the boys' foster parents for a long time, when the situation in the boys' biological family changed. The couple decided to interrupt the international adoption process and begin the adoption process for obtaining custody of the boys. The process lasted for a whole four years, mainly because of the boys' situation – Michael's disability did not affect the course of the process in this situation. The couple were granted adoption in 2011.

Life with three children is just as vivid as you would expect. The whole family is athletic, and they enjoy different active hobbies together.

The children shopping with their father.



The whole family at the court house in 2011, when they were granted adoption.



"If you talk to people about what a mom or dad did to make them a mom or dad, very rarely do something come up that could not have been done if the mom or dad had a disability."

–Michael Frogley

A British Example

In the United Kingdom, disability is no hindrance to adoption or acting as a foster parent (see, e.g., adoptionuk.org). The organisation Be My Parent states on their website that each candidate must receive a complete medical examination as part of the adoption or foster parent process. The impact of the disability is discussed with the organisation's employee. Several disabled people have been accepted as adoptive or foster parents through the organisation in the UK. In some cases, a disabled person can be seen to have more skills, determination or ability to raise, for example, a child with a similar disability.

www.bemyparent.org.uk
www.adoptionuk.org

The SAMAT Project Supports Disabled Parents

We started the four-year project SAMAT, *Similar – Different Parenthood*, in Oulu in March 2012. The project is carried out as a collaboration of Kynnys ry and Oulun Invalidien Yhdistys OIY (the Association of Disabled People of Oulu). Our sphere of operations is in Northern Finland, and the project is financed by Finland's Slot Machine Association RAY.

Four people with different disabilities and long-term illnesses and different educational backgrounds work on this project. Tanja Roth, Project Manager, is a rehabilitation instructor and authorised sexological counsellor. Minna Kyngäs, Care Manager, is a professional nurse and a socionom. Katja Kuusela, Responsible Manager, is a socionom. The project also employs Minna Annala, Project Secretary.

Background of the project

The 'mother' of the idea for the project idea is the Project Manager, Tanja Roth. She came up with the idea for the project when she was working as the regional secretary of Kynnys ry's Oulu office, and got the staff at Kynnys ry excited, too. She enlisted OIY as a collaborative partner, and so two old associations combined their skills and knowledge.

The underlying reasons behind the project were the social attitudes regarding issues related to the sexuality and parenthood of disabled people. Disabled people and people with long-term illnesses are offered very little consultation, guidance and peer support in matters related to parenthood.

The objectives of the project

The project aims to support disabled people and people with long-term illnesses in matters regarding parenthood, sexual and reproductive health and family life – regardless of their diagnosis. The objective is to educate young people of their right to start a family despite their disability or illness.

We strive to find the services, social benefits and aids, for example, for child care, that facilitate the family's everyday life. We want to increase the different aged people in our target group's knowledge of sexual and reproductive health. We also aim at facilitating peer support for similar and different families.

Our objective is to highlight the fact that even if one or both of the parents are disa-

bled, the family's everyday life with its joys and sorrows is exactly the same as in any other family.

Our services include case management, sexual counselling and phone counselling. We organise lecture events for the people in our target group in the form of courses, for example. The lectures are tailored according to the target group. We also educate professionals and students who work or plan on working with disabled people, for example on matters related to disabilities and sexuality.

What we have done so far, and what's up next

The first year of the project mostly involved getting the project up and running, finding the target group and collaboration partners and getting the project known about. We have started four peer groups: the Women's Sauna (*Naisten sauna*), the Men's Turn (*Miesten vuoro*), Family Meetings (*Perhetapaamiset*) and the Open-minded (*Avarat*).

At the turn of the year, the OIY women's forum and the Women's Sauna joined forces. The result is a peer support group for adult women with different disabilities and long-term illnesses. The discussions are all related to womanhood and femininity. The topics revolve around how the disability or illness affects one's identity and self-esteem as a woman. The Men's Turn is a similar group for men.

The Family Meetings are for families in which one or both parents are disabled or suffer from long-term illnesses. The parents get to take their time and engage in discussions; the children have their own programme in another room. The Family Meetings is thus far the only group organised both in Oulu and in Kemi.

The Open-minded is a group organised by the SAMAT project and the Oulu office of SETA – LGBTI Rights in Finland. It is directed at adults (aged 18 or over) regardless of their gender, sexuality or disability.



At the moment, the project is planning to organise a group aimed at young people. The discussion topics would revolve around matters and aspirations that are important to the young, such as relationships, family issues and sexuality. We also plan to start an online counselling service and an online discussion group for disabled parents, which they can reach regardless of time and place.

Experiences from our first year

The initial experiences have been good. We have achieved the objectives we set for this year. The project has woken the interest of both our target group and professionals in the field. Sexual and reproductive health has been of particular interest. After all, the sexuality of disabled people is still a taboo. The project has formed many different partnerships, and the students at the universities of applied sciences of Kemi and Oulu are working on theses around the project. However, the network still lacks one important partnership, namely, the prenatal and child health clinic, which has not, at least yet, begun to work in collaboration with us. We think that the staff at prenatal and child health clinics, in particular, would benefit from a partnership with us. In the course of their jobs, the staff meet disabled people who are planning on a pregnancy, are pregnant or are already parents.

You will find us at Kumppanuuskeskus in Oulu, Isokatu 47 (fourth floor), 90100 Oulu.

Welcome!

Kind regards,

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Whether he’s kite-surfing, paragliding, skiing, quad-biking or sailing, Christophe often finds himself in some out-of-the-way places – places he wouldn’t dream of being in if it wasn’t for SpeediCath Compact Male’s unique capabilities. Its ease-of-use, its discreet design and solid construction have rapidly made it indispensable for the Frenchman. He says: “SpeediCath Compact Male has given me back my joy in my sports.”



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¹ Results from SpeediCath Compact Male pre-evaluation, Nov. 2010 to Dec. 2010.