



Article published in RANZCOG O&G Magazine

Volume 5, Number 4, November 2003, pages 276-277

RVF Support Network Inc

An interview with Wendy Powell

Wendy Powell has been a long-term sufferer of a recto-vaginal fistula (RVF), which occurred during the birth of her first son in 1997. As with most serious perineal tears, the shock and impact that this injury caused to both Wendy and her family resulted in ongoing suffering in a variety of emotional, physical and social aspects of her life. 'It destroys social interaction, it is embarrassing and painful, it requires ongoing surgery and physiotherapy. The prognosis is uncertain and it will infringe on your family relationship', Wendy explains. However despite three, unsupported painful years of enduring treatment and repair of the fistula, Wendy had decided to 'do something about this' and so the Recto-Vaginal Fistula Support Network (RVFSN) was conceived.

BUILDING A NETWORK – A COLLABORATIVE APPROACH

The network currently consists of a management team of volunteers and its main goal is to provide support in a variety of forms for women who endure this type of tear. 'Primarily we see ourselves providing the realisation that [sufferers] are not alone with their injury. That they can discuss personal matters such as self-image, relationships and the practicalities for their condition.' Wendy explains that with this particular type of tear resulting from the birth of a child, there are additional pressures and ramifications that women have to cope with, other than the specific injury itself. 'Not only are you dealing with a newborn baby

and all the demands that entails, you are adjusting to parenthood, coming to grips with the medical world, facing surgery or ongoing surgery, physical pain, tiredness, embarrassment, dealing with disappointments if surgery fails, any long term effects of this injury, not to mention your personal relationship'.

Due to the nature of these type of injuries, the situation in which they occur and the widespread effect that they can have on the many different aspects of a woman's life, it is important that there are many points of contact among the health profession to guide women to the support network. 'One of our aims is for health professionals, such as obstetricians and colorectal surgeons to make their patients aware of our information, by providing our contact details. We would like to inform GPs, maternal health nurses and physiotherapists of our existence as these people may come into contact with someone suffering an RVF.'

As the women who endure these injuries are not the only people affected, Wendy recognises a wider role for the network to assist families of sufferers as well. 'While a patient is in the thick of it, so to speak, and bears the physical and emotional aspects of the injury, partners and other family members need information and support so they can come to terms with the impact this injury can have. This can be as much a shock to them as it is to the sufferer.'

HEALTH INFORMATION FROM A VARIETY OF SOURCES

Over the past two years, the network has been able to assist a small number of women who have discovered its existence and are seeking help and support for their own experiences of RVFs. Regular meetings of the management team have been held in order to discuss the direction of the network and to develop ideas to promote its existence. The plan to increase awareness includes development of a website, which is currently under construction and will 'provide a channel for sufferers to contact us and access information', as well as nurturing a closer relationship with health professionals for a collaborative approach to assisting women enduring this type of trauma. 'Going forward, our intention is to provide information and contact details regarding our network to relevant health professionals, and to hold regular briefings for interested parties. We will offer brochures and a newsletter and will provide information via a website in development. We value the opportunity to introduce ourselves to all health professionals.'

The information that will be available on the website will be a combination of personal experiences from sufferers like Wendy, as well as some images and basic medical information. 'This information will help someone going through this injury to have a clear understanding of what is happening to their body and provide helpful ways of dealing with the injury

in the form of medical, stomal (if required), specialised physiotherapy, psychology and other useful links.'

One of the sources of this information is Dr Nicholas Rieger, a colorectal surgeon based in Adelaide, who has been able to provide the network with answers to questions which have helped form the basis to the website content, as well as his own medical papers that have been written on the subject of RVFs. 'Valerie Jenkins from the RANZCOG has also been a tremendous help and fully supportive of our group as well as providing two other valuable contacts which we will take up shortly.'

It is this combined support between the RVFSN and the medical profession that Wendy recognises as being so important to the overall treatment of a tear for a woman. It is also recognised that this would be a reciprocative situation in that the network would also play a role in guiding women to receive appropriate care and assisting them in sourcing the information and advice that they require. 'There is no "one stop shop" containing all relevant information. You need expert medical advice, emotional support, specialised physiotherapy and stomal support.' However, giving out medical advice is not an option the Network intends to adopt. 'The RVF Support Network will not give treatment for a recto-vaginal fistula, or purport to give medical advice to members. Neither will it practice or promote therapies of doubtful or unproven value to people with a recto-vaginal fistula.'

ONGOING SUPPORT

The network has received some financial backing from the Department of Human Services as well as a donation from NEC Australia. However to date, most of the funds have been sourced by the network team through their own efforts, such as a movie night which called on the support of family and friends, and seeking free advertising in local newspapers. Wendy admits that it is not an easy road that lies ahead. 'We will be looking to plan a

calendar of dates for fundraising throughout the year. Actioning them becomes no small task with such a small team of already fully employed helpers.'

Wendy hopes that the information and support that the network is able to provide in the near future is available to anyone who needs it. From her own experiences, it is evident that Wendy and the management team of the network are keen to be able to assist women undergoing the trauma of a recto-vaginal fistula in as many ways as they can. 'In a nutshell, there are many support groups for various

illnesses and injury out there. There is no support group available for a fistula, especially sustained in childbirth. We sincerely hope very few women need our help but if they do we would like to be there to support them.'

For further information about the RVF Support Network, contact Wendy Powell, rvfsn@telstra.com.

The newly launched website: www.rvfsupportnetwork.org.au

Sharyn Toohey
RANZCOG

RVF Support Network Inc

A non profit incorporated association
available to support women who sustain a
recto-vaginal fistula through childbirth.

www.rvfsupportnetwork.org.au

rvfsn@telstra.com

ABN: 88 279 636 191

RVF Support Network Inc.
PO Box 9097
Brighton VIC 3186
Australia