

# Useful Information sources and specialist UK user group contact details

<b>(ASBAH) Association for Spina Bifida and</b>	UK registered charity providing information and advice about spina bifida and hydrocephalus to individuals, families <b>Hydrocephalus and carers</b> Tel: 01733 555988 <b>www.asbah.org</b> , <b>Email: info@asbah.org</b>
<b>Association for Contenance Advice (ACA)</b>	The ACA is a membership organisation for health and social care professionals concerned with the progression of care for Contenance and, as such, does not provide direct personal advice on Contenance matters. Tel: 01506 811077 <b>www.aca.uk.com/</b>
<b>Contenance Foundation - UK</b>	National organization for education, research and knowledge transfer on adult incontinence, involved in scientific and consumer publications. Helpline Tel: 0845 345 0165 <b>www.contenance-foundation.org.uk</b>
<b>Cystitis &amp; OAB Foundation</b>	Provides information and support to sufferers of bladder problems, including Interstitial Cystitis, Bacterial Cystitis and Overactive Bladder. Tel: 01908 569169 <b>www.cobfoundation.org</b>
<b>Diabetes UK</b>	The largest organisation in the UK working for people with diabetes, funding research, campaigning and helping people live with the condition. Tel: 020 7424 1000 <b>www.diabetes.org.uk</b>
<b>Incontact</b>	A charity providing information and support to people affected by bladder and bowel problems. Includes a moderated chat room and active message board. Tel: 0870 770 3246 <b>www.incontact.org</b>
<b>Manfred Sauer</b>	Helpline Tel: 0870 1904 150 <b>helpline@manfredsauer.co.uk</b>
<b>Stroke Association</b>	Information or advice about stroke contact call Stroke Helpline Tel: 0845 3033 100 (calls charged at local rate) open Monday to Friday, 9am to 5pm. <b>www.stroke.org.uk</b>
<b>MS</b>	The MS Society is the UK's largest charity for people affected by Multiple Sclerosis (MS) Tel: 020 8438 0700 <b>www.mssociety.org.uk</b>
<b>Parkinsons Association</b>	The leading charity dedicated to providing support, advice and information for people with Parkinson's disease, their carers, families and friends. Tel: 0808 800 0303 <b>www.parkinsons.org.uk</b>
<b>Promocon</b>	Provides a national service, working as part of Disabled Living, Manchester to improve the life for all people with bladder or bowel problems by offering product information, advice and practical solutions to both professionals and the general public. Tel: 0161-834-2001 <b>www.promocon.co.uk</b>
<b>RADAR</b>	National organisation run by disabled people. Bookshop, mailing list and email chat service. Links to other disability sites. Runs the UK Public Disabled toilet key scheme. Tel: 020 7250 3222 <b>www.radar.org.uk</b>
<b>Spinal Injuries</b>	The UK's national organisation for spinal cord injured (SCI). We strongly recommends anyone with a spinal cord injury to join this association as it provides a wealth of invaluable information and support for all aspects of SCI. Freephone Advice Line Tel: 0800 980 0501 <b>www.spinal.co.uk</b>
<b>Men's Health Forum</b>	The Men's Health Forum's mission is to provide an independent and authoritative voice for male health and to tackle the issues affecting the health and well-being of boys and men in England and Wales. (homepage contains links to Scottish, Irish & European Forums) <b>www.menshealthforum.org.uk</b>

## About the author

Barry Kaighin was born on the Isle of Man in 1961 and is the Managing Director of Manfred Sauer UK Ltd. Barry is pictured here in 2007 with his 10 year old son, Sam.

Barry has had paraplegia since 1988 following a road traffic accident. He spent 5 months in Stoke Mandeville spinal unit returning to work 10 months after injury. It was at Stoke that he started ISC and it is his experiences getting to grips with managing ISC over the years that have provided the inspiration for this tutorial booklet.

After working in the computer and record industries, Barry joined the Manfred Sauer Company in 1995, and became part of the international Manfred Sauer team, being involved in product development, expanding the business and running seminars and workshops about 'continence management from the users perspective' from Scandinavia to Saudi Arabia. When Barry started, the only product the Company had available on UK prescription was the 'Big Bendi Bag', a Wee drainage bag specifically designed for wheelchair users. The current product portfolio has since grown to the most extensive and diverse available in the UK, with more size options offered than any other company in the industry, because people come in all shapes and sizes not just small, medium and large as some companies would have you believe! All designed by people who use them and backed up by a wealth of 'real world' experience. Barry also started the UK Manfred Sauer Helpline, a unique service backed up by the accumulated knowledge of more than 10 colleagues, that like him have direct experience of managing their own Continence problems, as well as a wealth of knowledge about what products are available and how to use them!

**“ We are happy to share our experiences with consumers and professionals – if we don't know the answer you can bet we can pass you onto someone that does! ”**

“If ever I were to write a book about my life experiences a great deal of it would involve the 'trials and tribulations' I have encountered since the age of 27, from my perspective as a wheelchair user.



The title would be something like

**“ If only I had known then, what I know now! It seems to me that disability comes with more than its fair share of lessons that are learned from the 'School of Hard Knocks'. I found Continence Management to be one of the biggest hurdles to get to grips with. ”**

If you have ever had an 'incontinent episode' in a social situation you will know exactly what I mean, with the feeling of 'will the earth open up and swallow me please' being at the forefront of your mind. Let's be honest here, if you don't have control over your bladder and bowels, lots of other stuff that seemed a priority like mobility and sexual function, get relegated in your wish list! In writing this tutorial and by sharing with you my personal experiences and knowledge of the industry,

I hope to supplement the information given to you by healthcare professionals regarding the medical procedure of ISC and help you adapt it to your lifestyle in the world you live! ”

If I have left anything out that you think people need to know or if you are not happy with any of the content of this tutorial, I would be grateful if you could write or email your thoughts to our helpline?

## Manfred Sauer

Manfred Sauer is the Managing Director of Manfred Sauer GmbH and its subsidiary companies, he was born in 1944. Manfred has had tetraplegia since 1963 after a diving accident in the UK. He was rehabilitated at Stoke Mandeville Spinal Unit in the days of its founder, Sir Ludwig Guttmann. In 1965 he began to develop and market condom urinals. In 1976 he launched Manfred Sauer GmbH, now a firmly established business enjoying a large share in the rehabilitation marketplace for Continence systems in Europe and an increasing market share in mainstream Continence management in the UK. Recently Manfred has realised his dream in the shape of The Manfred Sauer Foundation, which has a core philosophy of "Giving meaning and regaining a balance to life", to help people and their families with the psychological rehabilitation after traumatic accident or illness.

The Foundation is a not-for-profit organisation which has been funded and is supported from the profits of the commercial Continence systems manufacturing company, Manfred Sauer GmbH and its subsidiaries.

Manfred has given 97% of the Company to the Foundation, so essentially all the profits from the commercial Company after reinvestment to ensure its continuing existence, go to support the Foundation. So there are no 'fat cat' shareholders here! This is Manfred's legacy to give something back both to the disabled community all over the world who use the products, as well as to the local community who have worked on the manufacturing site and made the Company such a success over the years.

The foundation is a building complex the size of a small UK Shopping Mall based on the edge of a nature reserve near the picturesque German University City of Heidelberg. It provides comfortable affordable accessible accommodation for people of all abilities with a Health Spa, Gym, Physio and many alternative therapies - all accessible. Also offered are workshops in various crafts, culinary skills, nutrition, basic and advanced wheelchair techniques, computers and sexuality, along with up to date conference facilities. Healthy cuisine using local produce where possible is the focus for the cafe and restaurant and it even has its own Micro Brewery. The Foundation is a resource to be used by all regardless of ability!

