

Top Ten Tips

- 1 BE NOSY.** Find out about your child's individual condition: knowledge is power.
- 2** Get to know which specific symptoms affect your child's well-being and how to avoid the pitfalls.
- 3** Keep emergency phone numbers, patient number and drug list handy. Make sure everyone knows where they are.
- 4** Keep at least two weeks supply of appliances in hand. Allow for Bank Holiday delays with deliveries.
- 5** Keep a spare set of everything at friends, in-laws, grandparents etc.
- 6** Find and use your allies.
- 7** Learn your limitations and accept that you are not superhuman. There will be times when you are pushed to the limit, so when you need time out take it.
- 8** Get to know the best local toilet facilities. It makes life a lot easier if you are out on your own and need a toilet quickly.
- 9 DON'T PANIC.**
- 10** If you need help ASK!

Bringing comfort to parents who feel isolated

by Tracey Callow

My main aim in writing this column is to give a little comfort to all parents who feel isolated, angry, frustrated and fearful of living with a child who has a stoma.

No matter what sort of stoma your child has, I hope I can help. My own son Lewis who is two and a half, was born with chronic kidney failure and at the age of one he needed a vesicostomy.

This was the most wretched time in all our lives and I promised myself that whatever I could do to promote child stoma care issues, I would do whatever it took. Hopefully, after 18 months of research, constant nagging and the help and support of our wonderful stoma nurse and medical team, I have built up a pretty good library of useful addresses and organisations who can help and advise parents in our situation with everything from welfare rights, medical aids, financial help, spiritual guidance, holidays, respite care and so on.

My greatest hope is that all new stoma parents will have a point of reference for any information they require on any aspect of caring for a child with a stoma. This is especially needed for parents of small babies who face problems not only because of the size and age of their babies but the awful situation where a six month old, or sometimes even younger babies, cannot tell you where it hurts or if you are pressing too hard. It makes things so much harder than for older children who can express their fears and anxieties. Whatever the age of your child there are a multitude of problems, social, ethical and medical for which we need to find answers. I hope through this column I can offer help and

advice and a shoulder to cry on. I know first hand that its the hardest thing in the world to see your child ill when you are powerless to help them. Here's where the self pity ends and the fighting talk begins. If you have a particular problem or even have a few hints and tips to share with similar families please send them in to the address on Page 2 and together we can try to make child stoma care issues less of a taboo and as acceptable as other sections of the stoma fraternity. Get writing to me now - I'll do whatever I can to help

If you are interested, ConvaTec is planning to make available a copy of my booklet Living with a Child with renal failure and a stoma. This will be available on their Website www.convatec.co.uk in the near future. The booklet contains more useful hints and tips for coping with a small baby with a stoma.