Handinhand

Real stories • Real advice

Issue 31

Jody

l've had to explain to many people there are numerous amounts of reasons why a person may need a stoma, regardless of your age.





Dear Reader.

I'm delighted you have taken the time to read this insightful edition of Hand in Hand and I do hope you enjoy the variety of subjects it covers.

We wanted to share with you all that after 29 years of working at CliniMed and SecuriCare our friend and colleague, Neil Freeman (Managing director) will be retiring this summer. We spoke to Neil about his time at the company, which you can find on page 10. We'd like to thank him for his herculean contribution and hard work in supporting our patients, ensuring they received the very best products and service over the years.

On day 7 of my return to SecuriCare I was pleased to be asked to write the opening



introduction to the latest edition of Hand in Hand. Back in 2003 when I first joined SecuriCare, we had the pleasure of working with our nurses and patients to create the first edition (left). During those subsequent years and 31 editions later, the magazine

has gone from strength to strength and is well received by its readers. That first edition focused upon the friendly support you can receive when you contact us, and we're pleased to say that is still the case today. There is an excellent head office team and a highly professional nursing service committed to exceeding expectations and delivering better healthcare.

Now that we are edging forward with the UK & World opening back up again, we are committed to interacting with our patients, nurses, and colleagues to better understand what more we can do to support and develop our services. Also, there might be the opportunity to get away for a break over the summer, so please do let us know about your experiences.

As ever I would like to thank all involved in creating this edition and particularly those that have taken the time to contribute.

Happy reading!

Ben Miles.

Newly appointed Managing Director, For SecuriCare (Medical) LTD and CliniMed LTD

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T: 01628 850100 E: editor@securicaremedical.co.uk

Thank you to everyone who has contributed to this issue.

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Hand Hand



We are pleased to introduce the ten fabulous ladies who decided to take off their clothes and get out of their comfort zone in aid of raising awareness and increasing body confidence. We asked them all to share a bit about themselves, read all about it below.

7 I'm Jody, 28. Due to having an auto-immune disease when I was 21, I was left suffering from very severe bladder and bowel incontinence for many years. In March 2020 I had a surgery called Clam which helped resolve my bladder incontinence meaning I now must self-catheterise every 4 hours. As much as this made my life feel a lot freer and enjoyable, I was still left with bowel incontinence, and this was making day-to-day life very difficult. Between the bowel surgeon and I, we decided to go ahead with stoma surgery which I had in October 2021. After having my surgery, I started adapting to a new way of life I decided to join an online stoma support group where I quickly learnt that both men and women were suffering mentally from having a stoma and adapting to it. After my surgery many people couldn't understand why I had or needed a stoma, as I'm young and look 'well'. I've had to explain to many people there are numerous amounts of reasons why a person may need a stoma, regardless of your age. I felt there isn't much information out there regarding stomas and this led me to the idea of a group stoma photoshoot. My hope is that others see it and feel less alone, feel more comfortable in themselves, and don't judge others. Also, to help raise awareness around using disabled toilets without looking disabled. I then put this idea out there on a support group and got a lot of interest, I arranged a date with a lovely photographer and started a fundraiser where all donations go to Colostomy UK. Through doing this shoot I've met

incredible women, and I have made friends for life! Let's break the stigma regarding stomas and start sharing more positivity.

Hi, my name is Kayleigh. I'm 27 and I spent 10 years misdiagnosed from GP's, having me believe my illness was in my head. Since then, I've been diagnosed with Crohn's Disease, lost most of my intestines and gained a stoma! How you choose to react to your stoma is entirely up to you, but personally, it's given me a life worth living and connected me to so many wonderful people. I want others to see the beauty in having a stoma. After all, they save lives. Just remember, you're not alone in this. We're stronger together!

Anna, 22 - I was diagnosed with Ulcerative Colitis in 2018 whilst studying at university and was given my stoma in 2020 after having emergency surgery. My stoma saved my life, and I am forever grateful for it! I decided to do the photoshoot to meet other ostomates like myself and to raise awareness of stomas to show that not all illnesses are visible and younger people have stoma's too.

Emily, 28 - My Ulcerative Colitis flared whilst pregnant with my second child. I spent a month in hospital and 2 years trying all the medicines and barely eating or leaving the house. I had my lleostomy in lockdown after the pain got unbearable for me. I did this photoshoot for my

own self-confidence as well as to spread awareness.

Hello I'm Catherine and I'm 64 years old. My story is a little different in that there was not actually anything wrong with my bowel. In June 2021 I was diagnosed with Retroperitoneal Liposarcoma which is a rare form of cancer. I had a large tumour measuring 50cm by 25cm which weighed almost 2 stones the only treatment being surgery. My surgery was undertaken in July 2021 during which the whole tumour was removed along with my right kidney, and my right ovary. To give clear margins to prevent the cancer from spreading, part of my liver, bowel, intestine and muscle were removed too. When I was taken into recovery from surgery it was noticed that I was haemorrhaging so I was rushed back in for transfusions and to stop the bleeding. The origin of the bleed was the bowel which had been caught and to stop the bleed a stoma was developed. It was a shock to be told I had a stoma but am grateful that it saved my life. I wanted to be part of the photoshoot and fundraising campaign to bring about awareness that a stoma may be needed for various reasons and at any age.

Hi, I'm Jan, I'm 65-year-old, I was taken to hospital for emergency surgery after just having a twinge in my side. It turned out to be a caecal tumour which was removed, and an anastomosis was performed, (where they take out the diseased part of the bowel and join it up) however this wasn't successful, and I got sepsis. I was then taken back to theatre a week later where I woke up having had an Ileostomy which, to say the least, was a huge shock. I was in the intensive Care Unit (ICU) for a week with continued sepsis. It was a rough 6 weeks, but it saved my life for which I am very grateful. The stoma groups have got me through some tough times and doing this photoshoot hopefully will help others to see you can live a happy life, once you get the hang of it. I'm eternally grateful to still be here and connect with others who totally understand and hopefully. the photos give others a different perspective. There is life after a stoma!

Hello I am Gaynor and 56 years young. I had a slow bowel and had to have 12 laxatives a day. In 2015, I had a Sub Total Colectomy which is an operation to remove the colon, leaving the rectum behind. A few years later in January 2018 I was going to the toilet between 10-20 times a day and could hardly leave the house. From February I had to work from home, then in September 2018, I had surgery for a stoma to improve my quality of life. I spent a month in the hospital and had to be tube-fed. It took me a day to eat a jelly cola bottle! After 'Shamira' my Stoma, I can eat anything and do anything I am so grateful to have my life back and feel so lucky. When Jody told me I was going to be in the photoshoot I was truly honoured. I feel like I now have 9 new friends each of who are so

brave and inspirational and that we can achieve anything.

Jeanette 57. in 2020 I attended routine bowel screening, where I was found to have multiple bowel polyps. With this and my family history, I was referred to the Familial Cancer Service, where following genetic testing I was diagnosed with AFAP (Attenuated Familial Adenomatous Polyposis) – an inherited condition where bowel polyps have the potential to develop into cancer, caused by an abnormality in the Adenomatous Polyposis Coli (APC) gene. To prevent this, I underwent a pan-proctocolectomy and end ileostomy in February 2021 and 'Betsy' was born. Until this happened to me, I had no idea of the variety of reasons for people having a stoma. The screening has enabled me to be in control, albeit life changing when I had no obvious symptoms.

Hi, my name is Elizabeth, I was diagnosed with Ulcerative Colitis (UC) a type of irritable bowel disease in 2019. After multiple hospital admissions and failed treatments, I had emergency surgery to remove my colon in 2020. I couldn't wait as I wasn't living a life. My stoma has given me the opportunity to live a better quality of life. I did the photoshoot to raise awareness for fellow ostomates.

Hello I'm Casey, I'm 29+1 years old. I was misdiagnosed all my teen years with irritable bowel syndrome (IBS) and finally had the correct diagnosis of Crohn's disease at 21, when I was pregnant. I had my first flare up during pregnancy and was treated with emergency care for me and my unborn baby. I was in remission for 7 years and had my second flare 2021. Medication didn't help and had a lot of my small bowel removed. It was either stoma or my life. We are strong, and I'm glad I had the chance to meet other brave women and for us to spread awareness.





Q&A with Jody

organiser of the stoma photoshoot

When and why did you have your Stoma formed?

After many years of severe bowel incontinence due to nerve damage I decided to go ahead and have my stoma formed in July 2021. After discussing this with my bowel consultant I went ahead and had the surgery done in October 2021, I only had a short stay of 3 days in hospital and was back home for Halloween with my children. Looking back on the many years of having accidents I wish I had agreed to have the stoma sooner!

What did you find was the hardest thing to adapt to after surgery?

For me having my stoma surgery has all been positive, as it has given me a better quality of life. I could go out more to socialise and doing activities with my two children rather than the constant worry and battle of having accidents out in public. However, I believe there is a great difference of how people adapt to their stoma, depending on their reasoning for having one. A good example is that many people have had a stoma formed due to emergency surgery being needed for many different reasons, therefore it's harder to adapt. I imagine it doesn't feel like a positive change for those people, making it harder to accept because in most cases they don't have the time to process it mentally, whereas I had a lead up of having it done. If I had to think of the hardest thing to adapt to, I would say the changing of the bag when out and about. It's a lot easier, convenient, and comfortable to do this in your home. I'd say another thing is seeing the stoma for the first few days made me feel squeamish, but I soon got used to it and it just became normal.

Q How has self-catheterising changed your life?

Wow this is a big one for me! Yes, as much as my stoma helped the quality of my life, I would have to say the biggest and best change for me was my bladder surgery! My bladder accidents were a lot more frequent than my bowel and I felt as though this was harder to deal with both mentally & physically. I had the surgery in March 2020, this is called Clam, it's a very rare surgery that doesn't happen very often as you must meet a very certain and specific criteria to be eligible to have this done. This consists of some of your bowel being taken away and added to your bladder, this has meant my bladder no longer contracts to be able to release urine on my own without the aid of a catheter. After the surgery, I no longer have any bladder accidents or leaks, keeping me dry and free from the constant battle of keeping clean. This has been life-changing for me, and I will forever be both thankful and grateful I was able to have this done.

Due to it being a very big surgery I had a long stay in Nottingham Hospital, which was quite far from home making it difficult mentally, I missed my friends family and home. The recovery was a very long and hard battle where I was hospitalised again and needed a lot of care however with this in mind, it was still very much worth it. The hardest part since

having the surgery and adapting to my new way of life is with the surgery being very rare, in my experience- when I've been admitted, monitored or for further surgery in hospital, not many nurses and doctors are aware of it. I've had to explain to them myself as most don't know about this type of operation and what it means for the patient. Self-catheterising gave me a new sense of life and brought me so much happiness, I felt my life was controlled by my bladder after having accidents starting from the young age of 21 and I finally got my life back thanks to the amazing surgeon and team at Nottingham hospital.

How did friends and family perceive your bowel and bladder incontinence?

Luckily for me all my friends & family have all been very supportive from the very beginning of my illness and what came with it, I was open about it from the beginning, so it wasn't hard to have to tell them one day further down the line. I was very comfortable telling them everything, there has been many times I have called them to say I had an accident somewhere bad! I've had an accident whilst having a job interview another time whilst having a tattoo and so on, we would all find a way to laugh about it making me feel a lot better about the situation.

My Husband has been amazing throughout the whole journey never looking at me any differently. Whether I was having bladder or bowel accidents, wearing incontinent pads or having my stoma, he's always made me feel beautiful and lifted my confidence. I think this is a massive help with accepting it yourself. He's helped me on many occasions when being out in public after having accidents and been very understanding about it all. Friends have helped me change my bag in public toilets by passing me everything I need rather than me having to put things down on unhygienic areas. They were all brilliant throughout me having both surgeries, they came to visit me and helped me through it. I'll forever be grateful for the people I have around me.

What made you join the online stoma group?

I joined the online Stoma Groups whilst I was in hospital recovering from the surgery patiently waiting to go home giving me a lot to read and keep me busy! I joined the groups to learn as much as I could about stomas and the new life I was about to face. I found so much information from these groups, so much love & support. I advise anyone going for a stoma or having one to also join, if possible. You don't feel so alone in a group of thousands of people all sharing the same journey. People share their own personal stories, ask for advice, sharing tips & tricks with managing things, such as the best creams for sore skin, what bags to use, discussing options and many more.

Of course, with every group there has been the odd bit of negativity on there from certain people but mostly it's such a wonderful group of people all willing to help each other. There are also the sad posts about people struggling mentally since having a stoma, having a hard time adapting and accepting, and finding it hard to open-up and tell loved ones. It was these



SecuriCare Sponsorship

We're thrilled to sponsor Team Colostomy UK for the fifth year.

In 2018, Colostomy UK formed their own Rugby League Team, Team Colostomy UK, with the aim to raise awareness around having a stoma and prove that having a stoma doesn't have to stop you taking part in even the toughest of team contact sports.

Team Colostomy UK were able to play multiple matches against other teams throughout 2018 and 2019. Unfortunately, the team were unable to play in 2020 due to the COVID-19 pandemic, however play resumed in 2021 once restrictions were lifted and the team are now entering this year's rugby season with a bang in an all-new kit!

We're thrilled to be able to sponsor the team kit for another season. If you fancy grabbing one for yourself, you'll be helping to support the charity and inspire others around you. The new 2022 kit is available to purchase at the Colostomy UK online store visit www.colostomyuk.bigcartel.com

TEAM Colostomy



If you're interested in getting involved, more details can be found over at www.colostomyuk.org/active-ostomates/team-colostomy-rugby-league

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Saying goodbye is never easy

Neil Freeman, Managing Director of CliniMed & SecuriCare has decided to retire this year. Honouring his 29 years of unwavering commitment to our team and commemorating the legacy of dedication he has left behind, we decided to do a Q & A to delve into his time at the company. Saying goodbye is never easy however we want to wish him the best in his retirement.

- How long have you worked for CliniMed?
- A I joined on the 17th of May 1993; I have worked here for 29 years.
- How many staff did the company have when you first joined?
- I would say across CliniMed and SecuriCare there might have been around 50 staff in total, it was pretty small. In comparison we now have 5 times that, with over 250 staff.
- What was your biggest learning curve?
- The biggest thing for me is that I've realised that you really do need to be a part of, and rely on a team of people, it's got to be a team effort. You can't do anything in isolation, you rely on everyone around you and certainly in the role I do now, I 100% rely on everyone to be pulling in the same direction. Teamwork has always been key for me, maybe not the biggest learning curve but I've realised it an important part of what we are about.
- Which one of our corporate values would you say mostly aligns with your personal values?
- Teamwork. Without teamwork we wouldn't be able to provide the services that we do.
- What is the biggest evolution you've seen the company experience?
- A I think in the time I've been here there would be a few things that come to mind, one being the introduction of the flushable pouch, that was a huge thing. For many people that don't know, the O2 arena, which was then known as the millennium dome, had a display called the spiral of innovation and our flushable pouch was featured in there for the whole world to

see. Outside of that, I'd say the evolution of the home delivery service over the years because that's the part of our business that has grown dramatically over the time.

- Which one of the CliniMed products did you find to be most innovative?
- A It's got to be the flushable pouch and then alongside some of the accessory items we have introduced over the years, such as Appeel and LBF.
- What was the most challenging time of your career?
 - For me personally, there was a time when I went and worked in the Czech Republic, I was given the opportunity to lead the project of setting up a manufacturing unit in a town called Vodňany. For this project I worked in Czech Republic for two and a half years, traveling on a Monday coming home on a Friday, leaving my wife and family here in the UK. Living out there on my own was new for me, in a country I couldn't speak the language, still didn't learn very much of the language towards the end. The building was empty when I got there, we turned it into a full scaled production facility, that's one of two things I'm proud of in my career. The other being offered this role of Managing Director. There were some funny times in Czech Republic too, one of the first few days when I was out there, I came across a drive





through Kentucky Fried Chicken (KFC). I thought that would be simple to do, I go to order and realised I can't speak any Czech and the person behind the counter couldn't speak any English, so I was trying to order my food by making impressions of chickens, but when it came to ordering fries, I couldn't quite work out how to make an impression of chips, it was quite funny. I learnt enough Czech to order KFC going forward.

What was the most enjoyable time of your career?

That's difficult to answer because I've enjoyed every role I've taken on, for different reasons. I've had many roles over the years, when I first started, I joined as the accountant, then later took responsibility for IT, then I looked after the facilities and went off and did a course in facilities management. I then went on to looking after the distribution side of the business, I also had the Czech Republic task and then came into this role. It's been one different challenge after the other and they have all been equally enjoyable. It's been nice to have the variety when I've not been completely able to do something at the start but giving it my best shot. Where I lacked in knowledge, I made up for it in effort. I'd encourage anybody to challenge themselves, the reality is when you get behind the smoke screen, you'll find you can do most things. You'll never know where you will end up. Don't restrict yourself!

How would you describe CliniMed and SecuriCare to someone who is starting new at the company?

A I believe we are very friendly and open; my door is always open to anybody who wants to talk about anything, and I think most people are like that, we get some great feedback through the inductions. We want to share what we do, and I believe we live up to our values.





What are your plans once you retire?

I haven't made any hard and fast plans; I always had an aim to retire at a certain point and this is the point. As it's getting closer and closer to the time, it's becoming more real, and I do have to start planning things. Initially I want to take some time out and relax maybe do some travelling. In the future I'd like to do some voluntary work, I'm even considering training to become a magistrate to put something back into the community



A fond memory

"I recall a sales conference where we had a fancy-dress theme. While Stuart, Neil and I walked to dinner Postman Pat (aka Neil Freeman) drew many a bemused look and comments. Hands down the best Postman Pat ever!"

-Mike Kerns (Operations Manager)

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Registered office: Cavell House, Knaves Beech Way, Loudwater, High Wycombe, Bucks HP10 9QY.

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Challenge yourself

Introducing our 3-day full body workout for ostomates

We've worked with Personal Trainer, Danny Callaghan, to create a 3-day workout plan for you to incorporate into your week. focussing on building strength across all muscle groups: upper body, legs, and core.

With the right support and guidance, weight training can be physically and mentally beneficial for ostomates.





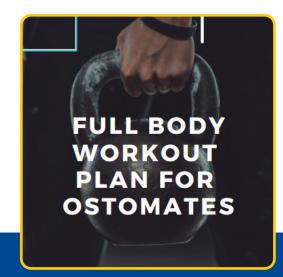
"If I'm training, it gives me the freedom of movement without worry and also gives me something to help heal the skin at the same time"

Danny Callaghan

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Being an ostomate himself, Danny has used exercise to help him focus on achieving goals, taking on new challenges, and proving that having a stoma doesn't have to hold you back.

Always ensure you speak with your stoma care nurse to make sure you're ready to take up an exercise routine.



Get your free fitness guide

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Celebrating

10 Years of Service!

PharmaCare, our in-house pharmacy, has reached its 10-year anniversary this year!

10 years ago, when we first offered the PharmaCare service, our aim was to provide an additional service, which enables SecuriCare patients to combine the delivery of their stoma or continence supplies with their medicines. Rather than having to collect prescription medicines from the pharmacy, PharmaCare enables patients to receive their prescription medicines along with their appliances in one convenient package.

The PharmaCare service was rated positively on the last survey we conducted, with 98% of people giving the service a rating of good or above. The PharmaCare team look forward to continuing to provide a great service for many years to come, as well as celebrating many more anniversaries.

PharmaCare



PharmaCare

Pharmacist 1



- Can PharmaCare offer me the services that I can receive from my high street pharmacy?
- Like any community pharmacy, we dispense NHS and private prescriptions. If you have questions about your prescription, we can offer a prescription advisory service to give specific advice about your medicines. Plus, we can support you with repeat dispensing, advice regarding new medications and prescription management. We can also deliver to family members at the same address.
- Can I receive my stoma/ continence supplies and medicines together?
- Yes, we can deliver your stoma supplies with your medications in one discreet package. We can also deliver separately when required.

- Can I speak to a Pharmacist?
- Yes, you can speak to a Qualified Pharmacist Monday-Friday 9am-5pm. Your dedicated Pharmacist will get to know your needs and can provide a personalised service every time and can provide you with advice regarding your medications.
- Is it easy to order?
- You can place your order via Freephone, post or email. If you are using the SecuriCare home delivery service, simply request to start using the PharmaCare service and start adding your prescription medicines to your future orders.
- What happens if I receive, for example, an acute prescription for antibiotics?
- We understand the urgency for certain medications, so depending on stock these would usually be delivered the next day.



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CliniMed Ltd. Cavell House, Knaves Beech Way, Loudwater, High Wycombe, Bucks HP10 9QY

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When the apprenticeship program ends, a career starts.

We are delighted to announce that three members of our team have now completed their apprenticeships and have become fully-fledged, Patient Development Specialists. As part of the apprenticeship role, they would have rotated across four different teams within the department, taking on various responsibilities. The apprenticeship program has been a huge success and we have asked them to share a little about themselves and their roles. We have no doubt that they will continue to shine, and we aspire to continue to develop and support their careers.



Amy Lockhart-Wheeler

Hi, my name is Amy I am one of the Patient Development Specialists at SecuriCare. When I left school at eighteen, I knew that I didn't want to go to university and despite my school trying to force me to go, I decided not to. I spent a couple of months working in a local fruit and veg shop - the place where I had held a Saturday job for the past couple of years. I knew I wanted a qualification, so I began looking into apprenticeships. The Business Administration Apprenticeship offered by SecuriCare was an ideal fit and I started in January 2019. During my time as an apprentice, I worked in both the administration team and Patient Services and on completion in April 2020 was offered a permanent position as a Patient Development Specialist. Whilst not

exclusive, I am responsible for patients in the Warwickshire area. The job has challenged me in many ways and built my self-confidence. When I started, I hated speaking on the phone, now it's second nature to me. Purely by chance I have met a truly inspirational young lady (28 years old) who is a user of our products, and she has made me realise that all our customers should never feel inhibited, excluded, or prevented from living their lives to the full because of needing our products.

During lockdown whilst working from home I took up exercise and in particular running. Last October I completed the Liverpool half marathon raising over £1000 for charity. Outside of work I have a horse named Boo who takes up a lot of my time. I try to ride as often as possible and my aim for this summer is to compete in horse riding. I also go to the gym regularly and have a keen interest in photography. Whilst studying for my apprenticeship, one of the units focused on Human Resources (HR) and this is the field, I would really like to work in. To that end I am currently studying for my CIPD level 3 qualification with the ambition of moving into HR at some point in the future.



Holly Norris-Hill

Hello, my name is Holly, and I was the first apprentice within SecuriCare, starting in October 2019 and finishing in November 2020. I started in our administration department for a few months to understand the handling and processing of prescriptions, sorting and distributing the post and setting up new patients onto our service. After gaining the knowledge and confidence in administration I moved over to the Patient Services Department where I was given part of the Durham and Darlington County. During my apprenticeship I was attending Henley College once a month to go through any coursework which I needed help with, or to complete any online exams. One of the first challenges I had was being on the phone, whether it was an incoming or outgoing call, as this was not something I had done

before. I learnt to be open and transparent with all patients and the importance of confidentiality. This gave me a bond and trust between me and my patients.

One of my biggest achievements was firstly passing the apprenticeship, but also when I was given the full Durham and Darlington area to look after.

One thing that I got used to and ended up loving were the nicknames I was given such as 'Petal' and 'Pet'.

I have currently been working here for nearly 4 years but have decided to venture into accountancy and I'm currently studying an AAT Foundation course in accountancy. This year I have signed up for the Midnight Walk to raise money for the Florence Nightingale Hospice. They have announced that this will be unfortunately the last one they will be doing so I am aiming to raise as much money as I can!



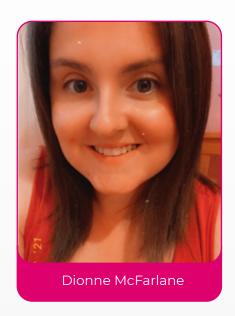
Rebecca Warren

I joined SecuriCare back in September 2020 on a Level 2 Customer Service Apprenticeship. During this apprenticeship I got to work in different departments, gaining a wide range of knowledge about the business. I started in the administration team, to learn how SecuriCare operates behind the scenes. For example, sorting out prescriptions, contacting GP Surgeries etc. After 3 months I then moved onto the Patient Services Team which was much more customer focused. I was in this role for 9 months and I had the responsibility of managing patients. This consisted of calling patients monthly to place orders, dealing with any stock issues, sorting out order queries etc. Whilst

I was working, I also had regular meetings with my college tutor, where I was set different assignments with deadlines to meet. To complete the apprenticeship I sat a test, alongside all of the hard work I completed over the year, I scored 100% and a top distinction grade! After my Apprenticeship came to an end, I considered my next step. I knew I wanted to stay at SecuriCare, but also had a passion for Sales. So moved into an opening in the Business Development team, at the beginning of the year and am loving every moment of it!

I first thought about completing an apprenticeship, in my last year of school as I was always keen to go straight into the work life environment. It was the best decision I've made as I love the fact, I am helping people as well as working. One of my favourite parts of the job is building the relationships I have made along the way, with both the patients and my colleagues. When you speak to the same patient on a regular basis, you build a good relationship with them, and you look forward to hearing how they are. Overall, I have really enjoyed being a part of SecuriCare and am excited to see where I go from here.





Endometriosis & Me

From the minute I started my periods they were always so painful and heavy. I assumed this was 'normal' and I held onto the hope that it would probably "get better as I got older," something I heard a lot over the years. I was in so much pain and there were times the pain stopped me from going to school. It was the type of pain that painkillers didn't touch. After 6 years of what I thought were crippling period pains, I was finally diagnosed with Endometriosis in 2016 after having laparoscopic surgery.

Endometriosis was a word I had never heard of, and in that moment, I didn't know how much my life was going to change. Endometriosis is a debilitating condition, it's when tissue (lining of the womb) grows in other parts of the body such as on the bowel or bladder. I was diagnosed with stage 4 Endometriosis which is a severe form of the condition.

I have had 4 surgeries for the condition and have tried multiple different treatments to try and manage it. I am currently on an injection

Decape triptorellin Powder for for intramuse IPSEN

Dionne's story

called Zoladex which puts my body into a chemical menopause. It's hard being 24 and experiencing menopause symptoms.

My day-to-day life is impacted massively by the condition, I constantly experience issues with both my bladder and bowel. From one of the surgeries I had, they found that I had endometriosis on my bladder, and this caused my bladder to become overactive. I had lived with bladder issues for years and suffered from Urinary tract infections (UTI) which would be treated with antibiotics. I wanted to feel as if I was managing the symptoms myself, so I tried some self-help approaches of taking supplements and drinking cranberry juice to see if it would help things.

At the start of the pandemic, I had to go to the hospital as I went into urinary retention, a condition in which you cannot empty all the urine from your bladder. From a scan, they discovered I had 700 ml of retained urine, so they inserted a catheter to drain my bladder.

After a few months, I had an appointment with Urogynecology, this is when I was taught how to self-catheterise. I wasn't aware of how endometriosis could impact the bladder until I started experiencing problems with passing urine. Being taught how to do Intermittent Self Catheterisation (ISC) was a bit overwhelming at first because I was worried about doing it wrong and it being painful. It took time to





adjust to learning how to do ISC, but I realised that the positive thing about it was that I didn't have to sit and struggle to pass urine as there was times, I would spend up to 45 minutes in the toilet straining and nothing would happen. It also gave me that reassurance that I was fully emptying my bladder and I noticed I was a bit more comfortable pain wise because when my bladder was full my abdomen would become distended, and I was in a lot more pain. self-catheterising is something I now do six times a day.

In terms of day to day and doing ISC I have found it helps to have a small bag which has my supplies in it. The most useful items I have found are disposable bags for putting used catheters into, I always carry a few catheters with me, hand sanitiser and some wipes. I've found when I'm out and about or at work there is a sanitary bin which I can dispose the catheters in, so I haven't had to worry about that side of things. It just helps me mentally also knowing that I have supplies at hand when I need them and because they're in a small bag and I can take that small bag into the toilet with me and have everything at my side ready to use. I have realised that doing ISC is nothing to be embarrassed about and I have met quite a few people who are in similar situations and use catheters. It's nice to be able to have a conversation about it and be open. It's the same with family I can speak to them about it and they're incredibly supportive.

I wanted to see what self-help options I could try to see if that helped my bladder symptoms, so I started seeing a Women's Health Physiotherapist at the start of January. At my first appointment I found it extremely helpful and the advice I was given was very useful and I learned a lot about the pelvic floor.

My physiotherapist is very supportive and knowledgeable about Endometriosis which really does help. She has taught me so much in that short space of time and has gone through pelvic floor exercises and done some work on the muscles. I have had a couple of sessions now and I've found so far that it is having some benefits.

I've always been quite open about my experience of living with endometriosis. I use social media as a platform for raising awareness.

I created an Instagram account called @endowarrior_x to share the reality of what living with this condition is like.

I receive so many messages from people who either have the condition or are waiting to be diagnosed and giving someone that space to talk about it is so important. Since talking about bladder issues I've had other people reach out and share their experiences with me.

Support when living with any kind of health condition is so important as it's easy to feel isolated and alone. I am quite open about the condition and am happy to speak with and support anyone. I know when a person is struggling it can be hard to reach out and ask for support but there is always someone who is willing to listen and be there to support you. I've also realised just how important bladder health is and how it needs to be talked about more. This is an area that I will continue to raise awareness about and share my experiences to help other people.

Jane's ISC Journey

In 2017 at the age of 60, Jane was diagnosed with stage 2A cervical cancer. Her treatment included a radical hysterectomy which caused nerve damage to her bladder resulting in her needing to use catheters. In this article, Jane shares some of the challenges and lessons she's learnt over the years.

Urinary Retention

Following my diagnosis of cervical cancer, my radical hysterectomy was performed using a robot assisted keyhole technique, which thankfully, has a quick recovery time. I was discharged from hospital the day after surgery with a Foley catheter and leg bag in place to help my bladder recover.

After a week with my Foley catheter, I had an appointment with a Gynaecology nurse to have a "trial without catheterisation" or "TWOC" and unfortunately was unable to pee a drop!

Over the following 3 weeks my catheter bag was replaced with a flip flow valve, and I had a course of medication to try to stimulate the bladder muscle. But to my dismay, I remained in total urinary retention.

When I had my flip flow, my bladder occasionally contained up to 700ml of urine. I was later informed that I shouldn't allow my bladder to fill beyond 500ml, to prevent it getting overstretched which can lead to damage of the bladder muscle!

22 Jane's Story

Starting Intermittent Self-Catheterisation (ISC)

After another trip to gynaecology outpatients, I was taught to self-catheterise by a nurse. The nurse asked me to sit on an examination couch with my knees bent and apart, a mirror and light positioned so I could view my urethral opening. I was then handed a foil packet containing a disposable catheter and the nurse talked me through the ISC procedure as I performed it. There was only time for 2 attempts, both of which I needed assistance. I was instructed to self-catheterise every 4-6 hours, and I was sent home with a carrier bag full of catheters.

I still remember walking to the railway station with a growing sense of fear and dread about how I was going to manage with a sensationless bladder, my questionable skill and a plastic tube.

The next 24 hours were challenging, I made my husband be with me while I self-catheterised, even in the small hours of the morning as my anxiety was off the charts.

In the afternoon of the following day, I only got about 50ml of urine from self-catheterisation and as the evening approached, I started to get abdominal discomfort. I panicked and called my GP surgery and through sheer luck, a district nurse was on site and came to my rescue. It turned out I had about 800ml of urine in my bladder! The nurse explained that once urine starts to flow, it's important to push the tube in a bit further (1-2cm) to ensure the eyelets of the catheter are fully in the bladder to ensure complete emptying.

So, I was now at a point where I could reliably self-catheterise, albeit I encountered problems with urethral trauma and discomfort whilst

inserting the catheter tube. I eventually realised that, as well as relaxing, it helped to imagine where my bladder was and to angle the catheter tube appropriately which made all the difference.

After about a month, I relieved my husband from his ISC supervision duties. I set an alarm to wake me to self-catheterise during the night as sleeping through to morning with an overly full bladder was a concern for me.

Urinating naturally

I was advised to try and urinate naturally before self-catheterising and after about 2 weeks, it was very exciting to feel a trickle of urine albeit little more than a spoonful. Celebrations unfortunately didn't last long as I received some bad news. My post hysterectomy histology results indicated further treatment was required and so, I underwent intense chemoradiotherapy for 5 and a half weeks. The whole process was very distressing and unfortunately, during that time, I relapsed back into total urinary retention.

To help with discomfort/ difficulties whilst inserting/ withdrawing the catheter:

- Place a small blob of suitable lubricant on the end of the tube
- Imagine where the bladder is and angle the tube appropriately (check online for a diagram if you're unsure!)
- Relax. Breathing out slowly whilst withdrawing the tube can be helpful.
- Body position makes a difference, so it's worth experimenting

Not long after finishing my treatment, it was a great relief to find I could once again urinate naturally and over the following few months, the volumes I could pass gradually increased, as did the sensation in my bladder!

Jane's Top tips for ISC

(Based on personal experience)

 Avoid letting your bladder contain more than 500ml of urine. Occasionally check residual volumes and if applicable, check volumes naturally urinated too!

To reduce the risk of UTIs:

- Follow medical advice on how often you should self-catheterise
- Wash hands before and after ISC
- Use a mirror to locate the urethra, touch or instinct work well for some
- If the tube touches anything before the urethra, use a new catheter
- Take care to empty the bladder completely. Once urine starts to flow, push the tube in a 1-2cm further to ensure all of the eyelets are fully inside the bladder. When the urine flow ceases withdraw the tube slowly and stop if more urine starts to flow
- Keep pubic hair trimmed
- Keep well hydrated, limit caffeine and alcohol intake
- Speak to your doctor or nurse about home remedies that can help reduce urinary tract infections



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Our competition winner tells all

By Chris Forbes

My story is a bit of a long one! So, I'll share the shorter version with you today.

About 12 years ago, I had an injury at work that resulted in my 2 lower discs prolapsing and pressing against my nerves. This left my back permanently in spasm, leaving me with severe pain in my legs and unable to go to the toilet. I spent about a year sleeping in a reclining garden chair in my living room as it was so hard for me to get up the stairs. On the days I could make it up the stairs I was so uncomfortable in my bed that I couldn't sleep.

There wasn't much that could be done medically to help me, it was just a case of wait and see what happens. I was very optimistic and determined to live my life to the fullest despite the accident. Whenever I came across anything that would or could help me, I was enthusiastic to try. That included things like catheters, walking aids, aids that helped me get dressed myself, who knew socks could be so difficult!

Fortunately for me, over the next several years my back began to spasm less, my mobility improved and the discs slowly, very slowly,

retreated into place, I was back to normal or so I thought. Around 6 years ago I started to feel a tingling in my feet when I went to bed at night. It felt like very mild 'pins & needles' and I didn't give it much thought. The pins & needles began to progressively spread into my legs, body, and arms, and I would start to feel it throughout the day. Slowly, the tingling turned into pain, mild at first but over the course of about a year or so, my mobility began to decrease. It started with me needing one walking stick, to eventually using crutches, to me then needing a mobility scooter to leave the house. Another indicator of how things got bad, was that I needed to use the catheters again. It was certainly worse than the first time around; my specialist doctors were at loss to explain what was happening to me.

When these issues started to resurface it really took a toll on my mental health, I couldn't stay as positive, this time around. I felt ashamed of what I was becoming, I felt like a failure as a husband and father, and I couldn't see a future for myself. If I had been on my own, I don't know where I'd be today. Not being alone and having my wife Rhonda made all the difference for me, she saw I was struggling mentally and encouraged me into counselling. Overtime, with the help of those around me, I was able to see that these negative thoughts I was having



share a goal you have on 'getting out and about' so I thought it was worth a try. My goal when I entered was to become more confident when going out and about with my wife and kids, which I haven't done much of since the injury, I also wanted to give my wife Rhonda a break, as she's been a huge support to me and the boys. After entering, I completely forgot about it, then a few weeks later I got a call to say I was a finalist, and they wanted some more info about my story, and they'd get back to me. I know everyone says this, but I genuinely didn't think I'd win but sure enough a week or so later I got the call to say that I had won!

It was fantastic news to receive before Christmas! We decided as a family that we wanted to go down to Chester Zoo, as the boys love watching it on TV!

were exactly that, just thoughts! And a thought can't define you!

It took a long time and there are plenty of ups and downs. I was able to see myself through the eyes of others, that I was loved, respected, and needed and slowly but surely, I could see a future for myself. I know that may all sound cliché, but it doesn't mean that it's not true, and although writing it down for a short excerpt makes it all seem overly simplified but if anyone reading this is struggling mentally then please, reach out and ask for help. Things may seem bleak, but there are people around you who love you and will fight for you! As things were getting better, last year I finally got some clarity when I got my diagnosis! I had developed Degenerative Spinal Disease as a result of my initial injury.

I still struggle a little bit with family days out, a small trip here or there is fine but to travel for any length of time and spending a day somewhere is a real physical struggle. We have 3 young boys and I'd love to be able to take them away for a 'special' day away rather than Rhonda having to do it by herself while I stay at home.

I came across the SecuriCare 'Looking after me' competition, I don't tend to enter many competitions, mainly because the ones I do I never win. To enter the competition you had to From where I live, it would be possible to do Chester as a day trip, but for me, there's no way I would be able to do it in one day, so I am glad we stayed overnight at a local hotel. It made the world of difference and opened up a dream family day for us. The boys spent the day being amazed by all the animals that we saw, and you could feel the excitement and joy exuding from them. I also wanted to make sure Rhonda got to do something without having to worry about us. SecuriCare also arranged for her to have a beauty treatment and afternoon tea. I can only give everyone at SecuriCare and the 'Looking after Me' team my genuine heartfelt thanks!!





n a partner suffering from an injury.

The stress that I felt wasn't put on me by Chris, he tried as much as he could to hide his pain, to mask the difficulties and to keep going. The reality however was that the normal things we had shared together he could no longer do, things like housework, cutting the grass, cleaning the cars, decorating, shopping, standing to cook was even at times too much.

At first, I was very much head down and just keep going, but the reality of that had to hit at some point and it was about 4 years later I had to take time off work to unravel my grief, of what could have been and what life now was.

One of the most difficult things was that no specialist was able to give Chris a definite diagnosis, we would spend months working our way towards an appointment only to walk out crushed, feeling there was no hope and no real help to enable Chris to manage pain.

Over the years we have had a lot of ups and downs, Chris can have some terrible days, there are falls, migraines, unmanageable pain etc. Over last few years we have had the challenges around accepting that Chris needing a mobility chair, we needed a downstairs bathroom and bedroom, as well as an automatic car and other aids. All difficult to face when you are not even 40 and the cost implications.

Our 3 boys simply see their dad as their dad, I used to cry over what they had missed but ultimately Chris has had to focus on what he can do with them especially on the good days. Our boys, our faith, family, and good friends are what get us through, and it has become our new normal!

Our 3 boys are the joy in our lives (and the crazy) so to find out Chris had won the SecuriCare Looking After Me competition was unbelievable; we've never won anything! Chris entered the competition as he wanted to be able to gain more confidence to go out as a family. SecuriCare arranged for us to go to Chester Zoo, the boys were so excited. We had our trip to Chester Zoo, and We all had a fabulous time and have created a lovely memory! Only made better for the boys by the gift shop!

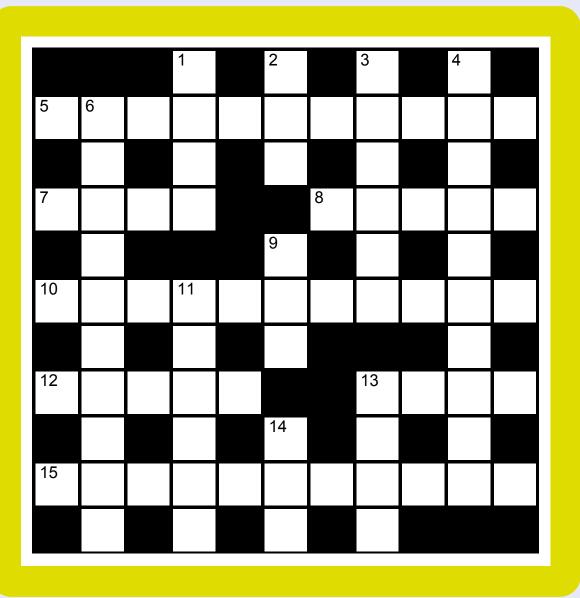
In hindsight the travel was a lot for Chris, which I am so proud of him for being able to do, although he needed a few days to recover he accomplished the goal he had set himself at the beginning of this competition!

Chris also said he'd love to give me back some 'me time' as I've always assisted him and the kids, SecuriCare also arranged for me to have a beauty treatment and afternoon tea which I can't wait to do. Chris winning the 'Looking After me Competition' has really given us something to look forward to, thank you to SecuriCare for giving us a day we will always remember.

Handin Hand Issue 31



CROSSWORD



Across

- **5** Petty (5-6)
- **7** Stump (4)
- 8 Farm bird (5)
- 10 Degree of excitement during a debate (11)
- 12 Open space in a forest (5)
- 13 Central Chinese desert (4)
- 15 Unentitled (11)

Down

- 1 Thick slice (4)
- 2 Large flightless bird (3)
- **3** Open up (6)
- 4 Quantifiable (10)
 - 6 Birthplace (10)
- 9 In favour of (3) 11 Dais (6)

- **13** Present (4)
- 14 Fenland cathedral city (3)



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Issue 31

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Ultra & Frame

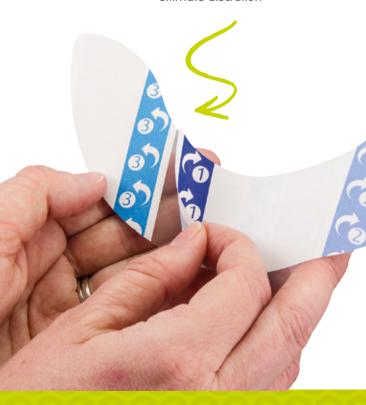
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Stema support groups 1000



Ayrshire & Arran Stoma Support Group

First Saturday of every other month (October, December, February...) 2pm – 4pm.

Ferguson Day Unit, Biggart Hospital, Biggart Road, Prestwick KA9 2HQ.

For further information contact Jim on 01292 220945 or 07729 771350 or email jimkraz@virginmedia.com

We request a small donation to the tea/coffee/ biscuits fund, a newsletter is sent out prior to each meeting for the price of five stamps or free if by email.



Bishop Auckland Stoma Care Group

Every other Thursday at 1pm. St Mary's Church, Vart Road, Woodhouse Close Estate, Bishop Auckland DL14 6PQ.

For further information contact Betty 01388 814535 or Maureen 01388 818267



Carlisle

Every 2 months (October, December, February...)
11am – 12.30pm.

Harraby Community Centre, Edgehill Road, Carlisle CA1 3SN



Cumbrian Bellies

Search 'Cumbrian Bellies' on Facebook and Instagram! For information about the next meet-up please email Nicola on rowson.nicola@yahoo.co.uk



Darlington Stoma Support Group

3rd Wednesday of the month between 6pm – 7.30pm.

Harrowgate Club and Institute, Salters Lane North, Darlington DL1 3DT.

For further information contact Sister Jacqui Atkinson on 01325 743005



Dartford Ostomy Support Group (DOGS)

3rd Wednesday of the month. St Anselms Parish Centre, West Hill, Dartford DAI 2HJ. For further information please contact Susan Norris on 0794 8974 350



Durham and Wearside Crohn's & Colitis Support Group

Every 3 months (June, October...) 2pm – 4pm.

Chester le Street Cricket Club, Ropery Lane, DH3 3PF.

For further information please email dw@groups. crohnsandcolitis.org.uk



Durham Stoma Support Group

First Monday of every month between 4pm – 6pm.

Old Trust Headquarters, University Hospital of North Durham, North Road, Durham DHI 5TW.

For further information contact Sister Katie Sewell on 0191 3332184



High Wycombe Stoma Support Group

12th July, 13th September, 8th November 2019 10.30am – 12.30pm. Wrights Meadow Centre Wrights Meadow Road, High Wycombe, Bucks, HP11 1SQ. For further information call 0800 318965



Horden Stoma Support Group

First Monday of every month between 10am – 12pm. Horden Youth & Community Centre, Eden Street, Horden Peterlee, Co. Durham SR8 4LH.

For further information contact Claire on 0191 5863520



Inside Out Stoma Support Group

Zoom 'Coffee Morning' meetings every two weeks St. Mark's Hospital, Watford Road, Harrow HAI 3UJ.

For further information please email Barry Caplan on abmc23@virginmedia.com or call 07811 084 514



Kirby Ostomy Support Group

Once a month on a Saturday from 10.30am – 12.30pm

For further information please contact Janet on 01162392844 or 07464957982

Email:

kosg2013@btinternet.com



Mercia Inside Out Support Group, South Derbyshire/ East Staffordshire

Bimonthly afternoon meetings from 1.30-3.30

Stanton Village Hall, Burton upon Trent, DE15 9TJ

For more information contact Sally Chester on 07500441442, or Gary on 0779218245 alternatively you can email

merciassgroup@gmail.com



Nuneaton Stoma Support Group

3rd Wednesday, every other month, (September, November, January...) 7pm – 9pm.

Manor Court Baptist Church, Manor Court Road, Nuneaton, Warwickshire CV11 5HU.

For further information contact Bob Burrell on 07564 680803 or email nuneatonstoma@aol.com

Penrith

Every 3 months (April, July, October...) 11am – 12pm.

Temple Sowerby Medical Practice, Linden Park, Temple Sowerby, Penrith, Cumbria CA10 1RW.

For further information, contact one of the Stoma Care Nurses: Jill Coulthard, Gillian Harker, Emma Ludi, Nikki Armstrong, Ruth Hetherington on 01228 814179



Peterborough, Cambridgeshire

2pm - 4pm.

Stanground Community Centre, Whittlesey Road, Peterborough PE2 8OS.

For information contact Pat on 01733 247135/07721189813, Maria on 01778 702237 or Allan on 01354 653290/07836 661102



The Shropshire B.O.Ts (Bums on Tums)

2nd Thursday of each month, at 2pm.

Memorial Hall, Oswestry SY11 2EG For further information call: Irene Constable - 01691 238357 or Carole O'Ryan - 01691 671624 Alternatively email: ireneconstable@phonecoop.coop



S.O.S Solent Ostomates Support

Last Wednesday of the month (excluding December) 2pm – 4pm.

Kings Community Church, Upper Northam Road, Hedge End, Southampton SO3 4BB. For further information call 07527 707069 or email

solentostomates@hotmail.co.uk

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Stevenage Ostomistics

Last Saturday morning of each month 10.30am – 1pm.

Oval Community Centre, Vardon Road, Stevenage SG15RD.

For information contact Judy Colston on 01438 354018 or email neilcolston@btinternet.com (each session is ended with chair yoga!)



Wing Stoma Support Group

Every 2 months, 11am – 12.30pm Wing Hall, 71 Leighton Road, Wing, Leighton Buzzard, LU7 ONN.

For information call 0800 03601



Workington

Every 2 months (October, December, February...)
2pm – 4pm.

Workington Infirmary, Park Lane, Workington CA14 2RW.



You are not alone, Chesham Support Group

Last Monday of the month, 10.30am – 12.30pm.

The Kings Church Chesham Offices, Unit 11 Chess Business Park, Moor Road, Chesham, Buckinghamshire HP5 ISD. For further details please contact Carla Wright

07846 354918 carla_wright@sky.com



Ostomates and continence patients often call our Careline asking for advice and support. So, whether you're a stoma or continence support group, we'd love to share your details.

If you'd like to share the details of a group to include in future editions of Hand in Hand please email info@securicaremedical.co.uk.



Help is a phone call away

Whether you are placing your next order with SecuriCare, in need of a friendly chat or advice about your stoma or continence care, help is closer than you think.

Useful phone numbers

SecuriCare Careline

0800 585 125

Colostomy UK

0800 328 4257

Urostomy Association

01889 563 191

Ileostomy & Internal

Pouch Association

0800 018 4724

Bladder & Bowel

Foundation

01926 357 220

Bladder and Bowel UK

(PromoCon)

0161 607 8219

SecuriCare Orderline

0800 318 965

Junior Ostomy

Support Helpline

0800 328 4257

Multiple Sclerosis Society

0808 800 8000

Spinal Injuries Association

0800 980 0501

Back Up

020 8875 1805

Mental wellbeing support

Mind

0300 123 3393

Samaritans

116 123

CALM

0800 58 58 58

Childline

0800 1111

Young Minds

0808 802 5544

The Silver Line

0800 4 70 80 90

Age UK

0800 678 1602

Cruse Bereavement Care

0808 808 1677

SecuriCare (Medical) Ltd, Cavell House, Knaves Beech Way, Loudwater, High Wycombe, Bucks HP10 9QY. Tel: 01628 850100 Fax: 01628 810839. Email: info@securicaremedical.co.uk. www.securicaremedical.co.uk. PID 10521

