

Looking back and moving forward

As you may know we have been researching the **Colostomy Association's** history in readiness for our 50th anniversary. With so much material in the archives it hasn't been easy! In the last half century, we have changed names three times and occupied five different premises. From humble beginnings in a London hospital, we now have over 23,000 registered supporters nationwide. More recently, through our Stoma-Aid campaign we have started to reach ostomates across the globe. To make sense of our history we have divided it into a series of periods, which you can read about below. First though, it's worth saying something about the context in which today's charity was formed.

Our origins can be traced to the 1960s. This was a torrid time as it had become clear that scientific advances were creating a cost dynamic in the fledgling NHS: with each advance, more people could be treated. In an attempt to reconcile the problem, government put its faith in technology and modernisation. They envisaged that building state-of-the-art District General Hospitals was the way to offer high quality healthcare while at the same time containing costs through economies of scale. With government convinced that 'modern' was good, some feared patients might just become 'medical problems' to be solved through the application of technology. Luckily, at the coalface, healthcare professionals were not prepared to allow this dystopian vision to become a reality. At one London hospital the therapeutic value of human contact was appreciated by one of the surgical registrars. In 1963 he approached Gertrude Swithenbank (herself a colostomate) and asked if she would visit his colostomy patients on the wards. It quickly became clear that her visits encouraged recovery. She provided the reassurance that patients needed and proof that it was possible to lead an active life after stoma surgery.

In the same year as Gertrude started her hospital visits she told Frances Goodhall about what she was doing. By 1963 Frances had been retired for some years, which suggests that the women may have known each other. One possibility is that they had worked together as nurses. Either way, it was an important connection. In 1966, as a

result of Frances' involvement, the King Edward's Hospital Fund provided the money to conduct a pilot study into the need for a national service for colostomates. 29 hospitals in London took part. The findings of the study led to the founding of the Colostomy Welfare Group, which advertised for its first member of staff in November 1966.



Frances Goodhall (1893–1976) CBE, MBE

Frances Goodhall came from a medical family. Three of her uncles worked at Guy's and in 1916 she began training as a nurse at the same hospital. This marked the start of a stellar career in which ophthalmic nursing became her great love. According to her biographer, Monica Baly, Frances' delicate hands and skill in the field became legendary. At the age of 35 Frances was appointed assistant general secretary of the College of Nursing. In 1935 she took over as general secretary. In this capacity she contributed to post-war discussions about the NHS, coming into contact with figures such as Nye Bevin. By the time she retired, Frances was well respected in medical and political circles.

The Colostomy Welfare Group (CWG) 1967–1989

The recruitment advertisement (reproduced in the last edition of *Tidings*) resulted in the appointment of Emily Brain as welfare officer. Emily went on to become our general secretary from 1968–79. The CWG



Emily Brain MBE, pictured in later life

began life operating out of two rooms at St Luke's Hospital, Chelsea.

As you can see, much was achieved in the years that followed.

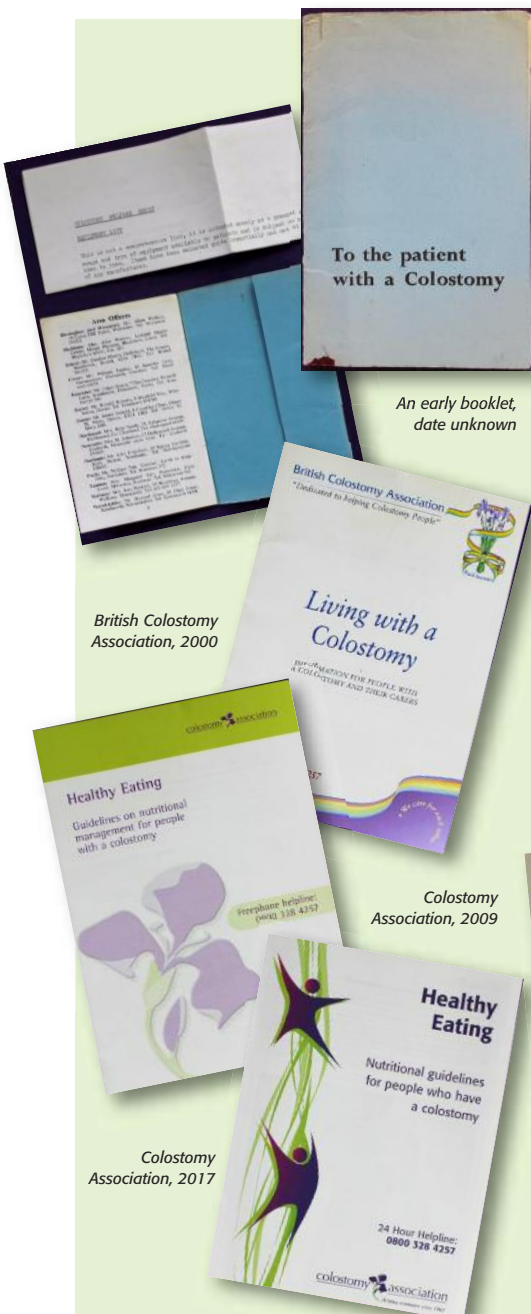
1967: With demands for the services of the group spreading to other hospitals, the CWG became a registered charity.

1970: As demand continued to grow, the charity struggled to raise sufficient funds. In order to continue its activities, CWG applied for, and was granted, £5,000 from the National Society for Cancer Relief (now Macmillan Cancer Support). This covered the bulk of operating costs.

1972: CWG moved to new premises in Ecclestone Square, London. It also became one of four 'associated charities' financed by the National Society for Cancer Relief. This arrangement continued for the next 33 years.

1980s: Consultant surgeon Mr Brendan Delvin CBE, FRCS, assisted in the preparation of support literature. Foreign language versions were also produced. As you can see from the photos, our literature has since undergone substantial change!

Late 1980s: CWG had developed a greater presence being mentioned in the publications of other charities, manufacturers and suppliers, as well as in leaflets written by healthcare professionals. By now, the CWG had also established a network of area organisers and visiting volunteers (all colostomates).



The British Colostomy Association (BCA) 1989–2005

As the CWG became well known, issues emerged with its name. The word 'welfare' was the problem. It was felt that this was misleading and gave the impression that financial support was on offer. Consequently, the name 'British Colostomy Association' was adopted in 1989, with the purple iris as its emblem. Rent increases led to the BCA relocating to Reading. It was from here that the first issue of *Tidings* was published, the 24-hour helpline was launched and the charity continued to build its impressive portfolio of literature. By 2005 BCA was taking in excess of 6,000 phone calls per year, sending out 25,000 leaflets to ostomates and healthcare professionals and had volunteers across the country visiting patients, talking to them on the telephone and attending open days. The BCA years had many other highs:

1992: Following a meeting with the IA and the Urostomy Association the three charities set up a co-ordination committee to organise the first World Ostomy Day. This event, which aimed to raise awareness of the needs and aspirations of ostomates, has continued ever since.

1998: The first issue of *Tidings* was published and announced that consultant surgeon, Mr Brendan Delvin (involved since the early days of CWG) had agreed to succeed Sir Ian Todd as the BCA's next president. Sadly, Mr Delvin died six months later.

2000: *Tidings* started to include advertisements as a way to cover production costs. Initially adverts were enclosed as loose inserts. The iris emblem underwent change with a new bolder look. This coincided with the release of a revised set of literature. Colorectal surgeon Professor Robin Phillips became the BCA's new president.

2002: Helpline hours were extended to include weekends and bank holidays.



The Colostomy Association, 2005–to date

In 2004, what was now the Cancer Relief MacMillan Fund, announced its intention to discontinue the financial support of 'associated' charities. The BCA thus faced the daunting prospect of trying to go alone, becoming a self-funding charity. Luckily both the appetite, energy and courage to

continue was there. The idea that ostomates might be left without support and that four decades of hard work could be lost was inconceivable. Eight people came forward to act as trustees and on 15 November 2005 the **Colostomy Association** was formed. To accord with the change, the new charity launched a website to further reinforce its message that help was there for people in need. The last twelve years have been exciting times, including the challenge of raising our profile on the internet and reaching out to ostomates in the new digital age:

2008 & 2013: Saw moves in premises, with the **Colostomy Association** ending up at Enterprise House in Reading, where we are today.

2010: Further improvements were made to the website making it easier for ostomates to access news and information. By 2015 the site was receiving over 513,000 visits per annum.

2012: The **Colostomy Association's** Facebook group was made 'closed'. Within a year it had 1,000 members. Today, this ever-growing and vibrant community numbers well over 4,500 and provides a vital, safe environment in which ostomates talk and support one another.

2014: Mr Ian Daniels took over as our president from his colleague Professor Bill Heald who had held the position since 2008 and was an internationally known colorectal surgeon. The **Colostomy Association** launched its Junior Ostomate Support Helpline aimed at providing support to the families and carers of children with stomas and other bowel and bladder dysfunctions.

2015: The first monthly e-newsletter was sent and in excess of 84,000 copies of *Tidings* were distributed.

2016: Saw the start of two new campaigns: Stoma Aid and Stoma Friendly Society. By the end of October more than 182,000 stoma bags had been distributed to developing countries, while our stoma friendly toilet stickers started to appear at sites across the country, following a letter and social media campaign.

Looking Forward...

We hope that you've enjoyed this trip down memory lane and seeing how the **Colostomy Association** has developed over the past half century. We are confident that the next 50 years will be just as exciting. As well as continuing to provide all our current services we have plans to expand the support that we give. We're looking forward to sharing these plans with you in the months and years ahead. In the meantime, don't forget our Open Day on 16 September. It would be great if you could drop by and say 'hello!' ■