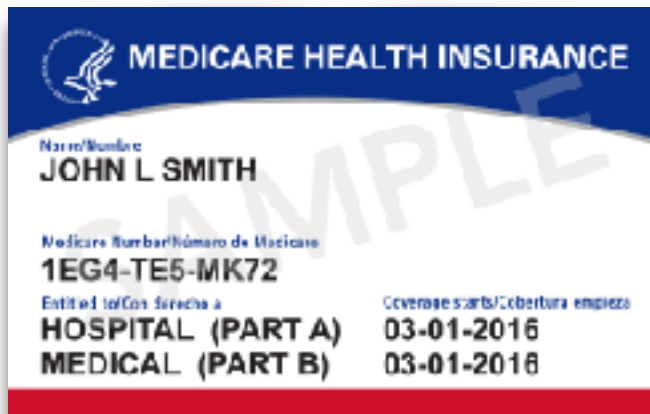




## New Medicare cards start mailing in April 2018

Starting in April 2018 through April 2019 Medicare will be mailing out the new Medicare cards. They are removing Social Security Numbers from Medicare cards to prevent fraud, fight identity theft, and keep taxpayer dollars safe. Florida cards will be mailed out in June of this year. Look out for it and have it handy when you place your order from your ostomy supplier!



Medical Care Products, Inc.  
 (904) 733-8500  
 (800) 741-0110

**Check Out The MailBag Now On FaceBook**

[https://www.facebook.com/JaxUOAA/?ref=aymt\\_homepage\\_panel](https://www.facebook.com/JaxUOAA/?ref=aymt_homepage_panel)

### Jacksonville Contact Information:

Patti Langenbach  
 (800) 741-0110  
 (904) 733-8500

[patti@ostomytcp.com](mailto:patti@ostomytcp.com)

Support group meets the 3rd Sunday of each month 3 p.m.  
 4836 Victor Street  
 Next Meeting: **Apr 15th**

### Gainesville Support Group Contact info:

Brinda Watson (352) 373-1266  
 Jean Haskins (352) 495-2626

Meets the 1st Sunday of each month (except Holidays)

at Hope Lodge 2121 SW 16th St  
 Gainesville, FL

Next meeting: **Apr 1st at 2pm**

### Ocala Support

#### Contact info:

Shirley Gonzalez-Day 352-209-4986

[www.ostomyocala.com](http://www.ostomyocala.com)

Meets the 2nd Sunday of each month (except July & Aug) at 2 p.m. at the Sheriff's Station 3260 SE 80th Street between Ocala and Belleview.

Next Meeting: **Apr 8th**

### Citrus County Support Group

Meets third Sunday of each month at 2:00 PM in the Seven Rivers Regional Medical Center, 6201 N. Suncoast Blvd., Crystal River, FL 34428, in the Community Room of the Medical Office Building

Next Meeting: **Apr 15th**

### Amelia Island Area Ostomy Support Group

(904) 310-9054

Meets second Monday of each month at 6:30pm UF North Campus

UF Health North 15255 Max Leggett Parkway Jacksonville, FL 32218

(Meeting Room 3-4)

Free parking

Next Meeting: **Apr 9th**



## “Gutsy’s FAB Gab-About: Stories of Ostomy ‘Glories/Gories!’”

“Speak Out and YOUR WORDS WILL Be Heard!”

By Linda Blumberg AKA “Mrs. Lips”

### Keith/Homer’s story:

BLOG: <http://www.worldhealthinnovationsummit.com/blog/2016/07/03/charity-marie-curie-keith-thomas-selfie365me-cancer>

YOU TUBE video: <https://youtu.be/8mGckGjVxXc>

“Hi Gutsy; here is my story, please share around the world. Keith...[globally and nobly!...]”

Hi, my name is Keith Thomas, I am from Swansea in South Wales and I will be 56 years old in July. I have been invited to share my personal story regarding a serious illness that I developed about 10 years ago and how it has affected my life. So here goes...

While in my early 40s I began experiencing a lot of bad stomachs, feeling unwell all of the time; I spent many hours- too many really- suffering with diarrhea and bloody stools. I always knew when it was about to flare up as I would have a burning sensation in my sides, truly as if my sides were on fire, and the only thing that would stop it at the time was a few ibuprofen tablets.

For most of my life from my teenage years I played football regularly, for several teams over the years. This meant outdoor football at weekends and indoor football during the week; so I was a very fit person. Little did I know that these episodes were to change my life so dramatically.

By the time I was 43, I had been a coach driver for several years and spent a considerable number of hours waiting around for passengers to return from their trips. Filling the time was mostly spent catching up on sleep (sleeping across coach seats) and lots of time snacking instead of following a sensible diet- so when I was getting these bouts of illness I just put it down to my life style.

I have never been a drinker. I’d rather have a cuppa to be honest; but, since an early age I had been a heavy smoker. One day after a smoke, however, I felt dizzy and started sweating heavily. I didn’t know what caused these symptoms but I took it as a sign to give up smoking. I used nicotine patches for 12 weeks and for the last 10 years I have been a proud “non-smoker.” It is amazing what you can do if you put your mind to it!

Now I have to say, it went through my mind quite often that my episodes of illness seemed to have gotten a lot worse after giving up smoking; but, maybe I was just looking for an excuse to go back to smoking. It was when I was diagnosed in 2008 with ulcerative colitis after many years of not knowing what was wrong, that the Doctor informed me that this disease was most common in non-smokers!

The diagnosis came about after yet another trip to casualty- I had become quite a regular in the A&E department in Morriston Hospital! But this time my symptoms had become a lot worse. I was in agony with pains in my sides, and I was passing lots of blood, which was a worry. I feared they were going to send me home with painkillers and antibiotics again, but the doctor who examined me realized how dehydrated I was and decided I needed to stay in hospital overnight on a drip to rehydrate. I ended up staying all weekend and it was only then that the nurses noticed my frequent visits to the toilet – a lot more than normal - I brought to the attention of the nurses how much blood I was losing during each motion and once they examined the sample I gave them, ‘alarm bells’ sounded and then things started to happen a lot quicker.

Previous visits to the hospital and then my GP had led to some tests which included a barium enema where they fill your bowel with a white liquid that will show up on an x-ray. It also involves air being pumped into the large bowel to make the x-ray easier to see. Then they move you around and x-ray you; I have to say I have been on better fairground rides! But this time, while I was in hospital, I had my first colonoscopy and being a big brave man decided to have it without sedation. Big mistake. It was ok for a while but soon got extremely uncomfortable; even joking with the nurses that this was the best TV I had seen in ages did not help.

It was after this colonoscopy that I heard the words ulcerative colitis for the first time. In actual fact, Crohn’s disease was also mentioned – not an entire surprise as my sister has suffered with that for many years. Either way, my condition had a name and they could start treating it with tablets. At first, they started me on 40mg of Prednisolone steroids, OMG - 10 minutes later I was a new man and ready to go home and put all this behind me, (no pun intended.) But it didn’t last. As instructed, I slowly began to wean myself off the steroids but as soon as I reached 10 mg I would have another flare up.

By now I was having regular check-ups with a consultant in Morriston hospital and he put me on Pentasa tablets and later on Azathioprine, an immunosuppressant. Those along with the steroids I was also on, plus the endless blood tests to make sure the tablets were doing no harm became pretty tiring. I was also required to have repeated colonoscopies- but now with sedation - so much better. Life however became pretty miserable. If I wanted to go out socially, I had to plan my day carefully. I couldn’t eat or drink as that would put my bowel into immediate action! I went through an awful lot of Immodium around that time I can tell you. Simple everyday things like going shopping were now out of the question, as on a bad day, I would have to find the nearest toilet within minutes. Going out for a meal in my local pub became pretty impossible - and that was something my wife and I always liked to do every week – a treat on pay day.

After four years of trying to control my condition with more than 20 tablets every day, including all the steroids, I arrived home from work one evening in May 2012 suffering really severe leg cramps. I have to say I was on the point of crying, but after a while it stopped. The next evening the same thing happened with the leg cramps so I phoned the “out of hours” doctor. I was told to attend the surgery in Morriston hospital that evening, and when I saw the doctor she said that I was to be hospitalized immediately as something was not right – I had a fever which suggested there was an infection somewhere. Looking back now, her swift action probably saved my life.

I went into Singleton Hospital in Swansea that night in May 2012 and the staff spent 10 days stopping my bowel from perforating-thankfully they did but I was told there was no saving my bowel. I was penciled in for an operation on 22nd June 2012, a day that gave me my life back.

### My Ileostomy and Stoma

First of all I had to decide whether to have a total colectomy or to have a J pouch. I took the opportunity to speak to people who had been through both procedures to make an informed decision. I decided that the “no pouch” option sounded far better so I went with the mind-set that it would be one operation – one recovery. My surgery was therefore a total colectomy and was done as a laparoscopy (keyhole surgery) so I had no big scar to cope with and this definitely made my recovery much quicker. I was in theatre for ten hours – did the surgical team go out for lunch? I was discharged two days later and after a six-week recovery period, returned to work. There were a few setbacks in that time, for example some of the stitching in my rear end came adrift a little bit so I had to visit a nurse daily over several weeks to have the wound packed and dressed. I also had a slight infection under the skin near my stoma that seemed to be more painful than my operation, but two days in hospital sorted that out.

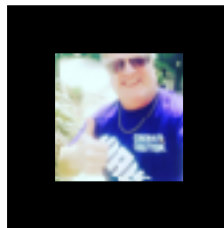
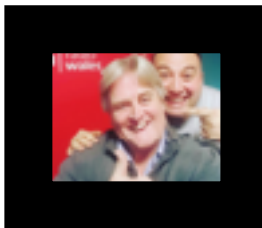
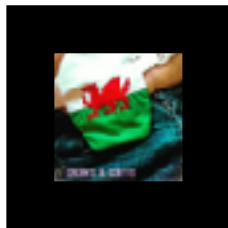
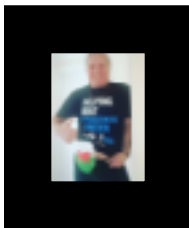
All through my illness I had changed a lot as a person. I had severe mood swings, depression (being ill changes everything - all the fun in life was gone). But it meant everything to have the love and support of my family; their strength gave me strength - they knew that it was still me – it was just the illness that made me that way. I got through it and now the old me is back. I need to say a big thank-you to my wife Jane (who had to inject me for 28 days to when I came home from hospital so I did not suffer DVT, in fact I think she enjoyed it a bit too much!!

There have been some adjustments to my routines, naturally; but the routine I have for managing my ostomy bag is no harder than looking after a baby. I have a loose stool collected in a bag now similar to a baby’s in a nappy. Sometimes I have sore skin like a baby but if it is looked after and the bag changed regularly, it’s another toilet routine and easy to manage. There are so many fantastic products out there, available from many companies, to make it easier and more manageable - and if you want to try something new you just order a free sample; it’s that simple. I have just tried a two-piece bag instead of a one piece so have decided to use two piece from now on as it works better for me.

After a while back in my factory office job, I decided that I was well enough to leave and go back to my passion for bus driving. A vacancy came up for a First Cymru driver based in Llanelli. I applied and got the job. I will have been driving for two years in June. I work a 40-hour week and now I am never late for work and more importantly, I have no time off ill.

I know I have a very positive attitude and this has definitely helped me cope and get me where I am today. Through writing my story for Pelican Healthcare and sharing it on Twitter I have had a story published in our local evening paper. This was followed by a radio interview on BBC Radio Wales and now I am writing this. By doing all of these things I have tried to raise awareness about the disease and the effects of it. I decided that having had such a life changing operation, I wanted to try to help others in my position who might be having to make the same choice. I hope I can continue to do so as every one person this helps is another smile. My message to all is, “There is life after illness - look at me!”

Thanks, @keiththom2016 😊



## A Couple of Ostomy Myths

by Bob Baumel, North Central OK Ostomy Association

This article is about two claims that I've discussed previously in this newsletter. Both are seen frequently in the ostomy literature but aren't true as stated, so can be considered "myths." And in both cases, the realities are more complicated.

### 1) The claim that stomas have no nerve endings:

This myth has been stated an awful lot, often by people who should know better, such as ostomy nurses. There is, to be sure, a factual basis behind this myth, namely, the observation that stomas are insensitive to certain painful stimuli such as cutting. This can be a genuine problem, as you can cut your stoma without being aware of it. However, it's a mistake to jump from this fact to the assumption that stomas have no sensation at all, or that they don't even have any nerves.

The intestine from which a stoma is made actually has a rich supply of both autonomic and sensory nerves. The autonomic nerves are responsible for certain reflex motions such as peristalsis—the wavelike movements that propel food through the intestine (and if you watch your stoma, you may see it change shape, showing that peristalsis continues to occur in this portion of intestine, illustrating its autonomic nerve activity). The sensory nerves are sensitive to certain kinds of pain, notably when the intestine is **stretched**. This can be evident when portions of intestine get distended, resulting in cramping sensations which are sometimes very painful. And even after the intestine is made into a stoma, you'll probably still be able to feel motions that involve stretching of this intestinal tissue.

There is, of course, a possibility that nerves supplying this portion of intestine might have been damaged in the surgery that creates the stoma. But this is unlikely. The intestine's nerve supply, as well as its blood and lymph supply, are provided through the *mesentery*, which is a membrane that connects the intestine to the abdominal wall. In making a stoma, surgeons must be careful to preserve connection to the mesentery because of its essential role in providing the intestine's blood supply (Without a good blood supply, you'll have just a dead piece of intestine). And, assuming that the intestine's connection to the mesentery is well preserved, its nerve supply should be preserved as well.

You can read previous articles that I've posted about stomas and their nerves at [www.ostomyok.org/newsletter/news1510a.shtml](http://www.ostomyok.org/newsletter/news1510a.shtml)

### 2) The hype about "sublingual" vitamin B12:

In calling this a myth, I should make it clear that sublingual vitamin B12 *does work* in delivering useful amounts of the vitamin. But it doesn't really deliver the vitamin sublingually (at least, not to any significant extent), so you needn't follow the instructions to hold it under your tongue. And other oral forms of vitamin B12 can be equally effective (although the "time release" versions should be avoided, especially by ileostomates).

Vitamin B12 is necessary for many metabolic processes including development of red blood cells, and also maintains normal functioning of the nervous system. Under normal conditions, it's absorbed in only a small section of the terminal small intestine (ileum), raising the possibility of B12 deficiency if that section of ileum has been removed surgically or damaged by disease. People who may have lost that portion of ileum include some ileostomates, people who've had a failed J-pouch or Kock pouch, and some people with urinary diversions (especially continent urinary diversions) made using the terminal ileum. A condition such as Crohn's disease may have damaged the terminal ileum, even if it hasn't been removed surgically.

Until fairly recently, it was believed that vitamin B12 taken orally provides no benefit for people who lack the normal absorption mechanism involving the terminal ileum, so these people require B12 injections. Then it was discovered that, in addition to the normal absorption mechanism involving the terminal ileum, a small fraction of B12 taken orally (typically about 1%) gets absorbed by passive diffusion, and this happens along the entire intestine.

This observation provides the basis for safe and effective oral treatment of B12 deficiency, although it requires pretty large doses. The current US recommended daily value for vitamin B12 is only 6 micrograms (and if you check the amounts in multivitamin tablets or B12-fortified foods, you'll see that they're at most a few times this value). However, if you absorb only 1% of an oral dose (because you lack the normal absorption mechanism involving the terminal ileum), you'll need to take 600 micrograms in order to absorb 6 micrograms. A typical recommended oral dose for treating B12 deficiency is 1000 micrograms per day (and if you have short bowel syndrome, you probably need even more). And although these doses are much greater than the usual recommended daily value, they're quite safe, as there is no known toxicity to vitamin B12, even in very high doses.

The medical establishment has, by now, agreed that B12 deficiency can be treated effectively with oral supplementation. Meanwhile, the companies that make vitamin supplements have been producing "sublingual" B12 products that supposedly provide the vitamin more effectively by delivering it through membranes under the tongue. However, there has never been any scientific evidence that vitamin B12 can be delivered that way. These products are presumably based on analogy with medications like nitroglycerin, which are known to be effectively administered sublingually. But it's a poor analogy. Nitroglycerin is a relatively small molecule (molecular weight 227) that passes easily through the pores in sublingual membranes. Vitamin B12 is a much larger molecule (molecular weight about 1357) which doesn't pass through those membranes so easily.

The instructions for "sublingual" B12 say to hold the tablets under your tongue and let them dissolve for a length of time (usually 30 seconds) before swallowing. In reality, at most a negligible amount of the vitamin gets absorbed through sublingual membranes. Then, after you swallow the dissolved tablets, they're absorbed lower in your digestive tract, as with any other oral formulation. Thus, the sublingual formulation "works," but not any better than other oral formulations of the vitamin.

Several studies have compared the effectiveness of “sublingual” and regular oral forms of vitamin B12. One [study published in 2003](#) compared the effectiveness of a 500-microgram dose, administered in either a sublingual or regular oral form, in treating B12 deficiency. The result: both were equally effective. Another [study published in 2006](#) did a randomized, double-blind comparison for a vitamin B-complex preparation (including 1000 micrograms of B12), administered in either sublingual or regular oral form. Again, both forms were equally effective.

The conclusion so far is that “sublingual” B12 is a marketing gimmick. The effectiveness of oral B12 depends only on its dosage, so you should just buy the lowest cost version available at the desired dosage. Unfortunately, there’s another complication. An awful lot of the B12 tablets sold in sizes of 1000 micrograms or more are “time release” versions. These should definitely be avoided, especially by ileostomates and anybody else with a shortened digestive tract, as they may pass through your whole digestive tract before releasing an adequate amount of the vitamin. Even for people with a normal-length digestive tract, “time release” B12 is a bad idea. Considering the small fraction of vitamin B12 that gets absorbed (in people who lack the normal mechanism for B12 absorption), delaying that absorption further makes no sense.

Thus, “time release” B12 should be avoided. You’ll want a version that releases the vitamin fairly rapidly, although not necessarily as rapidly as the “sublingual” versions that dissolve in the mouth. “Softgels” are a good alternative that dissolve soon after you swallow them. Sometimes, assuming that a brand of B12 tablets isn’t marked as time release or extended release, it may still be unclear how rapidly it dissolves. In that case you can try it but, if you have an ileostomy, watch to make sure the tablets don’t come through whole into your pouch. If your only choices are between “sublingual” and “time release” formulations, choose the “sublingual” version, but you can ignore the instructions to hold the tablets under your tongue; instead, swallow them directly as with any other tablets.

Finally, if you think you may be vitamin B12 deficient, or have any doubt whether you are doing an adequate job supplementing your B12 level, you can ask your doctor to check your serum (blood) B12 level. This test can be added easily to routine blood testing.

You can read previous articles I’ve posted about vitamin B12 at [www.ostomyok.org/newsletter/news0809a.shtml](http://www.ostomyok.org/newsletter/news0809a.shtml) and at [www.ostomyok.org/newsletter/news0906a.shtml](http://www.ostomyok.org/newsletter/news0906a.shtml)

## World Ostomy Day 2018 OCTOBER 6



<https://www.ostomy.org/event/world-ostomy-day-2018/>



Medical Care Products  
Now Carrying  
Ostomy Pouch Covers  
TOLL FREE 800-741-0110

**UOAA Discussion Board**

<https://www.uoaa.org/forum/index.php>

**Medical Care Products, Inc**  
**PO Box 10239**  
**Jacksonville, FL 32247-0239**

To: