



Welcome to the May Newsletter!

Hopefully most of us have been jabbed by now – perhaps even twice. Normality still seems far away but at least we have been able to meet others out of doors or in pub gardens. Fingers crossed that 17th May will mean we can meet indoors and that non-essential shops will be opened.



We have some very good news – we have secured a new venue for our meetings (with thanks to Phil Palmer, one of our new members who made the recommendation.) We will still be meeting in **Rottingdean** but in **the Whiteway Centre in Whiteway Lane**. There is parking there for users of the centre and entrance to Whiteways Lane is opposite The Plough Inn. However, we are **changing the day of our meetings to the last Thursday of each month (not Tuesdays)**. Hopefully our first meeting there will be on

Thursday 24th June from 2-4pm where we hope to have a bit of a tea party. So do bring cakes, sandwiches or biscuits. We shall also be having our usual raffle so raffle prizes will be welcomed.

We had an excellent meeting at the end of April even though Steve Tedman, our Chairman was unable to attend. The meeting was made very special by the attendance of Gill Hilton, Macmillan Clinical Nurse Specialist and a good friend of C-Side. Here are just some of the things we shared:



Steve

Steve was unable to attend this zoom meeting as he had two particularly difficult family problems to deal with. Firstly, his stepdaughter (Liliana's daughter) has just lost her father and needed support this evening. Secondly, Steve's mother has been having tests in Woolwich hospital and it is feared that she may have suspected oesophageal cancer. We wish you and Liliana well Steve and know you will navigate this difficult time with dignity.

Jackie

Lovely as ever, Jackie is well but still suffering from her MS with balance issues. She is

having her ears syringed soon at Specsavers and looks forward to hearing the world again. Jackie had given up her Thursday job at the Seahaven Storehouse (Seaford's food bank) but she was urged to return. This will prove a problem with our change to Thursday meetings, but Jackie hopes to negotiate an afternoon off once a month. She says what keeps her going (in no particular order) are pills, alcohol and a loving husband.

Maria

Maria is really well but is very sad, her younger brother died last weekend in Spain. The funeral occurred almost immediately so Maria couldn't attend, but she hopes to

return to Spain in a few weeks' time. Our sincere condolences to you and we really wish you well Maria in this difficult and sad time.

Sing Man

Sing is really suffering from lockdown syndrome and has been quite "down". She found it stressful not being able to see her special needs daughter who is in care, but can now visit her in a half hour slot every Thursday. Sing will have to try to reorganise this visiting time in order to attend our C-Side meeting. Sing's CT scan in January showed that an enlarged lymph node near her sacrum has gone down, but unfortunately, on the opposite side a cyst was found on her pancreas. An MRI scan in August should shed light on this, but meanwhile Sing is in some pain first thing in the morning. It eases when she moves about and she doesn't want chemotherapy, but it does get her down. Keep going Sing. You looked really good and we wish you all the best in your treatment.

Phil

Phil has had the results of his PET scan which showed a hotspot on the lung. He is in the frustrating position where he doesn't really know what is going on as he has not spoken to anyone who can explain his condition. An appointment has been arranged with Dr



Messenger from the lung team, but not until 14th May. Gill has helped by putting Phil on to a therapist as he is so stressed that he is not sleeping and finding the "not knowing" difficult. Physically he is feeling quite fit, cycling to Shoreham from Rottingdean and gardening in this recent lovely weather. His partner has been very supportive and patient, but Gill promised to send Phil a private message, and Don offered email support.

Sam

Both Sam and her family are well and she is pleased that her 12month follow up showed all clear. One issue arising from it was that there were 5 polyps which concerned her. Don who is a "polyp grower", said most of them are not a problem, but he continues to be monitored, although he is 5years cancer-free. Again, Gill said she would message Sam about it. Sam was also concerned about her uneasy digestive system. She suffers with bloating, discomfort and wind and is being seen by the GP who suspects it may be IBS. It is worse in the evening but relieved somewhat by Buscopan. Gill advised Sam to keep a food diary for a couple of weeks to see if any patterns or problem food groups emerged and said she would be happy to discuss it with her.

Moira

Moira looked really well and was delighted that such good news followed her last CT scan. Her son with his cat and dog have now left her and she is having to adjust to being without them. Her garden is benefitting and she is enjoying lockdown as much as she can.

Jim and Margaret

Really good to see Jim looking so well. He says he is still very anxious, but is so well cared for by Mags. They met Sarah Back in Brighton who said she was in contact with me. (See comment at the end of this newsletter.) Mags has had her hair cut at last and both she and Jim have joined a bowls club which should keep them fit.

Don

Both Don and Chris are very well and he apologised to Phil for not responding to his texts but says his use of his mobile phone is only one step above semaphore! However, he promised to reply to emails. Don sent apologies for our first face to face meeting on 24th June but he will be on holiday with friends. At the moment he can't see much as he sat on his glasses. A recent birthday

present from his family was an Amazon Echo (like Alexa) which connects him to the Internet. Don is trying to baffle the device by asking for obscure music! He loves meeting his son in the garden. Referring to our rogues gallery of members as children, Don says all ancient family photos are in a suitcase with his sister up north, but he promised to see if one of them could be found.

Kevin

Kevin and his wife are well and he was really pleased to see Gill. He expressed his gratitude to both Sarah and Gill for helping him through his cancer journey (as do we all!). Kevin is busy decorating. He and his wife bought a house with 7 rooms, all of which need decorating, so they will be busy for the foreseeable future. Kevin says he is having a haircut tomorrow – sorry Kevin, but that looks likely to be a quick job!

Marilyn

Marilyn said she was fine but has been suffering from Plantar Fasciitis which used to be called “Policeman’s Foot” a painful condition in the arch of the foot. She claims it



is the result of so much walking during lockdown. Marilyn has also been doing her music and a bit of writing. She is about to finish her second book where her two cats are now adventuring in Tasmania. It is a comedy text for adults. Now Marilyn just has to find a publisher!

Denise and Stuart

Both of us are very well and delighted that my 4year CT scan was clear. We are busy helping our daughter to prepare her house in Brighton for sale.

Sarah

Sarah emailed to say that she was back at work with the Sussex Bowel Screening Programme. She also wanted some leaflets. I did send her some but advised that they were now out of date because we had a new venue. I asked her to direct potential new members to our website until such time as a new brochure was ready. Gill said that Macmillan might be able to help us fund the new brochures and said she would keep in touch. When we have a quote we should let her know.

Gill

What a treat to have Gill with us! She has had an interesting year. Redeployed during the first lockdown she was suddenly sent to work in various hospital departments, but ended up working with Mark Danieletto (our founder) in Palliative Care. At one stage she had 6 people in the house including her two children and their partners. At least they did some decorating for her!

There is now a full team in the Macmillan Bowel Cancer team with Lucinda and Gill as the Senior Clinical Nurse Specialists. After Sarah left, her job was shared between 2 part time posts – Leanne and Kate both do 3 days each, overlapping on Wednesdays. They are both experienced nurses having worked with the community, in palliative care and oncology. This team of 4 complement each other and are of course joined by Claire Theobald who performs all the follow up tasks. Zoe has now returned after having baby Poppy so she is busy answering the phone and supporting on the helpline. Molly comes in 2 days a week as a support worker for Macmillan. Also clinics have become established. However, they are low on surgeons at the moment. This might be a problem as referrals are on the increase but posts are being advertised.

Today was a significant day in Brighton and the Princess Royal hospitals, as it was the first day that there were **no patients being treated for Covid!**

Other news from Gill is that Brighton Trust has been merged with Worthing Trust to create a super trust. There are new contact details if you wish to get hold of the Macmillan Bowel Cancer team:

email:

uhsussex.lower.gi.macmillansch@nhs.net

Phone – 01273 696955 ext. 67658

Gill also mentioned that Carley Rowe, who has been seconded for a year to work on developing health and well-being. Gill said she might want to get involved in C-Side, so we have a potential guest already for our new premises!

Finally ... a *rogues gallery* of “when we were very young”! Like to add one of yours? Scan or re-photo them and email to Steve on steve.tedman@sky.com)

