



Newsletter - October 2020

Hi Everyone! I have heard from a few C-Side people and rung others to find out how they have been managing during this very all-consuming pandemic. I thought it would be rather nice if we described a few of the things we have been up to and hope this newsletter will help to drive away a few of the Covid blues! Some offerings are longer than others, but that's no matter. Apart from mine, I have written in reported language. Apologies if I you feel misrepresented – Denise.

Denise

Stuart and I had just returned from Hayward's Heath Hospital in March of this year, following my 3-year follow up CT scan, when we heard of the lockdown. Of course we had no idea of the global implications of the pandemic. We just enjoyed the idea of being at home, doing the garden and being quite isolated. How things have changed!

We have mixed feelings about the lockdown now. It's painful not to see our two sons, one in Liverpool and one in Denmark and their families (our grandchildren).



Other things we miss include – the cinema; just popping into a pub or restaurant without booking; our folk music (we attended several clubs and other folk venues); our book group; going to the theatre; meeting up

with groups of friends, and of course, C-Side. I really miss everyone!

Thank goodness for video calling. Our family all speak regularly and our daughter in Brighton rings us almost every evening. Zoom meetings have also been interesting, although limited. However, it means that I can attend virtual meetings. I have joined a Black Lives Matter study group which is really informative. Also an International Women's group in Seaford and we have virtual book group meetings. Not ideal, but stops us feeling so isolated.

My two major pieces of news are that, sadly my younger brother died in July. He had lung cancer and asbestosis. He was so lovely too! He died in Oldham so we couldn't even attend the funeral.

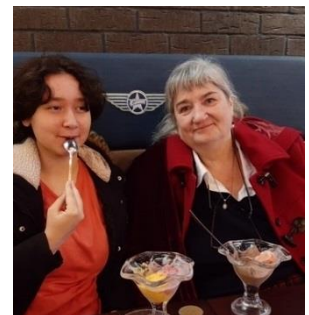
On a happier note, our special needs grandson, Oscar, now 19 has been rehoused in a super facility in Portslade, purpose built for young disabled adults, and has settled in remarkably well. We feel very blessed.

Stuart and I are well and incidentally, my CT scan was clear! So the next scan is March 2021. Good health to you all!

Steve

Steve has managed to get a part-time job. His daughter works for a payroll company in Brighton and has been working remotely from home since March. In April they needed to take on temporary staff to handle the effects of the government's furlough scheme on employees and their pay. She recommended Steve and he had a telephone interview and they gave him the job!

It largely involves data input and answering email queries. Six months later and he's still working for them! He works five mornings a week. The pay is not wonderful, but at least it keeps him busy! In the afternoons, he and Liliana have made the most of sunny days and



try to have fun days out with the grandchildren.

Moira

Moira seems to be recovering well since her operation December 2019. Her last blood test and CT scan were clear and she is enjoying a virtual exercise class on Zoom. (Of course there are no meetings or classes at the MHC at present). Continue to flourish Moira!

Jackie

Jackie has just become a grandmother for the second time. Her son Jonathan and his partner Samantha have given birth to a little girl, Florence (Flo). As far as I know Jackie is well and enjoying her garden with her husband Shaugn.



Marilyn

Marilyn is surviving the lockdown like us all, but like me is missing the folk singing community that we love so much. She continues to do her writing and is part way through another "cat" story. She wrote one about two cats who get addicted to putrefied kippers. Their addiction takes them into a life of crime so that they get their own fish and smoke them!

Erica

Erica is well and is being kept really busy co-parenting her granddaughter Rosie, who is now 15 months old. Although it is tiring work Erica is really enjoying it. Rosie is a very outgoing little girl and loves communicating. She has a large vocabulary and makes everyone laugh all the time. Erica says "It's a great blessing to live with someone who doesn't know or worry about the dreadful state of affairs we are in at the moment!" Rosie is like a parrot and mimics everything. If she hears someone say



"Thank you" she says "You're welcome!" Erica sings to Rosie and is amazed how songs that haven't been sung for a long time are still retained in the memory!

Bob and Lin Wootton

There is good news and bad news concerning Bob. His operation has been very successful and the plastic surgery required worked a treat. However, he was all ready to play golf recently when he damaged his Achilles heel. Now he is walking with two sticks and hopes to have an operation in February 2021 when he will have an artificial tendon put in his heel. Ouch! Bob assured us that it wasn't painful at all. We (Stuart and I) met them on Seaford beach on a glorious sunny afternoon and they both looked really well.

Margaret and Jim

Margaret and Jim enjoyed VE Day when they and several neighbours had a socially distanced street party. They all sat outside by their houses. The photograph shows them enjoying their VE Day tea by their garden. Margaret and Jim have also recently celebrated their wedding anniversary when their daughter and her husband arranged a surprise tea party for them.



Don Burnett

Don and Chris are doing OK in the main. Just at the moment Don is struggling a bit with an exacerbation of a long standing knee problem but thinks it'll resolve. They are able to see close family as Calum and Kym and the grandchildren are in Peacehaven, so only minutes away ... Don and Chris have been taking advantage of the fact that the National Trust have opened their venues to visit and stroll round a few of them ... Don says Its really nice just to get out. They can be on the edge of the South Downs just by walking round the corner from the house. There is a dew pond with a rustic bench

and the views are South over the Channel or inland to Lewes and the Downs. They also often come over to Seaford and walk to the seafront and stop for a coffee at the beachfront cafe by the Martello Tower. Chris also is in a walking group and they meet once a week for a socially distanced ramble, much more than Don can achieve. She is also in a book-club with the same people and they have their meetings Zoom and recently in some ones garden.

Don meets with friends via SKYPE on a Thursday evening and they do an online quiz and then a general knowledge crossword. The quiz and crossword are really devices around which they chat for about 2-3 hours ... otherwise books, newspapers, the lunacy of the USA elections and such like are their principle entertainment.

“My best wishes go out to everyone, I miss C-Side get-togethers and I do hope we can resume in the not too distant future”, he said.

Ernie

Ernie is well, as is Jane, and as active as ever. When I rang him in mid-September, he said he had been swimming in the sea the day before.



Very impressive Ernie! He has just returned from a few days in Shropshire with family. It included lots of lovely walks, properly shod and warmly wrapped up. Like many others, Ernie's thorax CT scan was delayed (four

months), but he's recently heard that it's all looking good.

Sing Man

Sing was delighted to be contacted and her words are worth quoting: “ This is a horrible time for the world. We are all suffering one way or another. We live and hope one day it will be all over and get back to some normality“ - I'm sure we all agree!

Like all the others Sing hasn't seen her family for a long time - since last December. She has

a further complication in that her disabled daughter lives in a care home in Barcombe. Sing couldn't see her for over five months. That was a hard and worrying time. When lockdown eased up in July, they were allowed to have one hour visit per week, now extended to two hours. She has to wear full PPE. Again that was hard. However, her daughter is well, safe and happy. Sing is so grateful to the care home and thanks them for taking such good care of Holly and all the other residents.

Sing has only just started to go out, but only to get essentials things and to visit her daughter. Life is very lonely.

All her hospital appointments were cancelled during the lockdown, but now it has picked up. ...a telephone consultation with her Oncology on Friday provided some good news:

The enlarged lymph nodes near her sacrum have reduced in size. So the medication is working. The side effects, though, are hard. The tablets cause joint pain and swellings on her fingers... Sing will be under observation and if the cyst grows any larger, then surgery may be needed.

Other than that, Sing is coping and safe.

Sing says she misses the C-side group and hopes everybody is well and safe. She passes on well wishes to the group.

Nicole, Bob and Joan

Nicole and Bob are also coping relatively well. They don't seem to get bored as there is always so much to do - looking after their house and the garden. She does spend a lot more time talking to friends over the telephone.

Nicole recently met Joan twice for a coffee in George Street in Hove. Joan is also coping well.

Nicole's feeling, right from the onset of this pandemic, was that this would last for at least a year. She hopes that we can soon have a vaccine so that life can go back to normality. Like all C-Side members Nicole misses our monthly meetings and cannot wait to see us all again, hopefully in the very near future. Nicole sends her love and best wishes to everyone in the group.

Kevin

Kevin agrees these are such strange times and society will be so different when we come out the other side of this. A friend of his says this is all good practice for the next virus which could be a lot worse than Covid!

Kevin hurt his back in an accident in the garden 9 days ago and intends to go to the chemists to pick up some anti-inflammatory tablets shortly but besides that he's been all

right.

Kevin's mother was due to have a hip replacement operation but unfortunately the anaesthetist cancelled it because she has heart trouble. He was certain that the doctor who was due to carry out the operation said he was OK with this. "Oh well," says Kevin, "This is the NHS. They just work in a totally different way and at a totally different speed."

Hope your back improves soon Kevin!

Gill & the BSUH Lower GI Macmillan Team

No newsletter could possibly be complete without a few words from the much valued Lower GI Macmillan Team.

"Hello all, I'm glad to share a brief update from RSCH. We are all now back in our 'normal' jobs after a brief period of redeployment during the acute phase of the Covid pandemic earlier this year. It has been fabulous to welcome two new team members recently, Leanne Tory is our new junior sister, she is working with the team three days/week. Leanne has a wide range of experience including GI surgery and cancer care. Molly Hughes is our new part time Macmillan Support worker, she will be supporting the team two days/week, she is also currently completing her Masters and has a particular interest in radiotherapy.

The lower GI Macmillan team is still short staffed due to vacancy and maternity leave. We are re-advertising for a band 6, junior sister/charge nurse role and hope we will be able to appoint at the interview late November. The post holder will work three days a week. We look forward to welcoming Zoe our Support worker back from maternity leave in March next year.

In order to ensure people at home have support the team is working differently and have been focussing support on the helpline, to respond as quickly as possible to enquires and help deal with issues and concerns. Due to the reduced staffing levels we have not been able to run our nurse-led clinics or support consultants in clinic but hope to restart these vital services as soon as we can once the team is fully staffed again.

Some tests both in diagnostic phase and follow up have been delayed by Covid but the teams involved are doing their utmost to get investigations done in a timely manner, if you experience any delays please do not hesitate to contact us or if it is a follow up test, contact Claire Theobald and do feedback to the Patient Advice and Liaison Service team about how the delays have left you feeling (01273 64511 or 01273 64973 or email at bsuh.pals@nhs.net)

The Macmillan Horizon Centre is slowly reintroducing services so it's worth keeping an eye on the web site every few weeks to make sure you don't miss out on any services

<https://www.macmillan.org.uk/cancer-information-and-support/get-help/centres/macmillan-horizon-centre>

We wish you all well and hope you and those important to you are keeping well during these 'unusual' times"