



2023 年 7 月 協會財政報告

6 月結存	£ 38,009.41
7 月收入	£2,872.20
7 月支出	£ 1,063.00
7 月結存	£36,200.21

蘇豪關懷癌症月會 (MCSG Soho)

每月第二週六・上午 11:00 至下午 1:00

Soho Outreach Centre (SOC), 166A Shaftesbury Avenue, London, WC2H 8JB

病友園地

Monica

我自幼四處流離七歲到香港，婚後照顧三名子女，丈夫經常外出工作。孩子們自立後，我跟教友到老人院做義工，看見長者們孤單又落寞，我害怕自己將來也一樣。神父建議我參加義學團，帶同文具書簿等，到山區贈送給貧窮孩子。我付出很少，獲得的喜樂和滿足感是難以形容。

我個子矮小，長期服血壓藥和降膽固醇藥，椎間盤脫位 20 多年。2018 年初左膝蓋退化，更換了膝關節。年尾，我尋求醫治腰背痛，骨科醫生勸喻我盡快全身檢查，豈料確診淋巴癌末期。兒女們為我選擇最適合的化療，我 6 次後癌細胞已經處理好，去了日本等地方旅行。2018 年在台灣過新年，看天燈升空很壯觀。回程飛機上人人搶口罩，我們不知新冠狀病毒正蔓延。2021 年 2 月，我申請 BNO 檢查肺結核，才發現肺積水及淋巴癌復發。我完成 6 次化療，10 月在香港上飛機時正懸掛 8 號風球及黑雨。到倫敦後 NHS 的防疫員家訪，確認我們居家隔離。原定與親家往歐洲旅行，豈料 GP 發現我的淋巴癌再次覆發。難得細女同住，全程照顧和翻譯：如果打流感針或防蛇針，只可接受非活體疫苗，輸血需要特別處理過的。化療六次我沒有不適，但在 3 月我感染了新冠，兩次化療後白血球下降，5 月我感染細菌導致肺積水。6 月我昏迷入 ITU 使用呼吸機，三名兒女趕來相見。豈料我甦醒過來，見他們四人站在玻璃窗外，在電話叫我加油和祈禱，真是上主的恩典！我 74 歲，醫院仍全力搶救，前後住院 6 週。出院信上寫清楚，我的八個器官性大問題都遂項治療。例如我體弱和使用多種抗生素，口和食道感染念珠菌，導致我吞嚥困難。出院時有交通安排，護士家訪後送來便椅、助行架、床邊扶手等，助我生活起居。護理員上門幫我沖涼換衫六週，物理治療師家訪教運動。我多謝 NHS 如此週到細心，兒女們交的稅項令我親身受惠。

家人擔心我能否繼續化療，我最怕的是護士多方努力才成功插入靜脈導管，但我的雙手已佈滿瘀腫。第三次化療前，護士見我非常瘦削和血管幼細，便立即為我安裝可以保留半年的 PICC Line。感謝耶穌！獲朋友介紹，我認識了癌症協會義工。她為我翻譯，又提議開設支持我的 WhatsApp 組群，以便我隨時提問。她提醒我向護士取驗血報告，解釋逐項指數的意義，令我了解自己的情況。有義工翻譯，我問清楚便安心與醫護合作。她不講我不知，原來 NHS 強調醫護需要尊重病人和家屬意願，不再是華人的傳統觀念，醫護高高在上決定一切。全家分工合作支持我繼續化療：女兒真本事，為我注射升白血球針，為我傳電郵和打電話給醫護。丈夫跟視頻學烹飪，煮健康湯水給我。

我避免外出，但每次化療後我都感染需求診急症室。第 5 次化療後，各項驗血指數都好轉，我期望 9 月初完成最後一次化療。

9 月尾，我雙腳腫左腳大拇趾有電擊感，是化療副作用。義工幫我按摩雙腿和穿壓力襪，步行輕省了。10 月初檢查 CT 後，放射師建議：「你順道去急症室吧！」鑒於以往經驗，我真的抗拒在急症室插靜脈導管驗血。兩日後沖洗完 PICC Line，為免家人擔憂，我便順道求診急症室。當時懂得在 PICC Line 抽血的護士已放工了，抽血員嘗試三次，終於在我左手插入靜脈導管，我當晚入院了。同病房的老人家不斷咳嗽，我非常擔心受感染。義工為護士翻譯：「病人在急症室早已確診喉和鼻感染了病毒。」我少了擔心。出院前一晚，床邊站了 4 位醫護，我不知發生什麼事。後來義工問護士，原來我的血氧低過 90 需要氧氣，但我不感覺氣促。3 日後星期五義工探訪時，正好三位我未見過的醫生前來，我得知右肺積水影響了呼吸。我的血小板降低但有 50，剛好適合抽肺積水。我簽紙同意，醫生抽取了一公升的肺積水，呼吸漸漸暢順了。血科醫生解釋，我服食的病毒藥物是標準藥物，不是試驗藥物，我才安心繼續住院治療。完成病毒和抗生素的療程，我的血氧逐漸回升，我拿去水丸出院，前後住院兩週。出院信顯示我的淋巴癌，已由橫隔膜上擴散到橫隔膜下，難怪我有腹水和腳腫。兩日後週五我覆診，醫生確認以往化療無效，需要更強的化療成效是 20-30%，副作用也更多。醫生在電話中多次叫女兒與家人討論是否接受，我聽見女兒的聲音沙啞慟哭。想到生命屬於自己，我就簽同意書，免得夜長夢多。在丈夫陪同下，我表明自己不希望急救，請醫生在電腦上記下 DNR。女兒放假一周陪我返聖堂參加彌撒，到牛津朝聖還我的願望。我思前想後，化療的副作用是嘔吐、肚瀉、發熱等，我豈不成為家人的負累，女兒如何應付得了，我決定不化療了。醫生早已告訴我的預期壽命是數月，舒緩護士家訪盡力緩解我的症狀。翻譯義工幫我表明自己的擔憂，想在舒緩護理院離世和不想急救，我講完便舒服了。

兒女的成就，就是我的成就。他們盡量滿足我的需要，帶我睇中醫減輕症狀。由 2018 年確診癌症至今，我沒有痛楚。我能睡能吃，又有耶穌在心中，真的一無所缺。將來全家在天上再見，我好有幸福的感覺。多謝醫護對我的忍耐和照顧，希望我的癌症故事能幫助其他癌友：積極面對治療，活在當下享受與家人的日子。

PALS 通過多種方式提供幫助。例如：

- 幫助您解決與健康相關的問題
- 幫助解決您使用 NHS 時的疑慮或問題
- 告訴您如何更多地參與自己的醫療保健



PALS 可以為您提供以下信息：

- NHS 服務體系
- NHS 投訴程序，包括如果您想投訴如何獲得獨立幫助
- NHS 之外的支持團體

PALS 通過傾聽您的疑慮和建議來幫助改善 NHS。

<https://www.nhs.uk/nhs-services/hospitals/what-is-pals-patient-advice-and-liaison-service/>

雙贏

張陳麗娟

2023 年 4 月中的一個黃昏，我抵達 Leeds 的旅店，為了參加翌日上午 10 時在「領導學院」舉辦的免費課程「講故事的力量」。兩位女導師都是經驗豐富的演講者和演員，在多方領域都有成就。她們抑揚頓挫的言詞加上身體語言，向 6 男 4 女的參加者示範不同類型的表達方式。我們是病人或照顧者，包括退休官員、護士、大學職員和翻譯員。5 名小數族裔中，我是唯一的華人。

上午的實踐環節，我選擇了 4 張圖片來呈現 R 家屬告訴我的故事。總結時，我問道：「NHS 一直強調早期診斷、及時治療才能獲得更好的預後。為甚麼這承諾沒有在我的癌友 R 身上兌現呢？」在授課時段，導師說：「講故事的重要和成功元素，包括語氣、停頓、動態……以便帶出聽眾的情感、激發興趣、引發行動或改變。」根據我身為護士和長期病人的經驗，病人的抱怨總是讓醫護感到責難和內疚，令兩者之間的關係變得緊張和對抗。事實上，醫護人員也可能成為病人。如果我們像導師所說的準備病人故事，目的不是讓聽者感到難堪，而是令他們受感動、願意改進、採取行動等，這正是病人所期望的，又可以帶來雙贏的效果。

下午我們再次實習，三位抑鬱症康復者講述了自己的漫長歷程，觀眾均給予鼓勵。隨後的退休人士，用幻燈片無言地表達信息。最後的一張影片介紹了其親人的死因，默默地展現了 11 個小錯誤同時發生，便奪走了一條寶貴生命。事實上，這些小錯誤可能發生在任何病房或病人身上，我深表同情和認同。男護士講述自己在職場倒下又重新振作，我聽了後首先舉手和擁抱他，因為我曾經有過類似的經歷。經過精心準備和改進的故事講述，真的打動了觀眾。臨近尾聲，主辦女士邀請說：「我們已經多次舉辦這樣的課程，裝備病人講述自己具影響力的故事，從而改善醫療服務。NHS 提供住宿和交通，歡迎更多照顧者和病人參加。請在

<https://www.leadershipacademy.nhs.uk/patient-carer-communities/>報名。」下午 4 時，我乘火車返回倫敦，從心底希望所聽見的不幸事故不再發生。除了講故事，「領袖學院」還提供多種在線課程，裝備病人成為領導者以改善醫療服務。NHS 有如此的胸襟，願意持續聆聽和改善，實在難能可貴。

誠邀出席《關懷癌症月會》MCSG

您，並不孤單！

我們是您抗癌路上的同行者。

歡迎癌症病友、家屬、照顧者和朋友，大家分享近況，互相關懷，祝禱支持。感謝義工齊心侍奉，出席者預備愛心美食，一同分享分擔，為抗癌勇士打氣！



癌症奪去我的社交，
但不能搶去我的友誼。

蘇豪月會 12/8 (星期六) 11am-1am

SOC, 166A Shaftsbury Ave, SOC WC2H 8JB & Zoom

8/7 16 人出席陳亮祖醫生的講座「癌症知多少？」



美倫月會 (普通話) 17/8 (星期四) 11am – 1pm Zoom

20/7 Zoom 5 人參加，互相支持。



美景月會 (粵語) 22/8 (星期二) 2pm – 4pm

Maggie's Centre,
Charing Cross Hospital,
Fulham Palace Road,
W6 8RF

25/7 13 人參加，
互相支持



參觀大英博物館

28/7 8 人參觀「中華文化展」





CACACA July 2023 Finance report

June Balance	£ 38,009.41
July Income	£2,872.20
July Expenses	£ 1,063.00
July Balance	£36,200.21

Monthly Cancer Support Group (MCSG Soho)

Second Saturday of each month - 11am - 1pm

Soho Outreach Centre (SOC), 166A Shaftsbury Avenue, London, WC2H 8JB

Patient's story

Monica

I moved to HK when I was 7. After marriage, I looked after my 3 children as my husband often worked overseas. Once my children grew up, I joined church friends to volunteer at a nursing home. Witnessing the loneliness & solitude, I worried about my future. A priest recommended I join a charity aiding poor children in rural areas with stationery & books. My minimal efforts brought indescribable joy & fulfilment.

I'm short, with a 20-year old prolapsed disc, & have been taking HT & cholesterol meds for a long time. In late 2018, I had a knee replacement. For my back pain, I consulted an orthopaedic doctor who advised a check-up ASAP. Unexpectedly, I was diagnosed with terminal lymphoma. My children helped choose my chemo meds. After 12 cycles, my life resumed & we travelled to Japan. The New Year of 2019 in Taiwan, we enjoyed the sky lanterns. On the flight back, everyone else grabbed a mask but we were yet unaware of C-19 spreading. In Feb 2021, the health check for my BNO application found a lymphoma relapse with pleural effusion. After 6 chemo, we flew from HK during Typhoon Signal 3 in Oct. Upon arrival in London, NHS officer visited to confirm our self-isolation. We & in-laws have planned a Europe trip but GP found my lymphoma recurred. Fortunately, my daughter took care of me throughout as a carer & translator. I could only have non-live vaccines for flu or shingles, & irradiated blood if necessary. Despite 6 chemos with no discomfort, I caught a virus in March & my WBC dropped after 2 more chemos. In May, I had bacterial infection & pleural effusion again. In June, I was in ITU with a ventilator. My 3 children rushed to see me. Surprisingly, I regained consciousness. Separated by glass, they encouraged me & prayed over the phone. A blessing from the Lord! Although I was 74, I was attended to well during my 6-week stay. The discharge letter summarised my 8 major organ problems & treatment. Transportation was provided for discharge. Nurses home visited to deliver a commode chair, walking aids, & bed rails to assist my daily living. A carer came for 6 weeks help me shower & change. A physical therapist taught me exercises. I am grateful for NHS's meticulous care. My children's taxes are valuable & benefitted me.

My family worried if I could continue chemo, but I was scared of the painful IV cannula insertion bruising my arm. Before my 3rd chemo, a nurse installed a PICC Line which lasted 6 months, I am grateful! I met a CACACA interpreter who suggested a WhatsApp group for my support. She explained my blood reports accordingly so I could cooperate with my medical staff. Without her clarification, I wouldn't have known

that NHS emphasizes respecting patients' & families' wishes, as opposed to the traditional Chinese belief that healthcare professionals have all the authority. My family were supportive: my daughter administered injections & contacted the doctors while my husband learned healthy cooking from videos. I avoided going out but needed A&E after each chemo. After my 5th chemo, my blood index improved. I hoped to finish the last cycle in Sept.

The end of Sept, my legs were swollen & toes felt electric shocks which were chemo side effects. The volunteer massaged my legs & put on compression socks which helped. In Oct, the radiographer urged me to visit A&E after a CT scan. I resisted IV insertion due to the past experiences. 2 days later, after a PICC Line flushing, I visited A&E to ease family's worries. The nurse struggled 3 times but finally inserted the cannula. I was admitted but worried about infection in shared room with coughing patients. The nurse clarified through the volunteer that I was already C-19 +ve, which eased my worries. The night before discharge, 4 medical staff approached. I did not know my PO2 was low & needed O2. 3 days later when the volunteer visited again, 3 doctors addressed my pleural effusion. My platelet count at 50 was low, but still suitable for a chest drain of 1L fluid from my Rt lung. My breathing improved. After learning my viral meds were standard, not experimental, I was relieved to stay. My PO2 improved while I completed the courses of antibiotic & virus med. I was in-patient 2 weeks & discharged with diuretics. The discharge letter declared that my lymphoma spread causing ascites & leg oedema. 2 days later at OPD, the doctor suggested a stronger chemo with 20-30% success rate & more side effects, urging my daughter to discuss it with us. Hearing her hoarse voice, I signed consent for treatment to avoid further discussion. With my husband, I requested DNR. My daughter took a week-long break to accompany me to church, & joined my Oxford pilgrimage. After much thought, I declined chemo due to side effects: vomiting, diarrhoea, fever. I did not want to burden my family, especially my daughter. The doctor already informed me I had a few months left. The palliative nurse visited to ease my symptoms. The volunteer conveyed my wishes: a peaceful passing at a hospice, with no resuscitation. I was relieved.

My children's achievements are my own. They fulfil my needs, took me to see TCM for symptom relief. Since my cancer diagnosis in 2018, I had no pain with eating & sleeping. Having Jesus in my heart, I am truly content. I feel blessed I will meet my family in heaven someday. I am grateful to medical staff for their patient care. I hope my cancer story aids others: face treatment positively & cherish time with family.

PALS provides help in many ways. For example:

- help you with health-related questions
- help resolve concerns or problems when you're using the NHS
- tell you how to get more involved in your own healthcare



PALS can give you information about:

- the NHS services
- the NHS complaints procedure, including how to get independent help if you want to make a complaint
- support groups outside the NHS

PALS also helps to improve the NHS by listening to your concerns and suggestions.

<https://www.nhs.uk/nhs-services/hospitals/what-is-pals-patient-advice-and-liaison-service/>

Win-Win

Naomi C

On the evening of April 2023, I arrived in Leeds to attend the free course "Power of Storytelling" at the "Leadership Academy" the next day at 10 am. The 2 female instructors were experienced speakers & actors in various fields. They instructed 10 carers or patients, 6 males & 4 females, including retired officials, nurses, university staff, & interpreters etc. I was the only Chinese among 5 BAMEs.

During the practical session, I chose 4 pictures to present the story told by R's family. To conclude, I asked, "The NHS always emphasizes that early diagnosis & timely treatment leads to better prognosis. Why was this promise not fulfilled for my cancer friend R?" In the lecture, the instructor said, "Powerful elements of storytelling include tone, pauses, dynamics... to evoke emotion, spark interest & inspire action or change." As a nurse & a long-term patient, I know patient complaints always make healthcare professionals feel guilty, creating a confrontational relationship. In fact, medical staff can also be patients. If we prepare patients' stories as the instructor suggested, we do not need to make listeners feel bad but can move them to improve & take action, which is what the patient expects, leading to a win-win effect.

In the afternoon, we practiced again. 3 depression survivors shared their long journey, gaining audience encouragement. A retired man used a slideshow to speak silently, revealing the cause of his loved one's death in the final slide. 11 minor errors which could happen in any ward took away a valuable life, which I strongly empathized with. Listening to the male nurse's collapse & recovery at work, I raised my hand, hugged him, shared similar experiences. The well-prepared & improved storytelling truly touched the audience. "We've held this course often, empowering patients to share stories for better NHS services. NHS offers lodging, transport, & welcomes more carers & patients to join. Register at <https://www.leadershipacademy.nhs.uk/patient-carer-communities/> " said the organizer. At 4 pm, I returned to London by train, hoping such tragedies would cease. Moreover, online courses equip patients as leaders to improve medical services. NHS's openness & willingness to improve are commendable.

Monthly Cancer Support Group

MCSG is open to individuals touched by cancers, patients, survivors, family, friends and carers.

We move forward together.

None of us is alone!

Big "thank you" to participations' dedication & wholesome food.

Cancer snatches at my social life but cannot snatch at my friendship.



MCSG Soho 12/8 (Sat) 11am-1pm

SOC, 166A Shaftsbury Ave, WC2H 8JB & Zoom
8/7 16 attended Dr Chan's talk 'Knowing cancer'



MCSG Macmillan 17/8 (Thurs) 11am – 1pm Zoom

20/7 Zoom 5 people supported each other



MCSG Maggie 22/8 (Tue) 2pm – 4pm

Maggie's Centre,
Charing Cross Hospital,
Fulham Palace Road,
W6 8RF

25/7 13 people supported each other



Visiting the British Museum

28/7 8 people visited the 'China's hidden century'

