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臉書 Chinese Association for Cancer Care



癌症協會 4 月份財政報告

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五月暫停 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 • 倫敦中華基督教會蘇豪福音堂地庫 Soho Outreach Centre (SOC), 166A Shaftesbury Avenue, London, WC2H 8JB

癌友園地

謝麗霞

2018 年我如常地為中港兩地的生意奔波,只做星期日的 基督徒。在農曆年假稍為休息,我摸到左乳有乒乓球大 小帶痛的硬塊。考慮到輪候政府醫院可能超過九個月, 我自費做超音波和取活組織、醫生按症狀已診斷我九成 患乳癌。兩三日後我看報告,確診第 3 級乳癌。切除 3.2 cm 腫瘤後,病理報告顯示淋巴結輕微受影響,是第 3 期的早期, HER2 陽性, 相比 HER2 陰性的生長和擴散 更快。我四次化療後,每日電療共 35 次,同時每三週 注射標靶藥九個月,每日口服荷爾蒙藥5年。

我確診後震驚地問:「為何是我?」若治療不好,女兒 以後如何生活? 弟弟誠邀我前往他的家居養病, 我當然 考慮到他已婚,不方便我長期入住。豈料隨後一年,我 的弟婦每半日叫工人姐姐為我定時預備有機食物、補充 劑和新鮮蔬果汁。弟弟的心臟良性瘤已治癒一年, 倆夫 婦廣泛研究健康食療,非常樂意應用所學來照顧我。弟 弟的住屋有天台,望着藍天白雲是我每日靈修親近耶穌 的好地方。某日,我聽見有聲音說:「我可以差遣誰? 誰肯為我們而去?」我流著淚無信心地說:「我在這 裏,請差遣我!」自從我 23 歲信耶穌後,我一直不冷 不熱,但耶穌祝福我並賜下平安。治療的副作用如脫 髮、疲倦和失眠等, 我留下的記憶不深。

2020 年我們在西雅圖等了三個月,女兒仍未能入學。9 月,全家以 LOTR 身份來倫敦後,女兒自行上網找學 校。翌日獲校長接見,再翌日便入讀八年級。如此順利 和平安,是耶穌給我家定居英國的印證。安頓住屋後我 認識了數個香港家庭,經常一起打球。2022年初,我左 耳失聽覺左鼻堵塞。數次覆診獲 GP 處方耳油、耳水、 抗生素等均無效,轉介去 A 醫院的耳鼻喉科。五月首次 覆診,鼻鏡窺探無異,兩個月後覆診和照 MRI。我自費 到倫敦求診私家醫生,鼻鏡窺探也無異。MRI 和診金各 需£800, 我便等候 NHS 的 MRI。原定在 8 月的覆診被取 消,同時教會的護士 F 姊妹認為 : 「那位年長的醫生 可能忽略了亞洲人患鼻咽癌的機會非常高。」我按她的 建議打電話去門診要求更換醫生,獲年輕男醫生接見。 當日抽取中耳炎的積液,同時將積液做活組織化驗。兩 週後覆診,確診鼻咽癌的噩耗令我像破碎了的玻璃不懂 發問題。醫生安排我 3 週內照 CT 頭顱和 PET,轉去 G 醫 院的腫瘤科。丈夫開車帶我到 Brighton 吹海風,翌日 早上我想通了: 「以往乳癌治療, 耶穌不單無離棄而且 多方面照顧我, 患上鼻咽癌不過是另一次磨練, 不會超 過我能承受的。」相對 5 年前的乳癌,當下我信心堅定 地說:「我在這裏,請差遣我!」

11 月中, 我接受每三週一次的引導性化療共兩次。在醫 院6至8小時化療後,接駁一細瓶化療藥回家,48小時 後回醫院拆除。最初十日很辛苦,嚴重嘔吐、反胃、頭 量和身體虛弱。安裝 PICC Line 的護士嘗試三次也無法 將導管推入我的心臟, 見他滿手血, 我只能祈禱。喚來 的高級護士成功推入導管時, 我的右手感到麻痺。入手 術室局部麻醉下,在胃部安裝「胃飼管」RIG,以便我 兩日後,即平安夜前,繼續在醫院每三週一次的化療, 和每日的電療共 30 週。電療初期蓋上電療罩令我呼吸 困難,一週後我消瘦了便較為舒服。電療的副作用逐漸 加劇,口腔潰瘍難以吞口水。我便經常吐口水,會較舒 服,後來被提醒口水內的消化霉是不可或缺的。普通止 痛藥無效,改為飲嗎啡水,每四小時由 5ml 增加到 10ml。半夜痛醒我飲下嗎啡水後 5 至 10 分鐘, 便能重 新入睡。我常備兩樽水放在床邊,冰水有效舒緩痛楚。 護士介紹網上購買的口水丸,含在口內 8 小時大大改善 口乾。 嗎啡導致我便泌五日, 肚腹非常脹實, 需要每日 服食排便藥。由於無法進食, 丈夫為我每 8 小時在 RIG 輸入營養液一公升。有三次早上起床後嘔吐大量的營養 液,我學會起床動作要放慢,又買了半坐臥式靠背椅來 睡覺,以便營養液進入小腸。普通漱口水外,醫院給我 阿士匹靈漱口水來止痛。我的乳癌荷爾蒙治療有血栓塞 的副作用,需要服食阿士匹靈。電療令我後枕掉頭髮, 頸部皮膚是嚴重曬傷的刺痛和脫皮,必須塗醫院提供的 潤膚膏和穿著柔軟的衣服。二月初我完成最後一次電 療, 豈料電療在皮膚和喉嚨的副作用繼續加劇三數週。

我非常欣賞 G 醫院, 當我進入診症室後, 營養師、言語 治療師、專科護士、腫瘤科醫生等,輪流進來給我一站 式的服務, 免除我前往不同診症室的困擾。他們的聆 聽、非常具體有效的建議和詳細的解釋,令我和丈夫對 治療安心。我借用乳癌治療的經驗,為自己早作準備, 例如從香港訂購補充劑,聘請照顧者處理家務兩三個月 等。F 姊妹回應無法為我找到照顧者,但提出她倆夫婦 可以前來照顧和煮食物,簡直令我受寵若驚。我便明白 自己為何住在 F 姊妹的附近, 耶穌真的早有準備。此 外,我的姐姐有兩名兒子,全家三位男士都願意做家 務,支持她在七月參加了教會的短宣隊,前往波蘭照顧 烏克蘭的難民。10月底,姐姐從波蘭過來照顧我的康 復。她抵埗後便可以照顧我,毫無時差等適應問題。我 得的比失的更多,沒有其他鼻咽癌病人因進食困難而消 瘦。完成治療後,我只減了四至六磅。我學會在日常生 活中,例如切洋蔥時心中與上帝對話。因著我的癌症, 團結了我的家人, 甚至失去聯絡的姨生女也從美國來探 訪我。我仍需要每年去 A 醫院覆診乳癌科兩次。兩次患 癌症,令我深深經歷苦難如何化成祝福。我衷心再次感 謝耶穌!

「病人經驗在線免費培訓」由 NHS 領導學院的「病人經驗圖書館」設計,涵蓋:

PATIENT EXPERIENCE WEEK

April 23-29, 2023

- 1) 病人經驗的證據收集過程中誰負責甚麼
- 2) 病人經驗的實務關鍵概念
- 3) 為甚麼病人經驗很重要
- 4) 聆聽病人經驗帶來的挑戰
- 5) 如何尋找不同類型的病人經驗作為證據
- 6) 如何開始理解病人經驗的證據

請到 https://leadershipnhs.uk ,選擇您所在的地區並開設帳戶,如果您已經是用戶請登錄,查找 Patient Experience in Leadership Modules 並開始學習!

五月暫停 蘇豪月會 (粵語)

8/4 (週六)11am-1pm 25人 參加。









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!

網上美倫月會 (普通話) 18/5(週四) 11am - 1pm

20/4 6人參加,互相支持。



美景月會 (粵語) 23/5(週二) 2pm - 4pm

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

25/4 7人參加,互相支持。



有主同在 活得自在

白花

當年丈夫患食道癌,三個月內離去。三年後,我從喪偶的傷痛和抑鬱漸漸康復,投入了翻譯工作至今。中介公司轉介醫院的預約,有時在我家附近的醫院,一程地鐵便到;有時需要轉三程車超過兩小時才到達,也有隨時候命的電話翻譯,我也甘心樂意去做。雖然 NHS 會支付我的交通費,但我不是為了工資,乃是以過來人的身份,陪伴病人和家屬面對覆診時言語不通的困難。

在門診翻譯前後,我以朋友的身份與病人和家屬交談,分享我的人生經驗,尤其信仰給我的支持,成為內心力量去面對家人的癌症。某些病人向我道謝,因為他們接受了我的免費輔導。我曾經陪伴病人入手術做心臟的通波仔、白內障手術、血液分析、糖尿病人更換小腿大塊爛肉的包紮敷料、和其它林林總總的雜症。注目螢幕上的手術過程,我不怕血淋淋的場景,可以冷靜地為醫生逐個治療步驟翻譯清楚。原來讓病人知道手術過程的細節,可以令病人放鬆,對治療有信心。近日在醫院,我雖然戴著口罩,老人

癡呆的病人也認出我,衷心多謝我以往的翻譯和陪伴。 到精神科翻譯又是另一番體會,病人的表達內容充滿情 緒問題和激動語句。我靠著耶穌給我內心的平靜,儘量 按照病人的語氣和內容傳達給醫生聽,事後我好快能夠 恢復下來。不是我的專業技術,乃是主耶穌幫助了我調 整內心世界,不受病人影響我的情緒。若有人對翻譯工 作有興趣,我也樂意分享經驗作為他們的借鏡。

十年來,我出席了多個癌友支援組。若時間許可,我也參與義工行列提供免費翻譯。起初癌友的分享令我觸景傷情,但我越敢面對、越分享照顧丈夫的癌症經歷,我越得到醫治。漸漸地癌友們的積極態度也激勵了我,我們建立了深厚的友誼,成為雙向的祝福。過去十二月天寒地凍,落雪的路面結冰濕滑。稍不小心我向後滑倒,幸好背囊托住了下墜的衝力,令我免受傷。我習慣了獨處也享受群體生活,也不介懷別人的評價。我存感恩的心過每一天,有耶穌同在便活得自在了。



UK Registered Charity Number: 1160496

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Facebook Chinese Association for Cancer



CACACA April 2023 Finance report

Mar Balance £ 35 215.83

Apr Income £ 2 274.56

Apr Expenses £ 19.20

Apr Balance £ 37 471.19

Monthly Cancer Support Group • MCSG Soho Paused in May

Second Saturday of Each Month ● 11:00 am – 1:00 pm

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

Patient's Story

Roma

In 2018 the CNY, I felt a ping-pong-ball size painful lump in my Lt breast. To avoid at least 9-months waiting for a government hospital appointment, I had a US & biopsy by a private doctor who diagnosed me with 90% breast cancer based on my symptoms. A call within 2-3 days confirmed the Grade 3 breast cancer. After a lumpectomy of the 3.2 cm tumour, the pathology report showed the LN removed was slightly affected, early stage 3, HER2 +ve which grows & spreads faster than HER2 -ve. After 4 chemos, I had a daily RT, in total 35 fractions, along with 9 months targeted injections tri-weekly & 5 years of daily hormonal therapy.

I was shocked at the diagnosis asking, 'Why me?' but was more concerned about my daughter if my treatment failed. My brother offered to take care of me but my long stay would be inconvenient as he was married. To my surprise, for 1 year, their maid prepared organic food, supplements & fresh fruit & vegetable juices for me twice a day. He had recovered from a benign heart tumour & they had studied healthy eating extensively. They happily applied what they had learned to me. On their house's rooftop with a blue sky & white cloud, I got closer to Jesus by daily devotion. Once, I heard a voice saying, 'Who can I send? Who will go for us?' I said with tears but no confidence, 'I am here, please send me!' Since I believed in Jesus at 23, I have been lukewarm. Jesus has not abandoned me but blessed me with peace. All the side effects, such as hair loss, fatigue & insomnia, are not well remembered.

In 2020, after 3 months in Seattle, our daughter could not start schooling. We arrived in London in Sept through LOTR. The day after registering online, my daughter was interviewed by the principal and started her Year 8 unexpectedly smoothly. My family saw it as Jesus' guidance for us to stay in the UK. In early 2022, I felt a loss of hearing in my Lt ear & a blockage in my Lt nose. After several consultations, GP prescribed ear oil, ear drops & antibiotics, but to no avail, so I was referred to Hospital A ENT. In May, the nasal endoscopy was NAD. I consulted a private doctor in London & the nasal endoscopy was fine too. The MRI & consultation cost £800 each so I waited for NHS treatment. The church Sister F, a nurse, mentioned that the elderly doctor may have overlooked that Asians have a very high risk of NPC. So, I called the OPD to ask for a new doctor, who did a myringotomy for my Otitis Media & sent the fluid for biopsy. 2 weeks later, the diagnosis of NPC made me feel like broken glass & I couldn't ask anything. CT skull & PET scans were scheduled & I was transferred to Hospital G Oncology. Later, my husband drove me to Brighton to enjoy the sea breeze. The next morning, I realised that Jesus had not abandoned me during my previous cancer and had taken care of me in many ways. Having NPC was just another trial, no more than I could bear. At that moment, I had the confidence to say, "I'm here, send me!" in response to 5 years ago.

In mid-Nov, I had 2 induction chemos tri-weekly. After 6-8 hours of chemo, I took an attached medicine vial home for 2 days. The first 10 days were hard, with severe vomiting, regurgitation, dizziness & weakness. The nurse failed to push the PICC line into my heart even after 3 tries. I could only pray as his hands were covered in blood. My Rt hand felt numb when the senior nurse pushed it in. Under LA in the OT, I had a RIG installed to continue chemo & started daily RT for 30 fractions 2 days before Christmas Eve. Initially, the RT mask caused difficulty breathing. After a week it was better after I lost weight. RT caused mouth ulcers & dysphagia. I spat to make me feel better but was reminded that digestive enzymes in the saliva were essential. The regular painkillers didn't work, so I was given Oramorph, increasing from 5ml every 4 hours to 10ml. I woke up at night but I could fall back asleep within 5-10 min after drinking Oramorph. I always kept 2 bottles of water by my bed, since the ice relieved the pain. The nurse introduced a saliva pill which I bought online, effective for 8 hrs. Morphine caused serious constipation for 5 days, I needed daily laxatives. Due to my dysphagia, my husband gave me 1L nutrient solution via RIG every 8 hours. 3 times, I vomited a lot in the morning, so I learned to get up slowly & slept on a semireclining frame so the nutrient feed could enter my small intestine easily. Aspirin mouthwashes eased the pain, in addition to the normal mouthwash. I also took aspirin for of my hormone therapy side effects. I had occipital hair loss. My neck skin stung & peeled like a bad sunburn, but the hospital creams & soft clothing helped. I completed the last fraction in early Feb, but the side effects worsened for 3 more weeks.

I appreciated G Hospital. When I entered the clinic room, the dietician, speech therapist, CNS, oncologist, etc., took turns coming in, providing a one-stop service without the hassle of going to different rooms. Their listening. explanations, & effective advice put us at ease. Learning from my breast cancer, I prepared by ordering supplements from HK etc. I was pleasantly surprised by Sister F, who offered to take care & cook food for me with her husband when she could not find a carer for me. I then understood why we lived near Sister F. Jesus had really prepared for this. Moreover, my sister's 2 sons were willing to do household chores, supporting her to join the church's short-term mission trip to Poland in July to take care of Ukrainian refugees. At the end of Oct, she came from Poland & looked after me without any jet lag after arrival. I gained more than I lost. NPC patients struggle with eating but I have lost only 4 to 6 lbs after all the treatments. I learnt to talk to God in my heart in daily life, such as chopping onions. My cancer has united my family. Even my niece, whom I had lost touch with, visited me from the USA. Today, I still have breast appointments at A Hospital twice a year. Having cancer twice has given me a profound experience of how suffering can be turned into a blessing. I thank Jesus from the bottom of my heart!

Online free training for Patient Experience is designed by the NHS Leadership Academy **EXPERIENCE** covering:

- 1) Who does what in patient experience evidence gathering
- 2) Key concepts in patient experience work
- 3) Why patient experience matters
- 4) Challenges of hearing from patients
- 5) How to find different types of patient experience evidence
- 6) How to start making sense of patient experience evidence

Please simply go to https:/leadershipnhs.uk, select your region & create an account or log in if you are already a user, & look for 'Patient Experience in Leadership Modules' to get started!

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.

Let us stand together to fight cancer!

MCSG Soho Paused in May

8/4 (Sat) 11am-1pm 25 people joined









PATIENT

WEEK

April 23-29, 2023

Zoom MCSG Macmillan 18/5 (Thurs) 11am – 1pm

20/4 6 people joined & supported each other



MCSG Maggie 23/5 (Tue) 2pm – 4pm

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

25/4 7 people joined & supported each other



With the Lord, I live freely

White Flower

Years ago, my husband passed away within 3 months with oesophageal cancer. 3 years later, I recovered from the lost & depression & worked as an interpreter. Through the agency, I work for hospitals, nearby only 1 tube ride away or it takes 2 hrs & 3 changes to get there. Sometimes I have to tele-interpret on a moment's notice, but I am willing to do it. Although the NHS pays for my transport, I am not doing it for the money. Instead, I accompany patients & their families who are struggling with language barriers during follow-up, drawing on my own experience as a person who has gone through a similar situation.

Before & after interpretation in OPD, I talk to my clients as a friend, sharing my life experience & how my faith has given me the strength to face my husband's cancer. Some patients thanked for my free counselling. I have accompanied patients for heart surgery, cataract surgery, blood analysis, diabetes wound care, miscellaneous ailments. Watching the surgical process on the screen, I am not afraid of the bloody scenes, calmly interpret each step. Helping them know the procedures in details, patient will relax & have confidence in the treatment. Recently, in the hospital, even though I wore a mask, a cancer

elderly patient recognized me & thanked me sincerely for my support. Working at the mental OPD is a different experience. Patients expressed their emotions & using provocative language. I relied on Jesus to give me inner peace, conveying their tone & content to the doctor as best I could. Afterwards, I recovered quickly. It is not my professional skills, but the Lord Jesus who helps me adjust my inner world, not be affected by the patient's emotions. If someone is interested in interpretation, I am happy to share my experience as a reference for them.

For the past 10 years, I have attended multiple cancer support groups. If time permits, I provide voluntary interpretation. Initially, hearing cancer patients' stories was painful for me, but as I shared my experience of caring for my husband I was healed. Gradually, cancer patients' positive attitude also inspired me. We built a strong friendship which is mutually beneficial. In the snowy Dec in 2022, the icy & slippery road caused me to slip & fall backwards. Luckily my backpack cushioned my fall & saved me. I have become accustomed to being alone & enjoy group living. I don't mind what others think of me. I live each day with a grateful heart. With the Lord by my side, I live freely.