

A QUARTERLY BULLETIN OF KDF

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DANCING THROUGH LIFE WITH LOUIS

KDF patient Louis Chia, 50, believes in lending a helping hand to the greater community through a unique role – as a freelance pallbearer for a bereavement services company.

In this special issue of KDF Link, we sat down and had a chat with Louis to better understand his challenges as a kidney patient, his unique choice of work, and about his motivations in life.

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HOW DID YOU REACT TO YOUR DIAGNOSIS?

When I was in my late twenties, I was diagnosed with diabetes. This affected my kidneys, and I only had about 25% of kidney functions left then. Due to my health condition, I was subjected to regular health reviews every year for the next 10 years or so. In 2017, my doctor found that my kidney readings had deteriorated further - below 10%! I was asked to undergo dialysis after. It was not surprising for me.

Back then, I was guite sure that I did not want dialysis because it was inconvenient and expensive. I even remember asking the doctor, "How long do I have to live if I don't go through dialysis? I don't print money you know." Turns out you can stay alive for 2 weeks without treatment, and I figured 2 weeks was enough for me. My wife and mother were extremely upset with my decision, and they tried to convince me to reverse the decision. In the end, I gostan¹ my decision lah, and agreed to start dialysis.

I was receiving treatment from a private service provider, and it was putting a toll on my family's

> finances. My motherin-law is also a dialysis patient, and my wife was struggling to afford our treatments.

I was finally transferred out and was accepted into KDF. It really lifted the financial burdens from her.

HOW DID LIFE CHANGE AS A KIDNEY PATIENT?

Shortly after my diagnosis, my father was stricken with end-stage cancer. Prior to that, I was working as a fulltime sales manager in the building materials industry for more than 10 years. I made the decision to quit my job and be my father's primary caregiver.

On top of caring for my dad, I had to work around diet restrictions and loss of strength. Dialysis was exhausting, and I was always weak after each session. My schedule is now fixed, I had to control my liquid intake, I can't eat many foods that I used to enjoy. I had to make peace with a lot of discontent. Dad fought the good fight and passed away 2 months later.

> In 2018, I underwent a heart bypass procedure, and my physical health went downhill. I could no longer walk long distances without feeling breathless, and it was normal for me to pass out from tiredness for long hours on the bed after dialysis.

It was sad that I could not be my normal self. I was only 46, but my body felt like an old man. I used to be a workaholic – I would drop everything for work. Now, I am too weak to manage a full-time job, and my wife had to take on the role of the sole breadwinner of the household. But I'm thankful for KDF's assistance, and the staff and patients, many who are now my good friends. In a way, this disease forced me to slow down and focus more on my wellbeing - bit of a blessing in disguise *lah*.

YOU WERE ONLY 45 WHEN DIAGNOSED. WERE YOUR FAMILY MEMBERS OPEN TO EXPLORE ORGAN DONATION?

My doctor did mention that I was considered young for a kidney patient. My wife actively considered donating her kidney to me. However, after a series of reviews and check-ups, we were not able to proceed as her family has a history of kidney-related diseases. My mother-in-law is also a dialysis patient for the past decade, so my wife is not a suitable donor.

My mother has tried broaching this topic with my five siblings. It's easy to get help from my siblings, both financially and mentally. But to ask either of them to donate a kidney to me, it's a huge, life-changing decision for them to make.

My family has been rather conservative about it, and matters have remained status quo. Ever since I had my heart bypass procedure, I am now no longer able to put my name on the public kidney transplant waiting list. Of course, I have my regrets, but it is too late to change anything now.

HOW WERE YOU INTRODUCED TO THE BEREAVEMENT CARE INDUSTRY?

When my father passed away, I had the help of a group of friends in church to assist with the funeral. Soon after, they reached out to me and said, "Louis, you're not working at the moment. Would you like to help as a pallbearer in the bereavement services industry?" I just thought, this sounds easy enough and I can earn some pocket money out of it as well, I agreed.

HOW DID YOUR FAMILY REACT TO YOUR DECISION TO BE A PALLBEARER?

laughs My father's side of the family were puzzled when they found out about my new 'gig'. You know how superstitious older folks can be. They were telling me, "Louis, why did you choose such a job? Why put yourself in such a position? You can work for the living, why work for the dead?" Being in bereavement care is a proper job, no matter what your role is. I've been a freelance pallbearer for Dignity Bereavement Services for a while now. I don't rob, I try my best to make an earnest living, and it's meaningful. I am also in a direct position to help those in need, so why not make the best out of it?

My wife has been extremely supportive of my job. She tells me all the time – "If you enjoy this, keep doing it." Due to my health conditions, some of the blood vessels at the back of my eyes are damaged. I experience severe vision floaters, making it difficult for me to see or work at night. So, If I take on any work engagements in the evening, my wife never fails to come by after her work to help me. I am extremely lucky to have her by my side.



DO YOU HAVE ANY INTERESTING WORK ANECDOTES?

The rule of thumb working in an afterlife services company is to never turn a grieving family away. We once received a referral from a family who had budget constraints. Regardless, the team went the extra mile and agreed to take on the engagement. They did their best to ensure that the deceased was able to get a dignified send-off.

At the wake, I realised that they were family friends. I guess that was a divine sign, that I was meant to be in this industry. **laughs** Even when I feel tired after dialysis, to the point that I find it difficult to walk, when a phone call comes in and I have another family to serve, somehow without fail, I am able to find a renewed sense of energy to accept the case and comfort the grieving family.

It's normal to face emotional family members in this line of work. Usually, words fail to provide the comfort that they need. What we can do is to show it through our bereavement services, and let our physical presence be a source of solace for the family during this difficult time

When I am able to provide proper closure for the deceased and their loved ones, it really shows on the faces of the family members, and that gives me a sense of satisfaction. Some of them are now my friends, and they call in to check in on me every now and then. It makes me want to continue what I feel I was meant to do.

YOU ARE ONE OF THE FEW KDF PATIENTS THAT HAVE SOME FORM OF WORK ENGAGEMENT. DID YOU FACE ANY THE CHALLENGES ALONG THE WAY?

Of course. I have faced employers who have asked me to leave with no valid reason, after I was upfront with that that I am a kidney patient. But we can't fully blame them. As a kidney patient undergoing haemodialysis, I can't work a regular 9 to 5 job for five days a week because 3 days would be for dialysis. Health scares can happen too. That's the reality of being a kidney patient.

The gig economy has been quite forgiving to us since flexibility is important. Some of us can even be private hire drivers now. More can be done to remove the social stigma of being a kidney patient. A little bit of understanding goes a long way. Earning your own keep, no matter how much or how little, can really empower us.

ANY ADVICE FOR FELLOW KIDNEY PATIENTS?

It's okay to be angry or upset in the initial stages of diagnosis, but don't let it consume you.

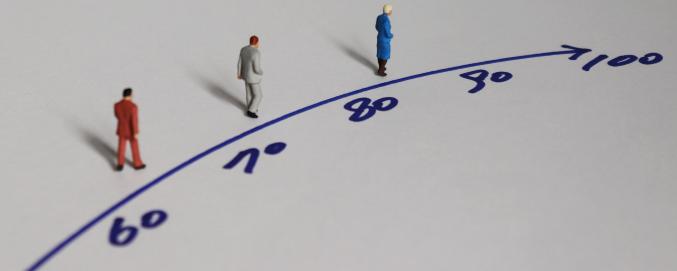
> It is important to come to acceptance in the end. Everything happens for a reason, and it is on you to make the

best out of the situation. Dialysis can add years to your life, but what you do with your added years is what matters more.

Spend time with your loved ones, do some volunteer work, help a family in need. In fact, after this I'm going to slowly make my way to pick my wife up from work. Make every waking moment count.

¹Singlish for reverse





LIFE MATTERS: INTRODUCTION TO ADVANCE CARE PLANNING

By Lawyers Tan Shen Kiat, Cheronne Lim and Angela Teo, Guest Writers from the Law Society Pro Bono Services

Whether you're raising a young family or have entered your golden years of later life, you may have concerns about what to do if your physical or mental health should fail one day.

Advance Care Planning ("ACP") is one of the tools to consider in futureproofing your care.

WHAT IS ACP?

ACP is an ongoing conversation that helps you to decide on future care options. You can nominate someone, such as your current or future caregiver, to make any medical decisions on your behalf.

Your wishes will be recorded in an ACP document, which can be updated anytime.

It is a roadmap to guide your appointed decision-maker on making care decisions on your behalf based on your preferences.

WHO SHOULD CONSIDER ACP?

Anyone can start the ACP process, regardless of age or health condition, to document their healthcare preferences.

For those who have chronic or terminal illnesses, early cognitive impairment, or are approaching the end-of-life, ACP would be of greater importance.

IS ACP LEGALLY BINDING?

While it is not legally binding, ACP should be an integrated part of your estate planning suite together with other legally binding documents such as the Lasting Power of Attorney ("LPA") and the Advance Medical Directive ("AMD").

Briefly: An LPA is a legal document that allows you to appoint one or more decision-makers (known as donees) on your behalf if you lose mental capacity. The donee will act on your behalf in matters relating to personal welfare and/or property and affairs. An AMD is a legal document stating your preference not to have extraordinary life-sustaining treatment in the event that you become terminally ill and unconscious.

Whilst each serves a different purpose, they all seek to communicate how you wish to be cared for when you no longer have the mental capacity to do so. If you already have an LPA and/or AMD, do include your appointed future caregivers in the ACP discussion.

Ideally, you should appoint the same

person or persons in the ACP and LPA, to avoid potential disagreements when they make care decisions on your behalf.

WHO SHOULD I APPOINT AS MY NOMINATED HEALTHCARE SPOKESPERSON?

Your Nominated Healthcare Spokesperson ("NHS") should be someone whom you know well enough to have an open conversation with about your ACP.

Someone whom you trust enough to speak up for your values, and to act in your best interests when you cannot speak for yourself. This may mean being able to make tough decisions under stressful circumstances.

You can nominate up to 2 persons as your NHS.

HOW DO I START MY ACP?

You may contact an ACP provider today for assistance. (*https://www.aic. sg/care-services/acp-directory*)

ACP providers include most hospitals, selected polyclinics, and community care providers. If you are already a patient at a hospital or polyclinic, you may wish to ask your treating doctor for a referral.

HOW CAN I PREPARE BEFORE SEEING AN ACP PROVIDER?

Some questions to consider include:

- What aspects of your current lifestyle are important to you? How can your caregiver preserve your sense of dignity where possible?
- Depending on the condition of your health, would you prefer a comfortfocused treatment or life-prolongingfocused treatment?
- Depending on your medical needs, what type of care options would you prefer? E.g. Hospital, nursing home, home, etc.

For more information about ACP, please scan the QR code for the AIC Advanced Care Planning Workbook

AIC Advance Care Planning Workbook

Find out more at the following links below:

- https://www.aic.sg/care-services/all-about-acp
- https://www.aic.sg/care-services/faqs-on-acp
- https://www.aic.sg/care-services/simple-steps-for-acp
- https://www.aic.sg/care-services/acp-resources

ABOUT LAW SOCIETY PRO BONO SERVICES

The Pro Bono Services Office of the Law Society of Singapore (Charity Registration No. T07CC2064L) and approved Institution of a Public Character (IPC Registration No. IPC 000571) was established on 10 September 2007 with the mission to help bring free legal assistance to those in need in our community, as part of the Law Society's stated mission – to ensure access to justice for all.

We run a wide range of programmes and activities that can largely be categorised under:

- Law Awareness initiatives such as talks, publications and partnerships with organisations for their members and beneficiaries
- Free Legal Clinics for qualifying applicants that run Mondays to Thursdays at the Central, North West, South East and South West Community Development Councils (CDCs); as well as Community, Criminal, Workers, Family and Civil clinics at the Community Justice Centre (CJC)
- Representation for qualifying applicants under the Criminal Legal Aid Scheme (CLAS)
- Help for Non-Profit Organisations and Social Enterprises that start with legal clinics and go onto transactional help where necessary.





CHARITY ICON 2022: ROARING IN THE LUNAR YEAR WITH THE PROSPEROUS TIGER

by Tan Pei Zhen

KDF's Charity Icon Launch Ceremony 2022 was a resounding success. To mark the lunar year of the tiger, KDF Charity Icon 2022 'Prosperous Tiger', made with exquisite amber 'liuli' glass, features a magnificent tiger atop a rock feature, ready to take on new endeavours.

The event held on 23rd April 2022 saw about 200 participants, raising a total of \$180,000 that evening at The Grassroots' Club.

A networking appreciation dinner at the Eternal Garden Restaurant by Qian Xi Group preceded the highlight of the day – the official Launch Ceremony for KDF Charity Icon 2022 'Prosperous Tiger'. This year, the ceremony reopened its doors to live audience, a first since the onset of the COVID-19 pandemic. The session was also live-streamed on Facebook.

Graced by Guest-of-Honour Senior Minister of State for Ministry of Transport Mr Chee Hong Tat and Special Guest KDF Chinese Community





Committee Senior Honorary Adviser Ms Tin Pei Ling, the launch was hosted by Getai Diva Lee Pei Fen and local celebrity Brandon Wong. The ceremony commenced with an upbeat 24 Festive Drums performance.

In his opening speech, Minister Chee appealed to the audience to bring out the strength in unity and support KDF's beneficiaries by generously adopting the Charity Icon. Accompanied by the KDF Chinese Community Committee, Minister Chee unveiled 8 'Prosperous Tiger' Charity Icons on stage and signed on each of them. These 8 exclusive pieces were to be awarded to the top bidders of the Charity Icon that night.

According to renowned local Fengshui Master, Master Hui, the Tiger is a



symbol of majesty, courage and determination, believed to possess the ability to preserve wealth and bring good fortune while warding off evil.



A series of amazing performances lifted the spirits of the crowd, from singing familiar favourites to a breathtaking martial arts performance. Hearty bursts of laughter also echoed through the auditorium amidst the friendly banter between local artistes Chan Tianwen and Brandon Wong, as they interacted with the audience.

Then, local "King of Hokkien Songs" Zhuang Qing Yu performed two songs with his signature sonorous voice. As a kidney patient himself, he explained to the audience that kidney disease is both physically and mentally taxing, the very reason why many kidney patients are unable to sustain their sources of income. He encouraged the public to empower kidney patients in need by donating generously to the Foundation.

Towards the end of the night, the charity auction closed and the top bidders of the nights were:

· Mr Benny Lee, Managing Director,

GET International Pte Ltd - **\$25,000**

- Mr Neo Kah Kiat, founding Chairman and CEO of NEO Group Limited -\$25,000
- Yu Long International Feng Shui -\$20,000
- Alpine Shipping Pte Ltd **\$10,888**
- Mr Ong Lian Kwang **\$10,000**

KDF Charity Icon Launch Ceremony 2022 concluded with an enthusiastic singalong to classic Hokkien hit -"You Have to Fight to Win" (爱拼才 会赢), and heart-warming applause in recognition of our big-hearted donors and performers. KDF would like to sincerely thank everyone for their generous support towards underprivileged kidney patients in Singapore.

The KDF Charity Icon is a meaningful fundraising initiative heralded by the Chinese Community Committee of KDF since 2003. You may adopt a KDF Charity Icon – "Prosperous Tiger" with a donation of \$888 and above. Proceeds from this fundraiser are directly channelled into providing subsidies for dialysis treatments, medication, transportation, and holistic care for our low-income kidney patients, many who belong to the

lowest 10% income tier in Singapore. Your every contribution will make a difference in the lives of our patients.



Adopt the "Prosperous Tiger"





KDF HAPPENINGS



26 APRIL 2022 KDF GivePlease Donation Microsite Goes Live

In collaboration with local fintech platform GivePlease, KDF's dedicated donation microsite was officially launched. This is part of the Foundation's initiative to simplify donation methods and make giving more convenient for a digitally savvy audience.



JUNE 2022 Recognising Steward Leadership Excellence in Asia-Pacific

The Kidney Dialysis Foundation was approached by the Stewardship Asia Centre (SAC), a non-profit centre established by Temasek Trust to contribute a perspective article to the Stewardship Commons as a steward leader in the healthcare sector. This is part of a larger initiative by SAC to feature perspectives derived from purpose-driven work across different industries, to inspire individuals around the world to take a stewardship approach. The Commons database will be live at the end of this year.



19 JUNE 2022 Cheng Hong Welfare Society Fathers' Day Luncheon

KDF patients were invited to a Father's Day luncheon at Qian Xi Restaurant at Paya Lebar by our friendly SSA neighbour and partner, the Cheng Hong Welfare Society. The luncheon was graced by Guest of Honour, Defence Minister Heng Chee How. Patients were treated to a sumptuous 8-course lunch over exciting martial arts and Teochew opera performances.

KDF活动



2022年4月26日 KDF GivePlease捐款微型网站推出

KDF与本地金融科技平台GivePlease合作,推出专 属的捐款微型网站。这是KDF为简化捐 款方式计划中的项目之一,也让精通 科技的公众可以更方便地捐款。



2022年6月 认识亚太地区的尽责治理领导

淡马锡信托基金会创立的非营利组织亚洲尽责治理研 究院(SAC)邀请KDF作为医疗保健领域中的尽责治理领 导为众包平台Stewardship Commons撰写一篇文章。 这是属于SAC一个较大的计划中的项目,跨越各领域从 多种有意义的行业中出发展示不同的观点,旨在启发全 球各地的人们实现尽责治理。平台资料库预计于今年底 在推出。



2022年6月19日 **众弘福利协会敬老尊长父亲节慈善午餐**

KDF病患受邀参加我们友善的社会服务机构邻居及伙伴众弘福利协会于巴 耶利峇千禧楼举行的父亲节慈善午餐。活动由国防部高级政务部长王志豪 先生担任主宾。病患在宴席上享用了八道美味佳肴,并观赏了精彩的武术及 潮剧表演。

2022年慈善福物: **虎虎生威**

陈沛祯 译



KDF 2022年慈善福物推荐会成 功举行。为纪念今年虎年,KDF 2022年的慈善福物《虎虎生 威》是由精致的琥珀琉璃 制作,猛虎威风凛凛 立于高山之巅,显现 出准备好迎接新挑战的

强大气势。

推荐会于2022年4月23日在基层俱 乐部举行,有超过200位出席者,当 晚共筹得18万元。 当晚的重点节目无非是KDF 2022 年慈善福物《虎虎生威》的推荐仪 式。在那之前,出席者在千禧集团的 永福楼餐馆进行社交鉴赏晚宴。今 年,推荐仪式从新冠疫情爆发以来, 首次向现场观众打开大门。该活动 也在社交平台脸书上进行现场直 播。

除了主宾交通部高级政务部长徐芳 达先生以及特邀嘉宾KDF华社委员 会荣誉顾问陈佩玲女士莅临现场, 当晚的推荐仪式也是由歌台天后李





佩芬、本地艺人黄炯耀一同主持。经 过一场振奋人心的节令鼓表演,精 彩连连的仪式正式开始。

交通部高级政务部长徐芳达先生在 开幕辞中呼吁观众凝聚集体力量, 热心捐款投标福物以帮助KDF的受 益对象。在华社委员会的陪同下,徐 部长为八座福物揭开面纱并献上亲 笔签名。这八座福物将颁发给当晚 投标数额最高的八位善心人士。

据本地著名风水大师慧师傅,老虎 是威严、勇敢、坚韧不拔的象征,被 认为是具有趋吉避凶和守财的作 用。

一系列精彩的演出将现场气氛推向 高潮,不仅有经典曲目演唱,还有令



人叹为观止的武术表演。本地艺人 陈天文、黄炯耀相互调侃,和观众进 行互动,让现场笑声不断。



接着,本地"福建歌王"庄清玉以他 经典的浑厚嗓音献唱了两首歌曲。 同身为肾病患者的他提醒观众,肾 病是对身体和精神的双重损耗,导 致许多患者无法维持收入,借此机 会呼吁观众慷慨解囊,为肾病患献 上爱心与希望。

夜渐深,投标活动结束,当晚的最高 竞标者为:

 Mr Benny Lee, GET International Pte Ltd 董事总经 理 - \$25,000
 梁佳吉先生,梁苑集团创始主席 兼首席执行官 - \$25,000
 Yu Long International Feng Shui - \$20,000

4)Alpine Shipping Pte Ltd -**\$10,888** 5)翁两光先生 - **\$10,000** 所有出席嘉宾一同合唱经典福建金 曲《爱拼才会赢》,并为当晚的善心 人士和表演者热烈掌声,2022年的

慈善福物推荐仪式圆 满落幕。KDF真诚地感 谢各位对于本地弱势 肾病患者的大方捐助。

KDF慈善福物是由本 基金会华社委员会自 2003年以来举办一项 富有意义的筹款项目。 凡捐款数额\$888及以

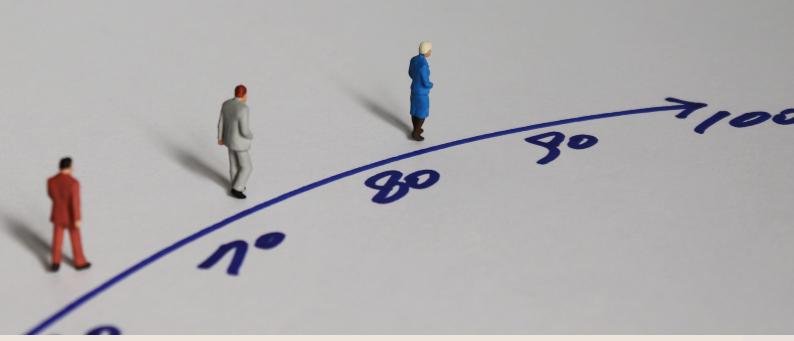
上者即可领取一座KDF慈善福物《 虎虎生威》。该项目筹得的款项将直 接用于为我们的低收入肾病患提供 洗肾治疗、药物、交通及全面照护的 费用津贴。这些病患大多数都属于 本地收入层最低10%。您的每一份 贡献都会为我们的病患带来深远的 影响。



扫描捐款领取 《虎虎生威》







预先护理计划入门介绍

作者:陈贤杰、林婉瑜、张玉 珊,法律协会公益服务办公室 特邀作者

无论您目前是在维持年轻家 庭或是已步入乐龄的黄金年 华,都可能会担忧如果身体或 精神健康出现问题,该怎么 办?

制定预先护理计划有助于 规划您日后的健康和 个人护理安排。

什么是预先护理计划?

透过预先护理计划,您与亲人能进 行有关健康和个人护理安排的对 话。您能委任自己信任的人士作为 您的决策代言人,如您目前或日后 的看护人。他能在您无法自行作出 决定时,以最符合您的利益的方式 为您作出医疗决定。

您可以把意愿记录在制定预先护理 计划手册里。只要还有心智能力,随 时都可以修改这份计划。

> 这份计划书是您的 治疗意愿指南, 可供您的决策 代言人在需为 您做决定时参 考。

谁该拟定预先护 理计划?

无论年龄或健康状况,每 个人都可以考虑把自己的 护理意愿记录在预先护理计划中。

预先护理计划对于患有慢性疾病、 绝症、轻度认知缺损、或在寿命末期 的人士更为重要。 预先护理计划是否有法律约束力?

虽然预先护理计划并没有法律约束 力,它应该是您遗产规划中的一部 分。预先护理计划应陪同其他具有 法律约束力的文件如,持久授权书 和预先医疗指示。

简单叙述:持久授权书是一份法律 文件,可让您委任至少一名"被授权 人"。被授权人在您失去心智能力以 及决策能力的情况下,代替您处理 个人福利与 / 或产业与财务事宜。 预先医疗指示是一份法律文件,可 让您注明若患上绝症、已陷入昏迷 状态的情况下,不必进行维持生命 的治疗。

虽然个别文件的用意有所差别,这 几项规划工具都传达着您失去理智 的情况下,心想收到的照护。如果您 已经立下了持久授权书或预先医疗 知识,请考虑与您指定的看护人谈 谈您的预先护理计划。

为了避免冲突,您在持久授权书下 指定的被授权人,以及预先护理计 划下指定的决策代言人应该是同 一/几个人士。

我应当委任谁做决策代言人?

您的决策代言人应该是您能敞开心 怀坦诚分享个人医疗意愿的对象。 这位人选该是自己信任的亲人或朋 友。一位了解您的价值观,在您无法 自己做决策时,以您的最佳利益为 您做决定的人。这也意味着代言人 有可能需面对在重大压力下做出艰 难决定的情况。

您可委任一到两位决策代言人。

怎么开始规划预先护理计划?

您可以联络预先护理计划协调员协 助您完成预先护理计划。

预先护理计划协调员包括大多数医院、几件综合诊所、以及社区护理服务中心。如果您已经在医院或综合诊所受治疗,您可以向您的医护人员要求推荐预先护理计划的协调员

见预先护理计划协调员之前应该准 备些什么?

该考虑的抉择包括:

- •您现有的生活方式当中,对您最 具有意义性的活动有哪些?您的 指定看护人怎么能最好保护您的 尊严?
- •取决于您的健康状况,您倾向于 舒缓为主的疗护、或全程急救治 疗?
- •取决于您的医疗需求,您倾向于 什么样的护理选项?如医院、疗养 院、住家等选项。

欲知更多预先护理计划相关信息, 请扫描下方二维码参见AIC预先护 理计划手册:

AIC预先护理计划手册

更多详情

想得知更多详情,请参考以下链接:

- https://www.aic.sg/care-services/all-about-acp
- https://www.aic.sg/care-services/faqs-on-acp
- https://www.aic.sg/care-services/simple-steps-for-acp
- https://www.aic.sg/care-services/acp-resources

关于新加坡法律协会公益服务办公室

新加坡律师协会公益服务办公室(慈善机构注册号码:T07CC2064L),即 获批准的公益机构(IPC)(IPC注册号码:IPC 000571),成立于2007年9月 10日。其使命是为我们社区中有需要的人提供无偿法律援助,正如法律协 会的使命——确保所有人皆有诉诸司法的机会。

我们提供一系列的活动和服务,可大致归类为以下:

- •提高法律意识的举措,如讲座、出版物以及与各机构合作,推广给他们的 成员和受益人
- •周一至周四提供免费法律咨询所,于中区、西北社区、西南社区及东南社 区发展理事会为合格申请人服务;也于社区司法中心建立社区、刑法、工 人、家庭及公民法律咨询所
- ·在法刑事法律援助计划(CLAS)下为合格申请者做代表
- •为非营利组织和社会企业提供法律咨询所帮助,并在需要时提供交易性的援助





您确诊的时候反应如何?

在我二十多岁时,我被诊断患有糖 尿病。这影响了我的肾脏健康,当时 我的肾功能已经只剩下百分之二 十五。基于我的健康状况,接下来 的十几年我必须每年定期参加体 检。2017年,医生发现我的肾功能又 恶化了,剩不到百分之十。医生嘱咐 我开始接受洗肾治疗。对此我并不 惊讶。

当时,我坚决不愿意接受洗 肾治疗,因为实在太麻烦, 也太贵了。我甚至记得 我问了医生:"如果不 接受洗肾治疗,我 还能活多久?你知 道我不是印钞 票的吧?"殊不 知,不接受 治疗还能 活两个 星期,我 想:两个 星期给 我已经 足够了。 我的太太和

> 对于我 的决定非 常不满 意,他们尝 试说服我改变主 意。最后,我决定 改变了啦,同意接受 治疗。

母亲

起初我在私人洗肾中心 接受治疗,大大加重了我家庭 的经济负担。我的岳母也是洗肾 病患,太太为了我们的治疗费用 一筹莫展。最后,我从私人洗肾中 心转出,来到了KDF。这为我太太 减轻了经济负担。

成为肾病患者以后,您的生活有何 变化?

我确诊不久以后,父亲被诊断出癌 症末期。在那之前,我做建材行业做 了十几年,是个全职销售经理。我决 定辞职,担任父亲的主要看护者。

在照顾父亲之余,我还需要注意饮 食限制,和大不如

> 前的体力。 洗肾会 让我

> > 感

觉

很

疲

倦, 每次洗完 。次 我都会 到虚弱 到虚弱 到虚弱 之力。现在我的 作息很固定,我 需要控制水的摄入 量,以前喜欢吃的许 多东西现在也都不能吃 了。很多不称心的事都要去 接受。我父亲跟病魔斗了两个月 后离世了。

2018年,我做了心脏搭桥手术,体 力大幅度下降。之前能走很远的路 也不会气喘吁吁的我已不再,洗肾 结束后虚弱得起不来床也是常有之 事。

失去正常的自己,我很难过。当时的 我才46岁,但是我的身体感觉就像 是个老头子。我曾经是个工作狂,为 了工作我什么都可以搁置一旁。现 在,我虚弱的身体无法负担一份全 职工作,我的太太也需担起家中唯 一挣钱养家的角色。但是我非常感 谢KDF的援助,还有这里的职员和 病患,他们很多现在也都成为了我 的好朋友。这个病情可以说是促使 我放慢脚步,更加重视自己的生活, 可以算是因祸得福啦。

您确诊时只有45岁。您的家人有考 虑肾脏捐赠吗?

我的医生确实说过肾病患者中,我 算年轻了。我的太太考虑过把她的 肾脏捐给我。但是,经过一系列的审 核和体检,由于她有肾病相关疾病 的家族史,我们的计划被终止了。我 的岳母过去十多年也是洗肾病人, 所以我的太太不适合捐赠肾脏。

我的母亲尝试过跟我的五位兄弟姐 妹提出这个话题。向他们寻求经济 和精神上的支持并不困难。但是要 任何一人捐一颗肾脏给我,这是个 会改变一生的重大决定。

我的家庭对此很谨慎,所以事情一 直没有任何进展。自从我做了心脏 搭桥手术,我的名字也已经不能列 入公共肾脏移植的等候名单了。的 确,遗憾是有的,但是现在要改变什 么也都来不及了。

您是如何加入治丧服务行业的?

我父亲逝世时,一群教堂认识的朋 友帮我办理他的丧事。不久后,他们 联系我说:"Louis,你现在没在工作 吧?你想不想加入治丧行业做护柩 者?"我想了想,这听起来不难,又能 从中挣一点生活费,我就答应了。

您的家人对于您成为护柩者有何 反应?

*笑*我父亲那一方的亲戚听说我的 新自由职业时,有些想不通。老一辈 的人可以有多迷信,你知道的。他们 告诉我:"Louis,你怎么选了这样的 工作?为什么要让自己在这种处境? 你可以给活人工作,为什么要为死 人工作?"

居丧关怀是正当的工作,无论职能。 我已经在尊严治丧服务有一段时间 了,担任护柩人员的自由业者。我不 偷不抢,尽力又老实地挣钱,也很有 意义。另外,我的身份让我能够直接 帮助他人,那为何不利用它作出更 多贡献呢?

我的太太非常支持我的工作。她经

的家庭朋友。我觉得这是上天的启示,说明我注定要在这个行业里。* 笑*就算我洗肾后很累,累得走路都 有困难,当一通电话进来说有一个 家庭需要服务,不知怎么,我无论如 何都能找到一份力量去接案子,关

怀居丧的家庭。



常告诉我:"你如果做得开心,就继 续做。"基于我的健康状况,我眼睛 后面的血管受损,导致严重的飞蚊 症,晚上看东西或工作时会有困难。 因此,每当我晚上有工作,我的太太 下班后都会来帮我。我非常幸运,有 她陪在我身边。

您在工作中有发生什么趣事吗?

在生命礼仪服务公司工作的经验法则是绝对不能拒绝任何居丧的家庭。我们曾经接到推荐,有个经济情况较为拮据的家庭。然而,我们的团队仍然答应接受这个任务,尽力办了一场丧礼,让逝者能够有尊严地 走完人生的最后一段路。

在丧礼上,我发现逝者家庭是我们

我们做这一行,难免遇到 情绪比较激动的家庭成 员。通常,语言是无法为 他们带来足够的安慰的。 我们能做的只是通过治 丧服务做出表示,让我们 的实际存在为这些处于 困难时期的家庭带来一 丝 慰 藉。

当我能够为 逝者和他们的亲 人带来一个圆满结 局,这在亲人的脸上 是看日出来的,我 也会因此获得很 大的成就感。他们 现在有些已经成 为我的朋友了, 偶尔还会打电话

来问我过得怎么样。正是这样, 让我想要继续这份我认为是命 中注定的事业。

您是KDF病患中少数有接工作 的。在这个过程中,您有没有遇 到什么挑战?

当然有。我曾经在向雇主坦白肾 病情况后,没得到任何正当理由就 被辞退了。但是这也不能完全怪他 们。作为血液透析病患,一周有三天 需要去洗肾,所以一般早九晚五、一 周五天的工作我都做不了。偶尔也 会有突发健康状况。这就是肾病患 者的现实。

自由职业领域对我们算很包容,毕 竟灵活性对我们很重要。现在我们 有些人还能去当私人出租车司机。 要打破对于肾病患者的刻板印象, 还需要很多努力。一点点的谅解可 以有远大的影响。挣自己的生活费, 无论多少,真的都能赋予我们能力。

有何分享给其他肾病患者的建议?

刚诊断时,愤怒和悲伤都是正常的, 但是千万别让它们吞噬你。最后能 够接受病情是很重要的。事出必有 因,在困境中尽力而为,是我们本身 的责任。洗肾是可以延长寿命,但是 在多出来的时间里,我们要完成什

么,才是更重要的。

您可以多陪陪您的亲人、 做点义工或帮助有 需要的家庭。其 实,在这之后 我就要慢 慢 走 去 接我

的太太下班了。请让每一 个活着的时分都变得值得。



四月 – 六月 2022



肾脏透析基金简报
ISAN A Control of Contr

患Louis Chia (50岁)坚 信通过其特殊角色—— 生命礼仪公司的自由业 护柩人员,为广大社群 伸出援手。

这期KDF报刊非常特别,我们找了Louis一起 聊聊,作为肾病患者经 历的挑战、他特殊的职 业,以及人生的动力源。

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KDF活动

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