

肾 Love 有 Triumphs



13 INSPIRATIONAL stories written by the CAREGIVERS of kidney patients 十三个启发人心的故事。 由腎脏病患看护者 亲笔撰写 Love Triumphs:

13 inspirational stories written by the caregivers of kidney patients

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13 inspirational stories written by the caregivers of kidney patients 十三个启发人心的故事, 由肾脏病患看护者亲笔撰写

Foreword

Kidney failure is a life-changing disease, and patients often rely on their caregivers for their daily activities and medical care. Caregivers play a critical role in the lives of our dialysis patients as their support is fundamental to the patients' journey towards rehabilitation and in leading fulfilling lives.

Caregivers may face challenges in fulfilling their caregiving responsibilities, and it is also important to look after their well-being. Some have had to leave the workforce while others continue to work and support their family. At times, fatigue, stress and burnout may kick in, and it is important that we provide our caregivers with strong socio-emotional support to better manage the challenges they face. I'm heartened that NKF has been doing more to reach out to our caregivers and provide them with greater support. This includes equipping caregivers with knowledge and skills in areas such as self-care, spotting early signs of burnout or mental stress and crisis management.

As part of its efforts to empower caregivers, especially the younger ones, NKF also encourages them to write down their personal experiences, challenges and feelings of caring for their loved ones with kidney failure, in the hope that the writing process will provide a healing effect. Love Triumphs is a collection of 13 stories that were written by these caregivers, seven of whom are aged between 19 and 26.

I hope that the stories will inspire other caregivers and be a source of strength for them – in knowing that they are not alone. The launch of Love Triumphs is timely and reflects NKF's commitment to strengthen support for caregiving, and partner caregivers in their caregiving journeys. I commend NKF for its efforts in making a difference to the lives of patients and their caregivers.

I would also like to congratulate NKF as it celebrates its 50th anniversary this year. I wish NKF all the best as it continues in its mission to partner the community to provide sustainable, quality and holistic renal care for patients, while raising awareness on kidney disease and its prevention. May NKF continue to grow from strength to strength for many more years to come!

Mr Chan Chun Sing Minister for Trade and Industry

CEO's Message

When a loved one has kidney disease, you might not know how to help. You might feel frustrated that you cannot make your loved one better or you might feel stressed about fulfilling your other day-to-day obligations while caring for your loved one.

In conjunction with NKF's 50th anniversary, NKF would like to recognise the need for socio-emotional support for caregivers. We have widened our scope and reached out to provide support by equipping caregivers with relevant knowledge and skills such as how to support loved ones, spot early signs of burnout or mental stress, self-care, effective communication, crisis management and more.

We also encourage caregivers to share their real-life experiences so that they offer console to any caregiver, especially the fellow caregivers of kidney patients, in knowing that they are not alone. It took us more than a year to present you with this collection of 13 short stories entitled "Love Triumphs" as we celebrate our 50th anniversary. Like caregiving, these stories celebrate life, love, empathy and bonds, and it will resonate well with caregivers across all ages from all walks of life.

We would like to express our heartfelt thanks to all the caregivers and patients for penning and sharing their personal stories. We hope the genuine and inspirational stories in the book will offer you a respite from your responsibilities, and impart uplifting and comforting insights, to fill you with renewed hope, courage and strength.

Savour the stories, one at a time. We hope you will laugh, cry and be in admiration as much as we were while reading them, and share them with your families and friends.

Mr Tim Oei Chief Executive Officer The National Kidney Foundation



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'This journey had made my family more united and closer " 01

A blessing in disguise Written by Lynn

y mum is a kidney patient who was diagnosed with kidney failure 4 years ago in August 2013. She is the strongest and healthiest person whom I know. She would go to bed at 10pm, wake up early in the morning and head down to the market for grocery shopping.

My mum used to work as a nanny who cared for my toddler nephew before she was diagnosed with kidney failure. Every day at 7am, my nephew would arrive at our place to be cared for while his parents went to work. Despite the immense effort and energy required to take care of a toddler, she found joy in such work and was happy doing it. She would also help out at her friend's provision shop whenever she was short-handed.

One day, my mum came home from her friend's shop, and my dad noticed that her face was a little more swollen than usual. She also complained that her feet had been swelling lately. My mum decided to consult with the doctor at the neighbourhood clinic the following day. The doctor advised that she saw a specialist at the hospital immediately. As I had to attend school, my brother accompanied my mother to the hospital and informed me shortly after, that she had been hospitalised.

This incident did not hit me hard initially as I had assumed that my mum would be returning home after one night of observation. It was only when she was forced to be hospitalised for 3 weeks that I realised her condition may be more severe than I had imagined.

During my mum's hospitalisation stay, I realised that I had been very pampered and I had taken her for granted. It was not an easy task juggling between household chores and school work, and on top of that, I had to make time to go visit my mum at the hospital for at least thrice a week on weekdays after school.

The Kopitiam at SGH then became my favourite place to revise for my preliminary examinations as it was the examination period. There was one time when I broke down crying immediately after completing my Chemistry examination paper in the examination hall. At that point in time, I really did not know who to share my sorrows with. After all I did not think that any of my close friends had met with anything similar.

I felt really lost. I had no idea how serious my mum's condition was as this illness was very alien to me then. I often wondered how our family's financial situation was and whether my family was going to become bankrupt due to the hefty medical bills that my mum had incurred. My dad did not share much information with me as he did not want me to worry.

My mum was discharged three weeks after she was admitted and her insurance company had taken care of the hospitalisation bills that she had incurred. I was over the moon to have her back.

My mum is now livelier and happier, she has since been very active, participating in almost all the activities that are organised by NKF. She also forged friendships with patients who were receiving dialysis treatment in NKF and even made friends with the medical team. In fact, she has fostered such strong ties with the patients in NKF that they often travel overseas together.

I think this entire roller-coaster journey had made my family more united and closer than before. I feel that somehow, this whole journey has been a blessing in disguise.



知苦方知福

在Lynn的印象中,母亲是一个精力充沛的人。她似乎总有着做不完的事:买菜、做家务、照顾宝宝、去邻居的店铺里帮忙……从早到晚,一刻不闲。这么一个健康有活力的人,又怎么会生病呢?Lynn一直都是这么认为的。然而,母亲有一天因为双腿和脸颊水肿而去诊所看医生,却被建议立即住院观察。直到那时,Lynn才惊觉,原来肾衰竭已经以悄然而令人措手不及的态势,夺走了母亲的健康。

母亲在医院一住就是3个星期。每一天对Lynn而言都是无比的煎熬。她不仅担心着母亲的身体,三天两头地往医院跑,在家中也肩负起家务的担子,还要为期末考试做准备,这一切都让她心力交瘁。她还记得,在考完一场考试后,那期间累积的无助和难过终于决堤,令她痛哭一场。

还好,最困难的时期,终究是熬过去了。母亲开始在 NKF洗肾,慢慢恢复以往的精神样子,还和洗肾中心 的护士和肾友打成一片。Lynn庆幸,自己的家庭并没 有因这场突如其来的变故而瓦解,反而更懂得珍惜彼 此,家人间的感情也更深厚了。



Always my beloved little brother

Written by Rohani

was not particularly close to my brother Affandi when we were children. He is one of my nine brothers and I am the only girl. My mother was the one who took care of Affandi, but when she passed away in 1994, I took over the responsibility of caring for Affandi.

Affandi is 57 years old and he is a grown man, but he behaves like a little boy. He lives with one of our brothers, but he had to work and Affandi could not be left alone, so I moved in to live together with the both of them. Fortunately, my husband does not mind, and I would go home to see my husband a few times a week.

I do not really know what caused Affandi's kidneys to fail. He felt very sick one day in 2010 and the doctor said his blood pressure was very low. He urged us to take him to the hospital immediately. The doctors said that his kidneys have failed and he needed to go on dialysis at once.

As Affandi is wheelchair-bound, we use an ambulance to send him to the dialysis centre three times a week

and I would accompany him each time. At the centre, the nurses will sometimes coax him to talk, and they are delighted whenever he answers them.

Although I am Affandi's sister, I feel like his mother. I take care of all aspects of his life, like cooking, showering, toileting and making sure that he takes his medication. I take him with me everywhere I go, even when I go for my own medical appointments. He cannot be left alone because he can be very naughty. Once, I left him alone for a while when I went to meet a friend, and when I returned home, I was shocked to discover that he had been meddling with the kettle. Fortunately there was no hot water in the kettle, otherwise he would have scalded himself. Although it can be tiring, I feel happy taking care of him and I do not feel that it is a chore at all. Nonetheless, there are days when I needed to be alone – just to get away and be alone for a while.

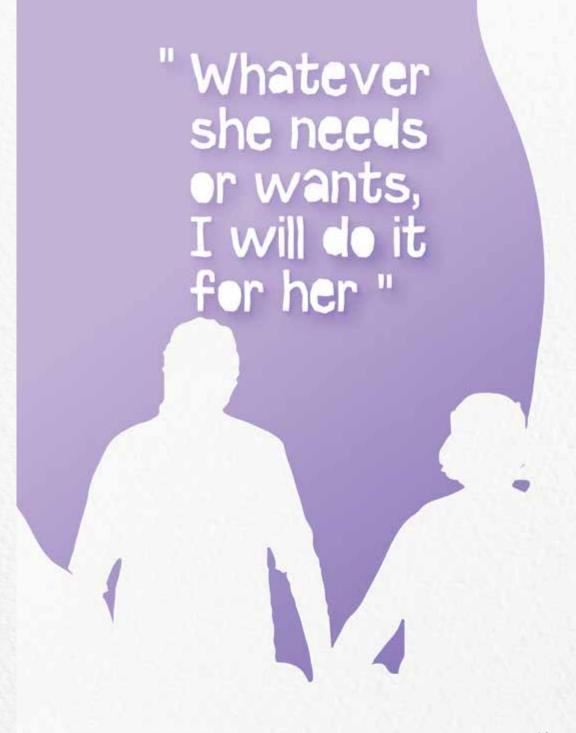
Affandi is a joy to be with. His favourite possessions are his toys. He loves Power Rangers figurines. Whenever we take him out, he will ask us to buy toys for him. I hope that he will remain cheerful and happy always, but I am already 66 years old and I worry about who will take care of him in the future.

永远爱你, 我的弟弟

罗哈妮小时候,与弟弟阿凡迪其实并不亲近,他只不过是9个兄弟中的其中一人。当时她没有想到,自己会在母亲过世后,一肩扛起照顾阿凡迪的责任,打从心底呵护着这个不幸患有智力障碍的小弟弟。

阿凡迪如今已经57岁了, 无奈智力和言行举止如同孩子, 平日里必须时刻由罗哈妮照料, 包括洗漱、饮食等。自阿凡迪患上肾衰竭后, 罗哈妮又多了一重责任, 就是每星期3次陪伴弟弟去洗肾中心。纵使劳累, 她却毫无怨言。唯一的担忧, 就是将来自己走后, 弟弟无人照料。不过, 走一步算一步。对66岁的罗哈妮来说, 只要阿凡迪目前还能露出无忧无虑的笑容、继续玩他最喜欢的超能战士玩具, 就足够了。





Commitment

Theresa Goh and Fong Wai Thong's story

adam Theresa Goh and her husband, Mr Fong Wai Thong, both 89, thought that the bad hand that life had dealt them with was over when Theresa survived her colon cancer diagnosis in 1999.

It therefore came as a shock in 2014 when they were told that her kidneys have failed and that she would require dialysis for the rest of her life.

Feeling overwhelmed and upset, Theresa had refused dialysis initially. "I was so old already; if it is time for me to go, I will go," she said. "Besides, my cancer treatment had wiped out all my savings. I have no money for dialysis."

Theresa's daughter, husband and the doctors persisted in persuading her to go on dialysis and not to give up on life. They assured her not to worry about the treatment costs, and to take a chance on life, but it was a young doctor's words which impacted Theresa strongly.

He told her that although she was old, she still looked strong, and he believed that she would be able to survive dialysis.

Eventually, for the sake of her family, Theresa decided to start dialysis, and thus began her thrice weekly trips to the dialysis centre.

Wai Thong, who believes that Theresa's kidney failure was caused by hypertension, said he was very shocked and shaken when his wife received the kidney failure diagnosis. In fact, it took several months for the shock to subside. Now, he is just happy that she is alive.

Although she is still active and mobile, he would always accompany her to the dialysis centre. He cheerfully said that he treats the walk from their home to the centre as a form of exercise. After her treatment, they would walk home together again.

On being Theresa's caregiver, Wai Thong said, "It is my duty as her husband to take care of all her needs. Whatever she needs or wants, I will do it for her."

Besides taking "walks" to the dialysis centre with Theresa three times a week, Wai Thong and Theresa also participated in the patient activities organised by NKF whenever Theresa's health permits. Wai Thong says, "We enjoy the activities and each other's company."



执子之手, 白头到老

当89岁的Theresa得知自己患上肾衰竭时,绝望感如汹涌的海潮般席卷而来。她在数年前才经历一番苦难,好不容易战胜癌症,不想命运又造化弄人。确诊后,她的第一反应是告诉身边的丈夫:"我老了,看样子是气数已尽。之前为治疗癌症已花光我们的积蓄。这次,我不要治疗了。"

但深爱她的丈夫 Wai Thong 不允许她就此放弃。在丈夫、女儿和医生的极力劝说下, Theresa决定开始洗肾, 延续生命, 而Wai Thong便成为妻子的看护者, 每次洗肾, 必定从旁陪伴, 然后再与Theresa相互搀扶着从洗肾中心回家。NKF举办的肾友活动中, 也常常可以见到这对年近九旬伉俪的身影。

Wai Thong说, 只要妻子能好好活着, 对他就是最大的满足。夫妻二人经历各种坎坷, 不变的是相濡以沫的承诺。他们鹣鲽情深的样子, 让人真正理解了什么是"执子之手, 白头到老"!



Creating good memories

Written by Angie Go Geok Buay

hen I was a young girl, I wanted to become a nurse. I thought that taking care of the sick was a noble profession, and I liked helping people. My mother, however, objected to my career choice at that time because she felt that nursing was a "dirty" job since nurses have to clean up after patients and literally get their hands dirty.

Despite my mother's reservations, I pursued my dream and joined the nursing profession in 1991. I worked at SGH as a nurse for a number of years before taking on a non-clinical clerical job eventually. Little did I know then that although I had switched careers, my training as a nurse would still come in handy one day.

As my parents became frailer in old age, I took on the role of their caregiver. I started taking up jobs on a contract basis instead of a full-time job so that I could have flexible working hours and could devote more time to caring for them. After my father passed away in 2010, my mother also became weaker. In 2014, the doctors informed us that my mother's kidneys had failed and she had to rely on kidney dialysis to if she wanted to live. My mother had been

living with hypertension and diabetes for years, which contributed to kidney failure.

At first, my mother found the diagnosis difficult to accept. She had wanted to give up on life, but after much persuasion from family members, she finally agreed to start dialysis. Due to her multiple conditions and being prone to falls, my brothers and I decided that I would stop work to take care of my mother full-time.

Although I had not been a nurse for many years, all my training came back to me as I took on the role of my mother's full-time caregiver. The skills that I had acquired during my training as a nurse turned out to be very useful indeed.

Our roles are now reversed; she used to take care of me, and now, I am the one taking care of her. Sometimes, she behaves like a child and gets impatient and restless while I have to be patient with her. When she is difficult, I try to put myself in her shoes and empathise with her. Being a full-time caregiver is not easy because it is not just about taking care of my mother's physical needs. Sometimes, I feel sad and sorry to see her suffering from her illness. People often comment that they are amazed by the things I do for my mother, but I do not think that it is such a big deal. Even though my mother can still walk I worry that she could fall if I am not around, so I hardly leave

her alone. I cannot entrust her care to anyone else and I cannot bear to send her to a nursing home.

Taking care of my mother is not a sad thing for me. We have many moments of joy. We go out together sometimes and one of the things we enjoy doing most is to sing and read the Bible together.

My greatest wish for my mother is that at the end of her life, I will not have any regrets and that we will only have good memories of each other.



父母养我小, 我养父母老

Angie曾是一名护士。在医院久了,见过不少"子欲养而亲不待"的憾事,也就比谁都更深知这个道理。因此,当父母年纪渐大而健康却大不如前时,她毫不犹豫地从全职转为合约制雇员,以便腾出更多时间待在家里照顾双亲。在父亲去世后,Angie 原本就患有糖尿病和高血压的母亲于2014年被诊断出肾衰竭,从此需要洗肾维持生命。由于母亲的身体虚弱,容易跌倒,Angie又不放心交予别人照顾,索性将工作全部辞去,就此成为母亲的全职看护。

作为看护者, Angie不仅将母亲的衣食住行打理得妥妥帖帖, 也不忘照顾母亲的情感需求。母亲有时会如小孩般使性子、耍脾气。这时候, Angie反而会像妈妈一样, 关爱包容母亲, 耐心与她沟通。

对Angie来说,照顾母亲不是件难事。她最大的希望,就是母女二人能每天创下许许多多的美好回忆。这样,在母亲最后的时光中,留下的不是遗憾,而是彼此之间最温暖的亲情。

"She is important to me and I care about her"

Grown-up little boy War War and Arthur's story

rthur practically grew up at a dialysis centre. He was only six years old when his mother suddenly took ill and had to go to the hospital. When she came home from the hospital, Arthur's mother started going to a strange place called a "dialysis centre" three times a week. As his family moved to Singapore when he was a baby and they did not have relatives here, there was no one to help babysit Arthur during his mother's dialysis and she had no choice but to bring him to the centre with her.

As a child, Arthur would play by himself at the centre while his mother received treatment. He did not understand what was happening and why his mother had to have thick needles inserted into her arm three times a week and why there was so much blood in the tubes.

"One of my earliest memories was my mum feeling unwell during her dialysis. She had to be rushed to the hospital, but I was left behind at the dialysis centre. I remember being very scared and I was crying. I had to wait at the centre for my father to pick me up after work before we could visit my mum at the hospital together," recalled Arthur.

"It was only when I was nine or ten years old when I begin to understand what was wrong with my mum," added Arthur.

Arthur started shutting himself off from the world, but became more well-behaved towards his parents. He also began to focus more on his studies.

He began to stick close to his mother. Every time his mother undergoes dialysis, he would go to the dialysis centre to wait for her so that he can go home together with her. While waiting, he would do his homework at the centre.

"My mum sometimes feel giddy after dialysis. I'm worried about her fainting on her way home," he explained.

Besides escorting his mother home from dialysis, Arthur also accompanies her on her hospital appointments. "I want to accompany her on all her medical appointments, but she doesn't allow me to go on school days," he said.

Arthur also started taking over the household chores as he grows older. He cleans the house, does the laundry and cooks. He said proudly, "I know how to cook steak – it is very easy and I got the recipe from YouTube. I can also cook prawns, and other dishes." He would go to the market with his parents occasionally to buy groceries.

Speaking of his mother's illness, Arthur became pensive. He said, "My mum is sad because of her illness. I want to donate my kidney to her, but she won't hear of it. She also does not want to accept a kidney donation from our relatives who offered to donate a kidney to her. I hope that she can have a kidney transplant soon so that she will become well and we can do more things as a family, like going overseas for holidays."

"I don't feel tired taking care of my mum at all because she is important to me and I care about her."

Madam Mar War War Win Maung, 49, was stricken by kidney failure when she was 42 years old. The diagnosis was unexpected and came as a huge blow to the mother of a young boy. However, she found comfort in the unwavering love and support of her son.

War War said that one day, seven years ago, she went to the polyclinic because of puffiness around her eyes. The doctor discovered that her haemoglobin levels were dangerously low. She was hospitalised and given blood transfusions. Initially, the doctors believed that she was suffering from menstrual problems and went through a battery of tests for six months with no improvement to her condition. Finally, after a thorough health check, she was diagnosed with kidney failure.

War War was devastated. Her son was only six years old and she could not imagine how she would be able to take care of her young child while battling with kidney failure. Her husband, who worked in the engineering sector, was the sole breadwinner of the family, and was unable to accompany her to the dialysis centre for treatment.

War War said, "I started to notice a change in my son. Before I fell sick, he was a very playful boy, but since I had to start dialysis, he would stick close to me. Instead of going to kindergarten or playing with other children, he would choose to stay close to me. As my husband and I have no other family in Singapore, I had no choice but to bring him to the dialysis centre with me three times a week."

War War's son continued to accompany her to the dialysis centre and as he grew older, his role also changed gradually. Instead of the little boy who clings on to this mother, he has grown into a teenager who takes great care of his mother.

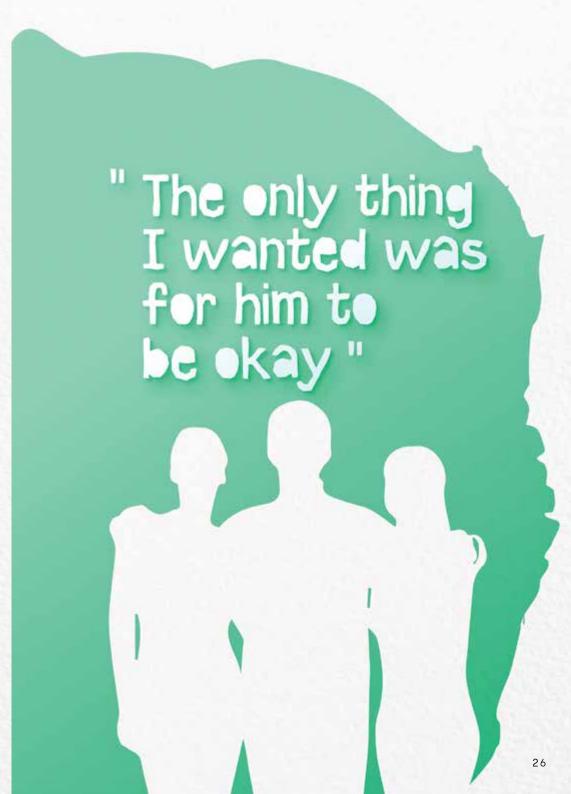


爱,使人成长

Arthur的母亲洗肾那年,他才6岁,对"肾衰竭"这个疾病毫无概念,只知道妈妈开始带着他频繁地前往一个叫做"洗肾中心"的地方,一呆就是好久。在那里,母亲的手臂会被扎进很粗的针头,她皱眉忍痛的样子,和流入导管的汩汩鲜血,让年幼的Arthur既害怕又难过。

这样的日子, 贯穿着Arthur的整个童年。有一次, 母亲在洗肾时突然身体不适, 需要紧急送入医院, 只能留下9岁的Arthur一人在洗肾中心, 直到下班后的父亲来接他一起去医院。那时候的恐惧和不安, 深深烙印在他的记忆中, 也令Arthur想要快点长大, 好帮妈妈分担一点压力, 让她不再那么辛苦。

这份心愿,促使着Arthur从一个顽皮的小男孩,逐渐 蜕变成懂事、成熟的少年。他不仅会独立学习,在家里 还会主动煮饭、做家务。如今,陪伴着母亲去洗肾中心 的,已经不再是那个懵懂不知的幼童,而是一个已经 成长、懂得照顾母亲的好孩子。



Hoping for a brighter future Written by Naomi

y dad was diagnosed with kidney failure a few years ago, which led to tremendous changes in our family. Before his diagnosis, there were already some signs that he was sick, but instead of seeking medical treatment right away, he chose to ignore the symptoms and pretended that nothing was wrong. A sudden lost in appetite, extreme fatigue, itchy skin and a change in temperament were the few signs that he displayed then.

For a person who had not gone through what my dad had, it was hard for me, as his daughter, to understand the pain (physically, mentally and emotionally) that he was going through. All that appeared to me was a change in his personality. Instead of being his usual happy, funny and optimistic self, he became unhappy, unfriendly and angry most of the time. It was practically impossible to find a smile on his face.

Looking back, it was a tough time for him, but to be honest, it was hard for us to understand at that time because whenever we tried to talk to him, he would either shun away from us or scold us for no reason. The atmosphere at home was tense and gloomy.

My dad's behaviour persisted for some time until my mum lost her patience and forced him to visit the hospital for a check-up. We have tried to ask him to see a doctor previously, but he refused to and scolded us for being 'kaypoh', claiming that everything was fine.

On that day that my dad visited the hospital, the doctor hospitalised him and he was being admitted into the ICU. I remembered the scene vividly. I was in the school canteen having my lunch when I got a call from my mum saying that my dad had been admitted into the ICU. My heart shattered when I learnt how severe his condition was.

My mum tried to coax me into believing that everything was alright and told me to continue with lessons, but I found it a huge struggle to focus in class as bad thoughts kept swirling in my mind. Bad news did not just stop there.

When I returned from school that night, we received a call from the hospital, telling us that my dad's condition had worsened. The hospital warned us to be mentally prepared and advised us to gather all our family members and make a trip to the hospital immediately. I had never felt so helpless.

When we reached the hospital that night, my dad was in coma. He looked like he was in extreme pain with all the tubes attached to him. He was fighting for his life and we were unable to do anything except to pray for him. At that point, the only thing I wanted was for him to be okay.

Miraculously, my dad woke up from the coma the next day. Even the doctors and nurses were amazed as they explained that it was almost impossible for him to survive due to the high level of toxins in his blood. Not only was I extremely grateful that God chose to deliver him from death and gave him a second chance, I also believed that if he was strong enough to survive the coma, he would be strong enough to overcome his illness.

My dad was since diagnosed with kidney failure and has to depend on dialysis to remove the toxins from his blood. He attends dialysis three times a week. It is not easy for him because he has to work during the day and attend dialysis after work. I think my father is "superman".

After having gone through the ordeal of kidney failure my dad can now empathise with other kidney patients and he wants to help other kidney patients. He attended a few courses on counselling and wishes to pursue counselling as a career. It is unfortunate

that despite his enthusiasm, he has been turned down in his job applications to be a counsellor. I can only hope that more job opportunities can be given to people who are living with kidney problems to be reintegrated into society to lead more fulfilling lives.



明天会更好

Naomi的父亲在确诊肾衰竭前,其实是有迹可循的。 只不过那时候,他选择采取回避态度,宁可默默忍受 病症的折磨也不愿就医。Naomi虽然隐隐觉得不对, 但仍未了解情况,她只觉得父亲好似变了一个人,从以 前的乐观开朗,变得不苟言笑,动不动就发脾气。眼看 家里的气氛日渐凝重,Naomi和母亲终于说服他去医 院检查。谁知,原本以为只是一个简单的体检,父亲却 被紧急送入加护病房。直到那时,全家才意识到病情 的严重性。由于血液里的毒素过高,父亲甚至陷入昏 遂,随时都可能离开这个世界。接到通知的Naomi顿 感晴天霹雳,惊惶悲痛之情油然在心中升起。

所幸父亲凭着一股毅力,奇迹般从昏迷中醒来,让 Naomi如释重负。出院后的他为了能继续养家糊口, 白天工作,下班了才赶去洗肾中心。自从患上肾衰竭开 始洗肾后,父亲其实亲历了不少偏见与人情冷暖,这些 Naomi看在眼里,疼在心里。她由衷地期望,这个社 会能够多一分包容和理解,少一分冷漠,让每个人都 能追求更美好的明天!



Love is not a burden

Kelvyn Zhuang's story

elvyn Zhuang, 35, feels exhausted most of the time as he rarely sleeps for more than four hours every night. On some nights, he even gets up from bed several times throughout the night. Unlike most people his age, his lack of sleep is not due to an active social life, climbing the corporate ladder or taking care of his young children. Most of Kelvyn's free time outside work is spent taking care of his elderly grandparents.

During the day, Kelvyn works full time as a software engineer. After work, he returns home to the two-room flat that he shares with his elderly grandparents. There, he takes on the role of a caregiver to his grandmother, who has mild dementia, and his stepgrandfather, who suffers from kidney failure.

After dinner everyday, Kelvyn starts to prepare his step-grandfather, Mr Tan Choon Seng, 84, for peritoneal dialysis. He begins by carrying a 10kg bag of dialysis solution into the room before cleaning Choon Seng's wound and attaching the permanent catheter in Choon Seng's abdomen to the dialysis machine.

By the time Choon Seng is attached to the dialysis machine securely, Kelvyn would be perspiring profusely, but he remains cheerful and does not utter a single word of complaint. Kelvyn is the sole caregiver to his grandparents. His parents divorced when he was a baby, leaving him to be raised by his maternal grandparents.

"My grandmother remarried many years ago, so my grandfather and I are not related by blood, but he loves me like his own and even used his savings to put me through college overseas," Kelvyn said.

Choon Seng's fondest memories are made up of the three of them having meals outside. He said wistfully, "We used to go out for dinner together. We would go and eat satay and other local food. When Kelvyn grew up, he also brought us out for meals, but now, with our mobility issues and my dietary restrictions because of kidney failure, it has become harder for him to take both of us out at the same time." One of his most treasured possession is a photograph of the three of them, taken in a restaurant where they were celebrating Kelvyn's birthday.

The elderly couple's health has, unfortunately, deteriorated over the years. For the past decade, Kelvyn has been shouldering the role of the family's sole breadwinner and caregiver, leaving little room for anything else in his life.

Choon Seng was diagnosed with kidney failure three years ago. He now has to undergo peritoneal dialysis every night. On the other hand, Kelvyn's grandmother, Madam Wong Li Cheng, 78, suffers from diabetes, hypertension and mild dementia. The family's financial burden would have been much heavier, if not for the subsidies provided by The National Kidney Foundation (NKF) for Mr Tan's dialysis.

He helps with grandfather's dialysis twice a day

When Mr Tan was diagnosed with kidney failure, he became depressed and even refused dialysis treatment. Kelvyn fought back his tears as he recalled that particularly difficult period, "I had to travel back and forth from the hospital every day and spent weeks trying to convince him to take up dialysis. He was reluctant because of the cost of treatment but I insisted that his survival was my priority. Given time, I could earn the money, but if he were to die, we would lose all the time that we could have had together. Eventually, he agreed to begin dialysis."

As all his aunts and uncles were unable to take care of his grandparents, Kelvyn took on the role all by himself without hesitation. He explained, "I used to have asthma when I was a child. Whenever I had an attack, my grandparents were the ones who took care of me. Now that they are ill, I should be the one taking care of them,"

Awarded "Dedicated Caregiver" award

In face of life's hardships, the family of three supported one another to the best they could. The exit-site of Mr Tan's catheter, which was inserted into his abdominal cavity when he started peritoneal dialysis, has been infected recently. As such, Kelvyn wakes up several times in the middle of the night to make sure the dialysis process goes on smoothly for his grandfather. Mr Tan's dialysis hours take place from 10pm to 8am the next day.

Despite feeling tired most of the time, Kelvyn still tries his best to appear cheerful for the sake of his grandparents. A constant gesture of affection from Kelvyn is a gentle stroke of Mr Tan's head every morning before Kelvyn leaves for work. The pair will also playfully call out to each other in cat meows and dog woofs, as if it is a secret language shared between them.

To honour Kelvyn's continuous dedication to his grandparents, NKF presented him with the "Dedicated Caregiver" award last year.

"If the love is there, then don't feel that they are a burden to you. Persevere, and do it for them," Kelvyn said.

No time for social or love life

With his full-time job and commitments to his grandparents, Kelvyn does not have much of a social life, nor does he have the time for a girlfriend.

"Kelvyn is a filial grandson. He rarely goes out to socialise. When I need to see a doctor, Kelvyn has to bring his grandfather along as well, because we cannot leave him at home alone. After we are back from the clinic, he still has to work. It really takes a toll on him," said Madam Wong.

Hoping to lessen Kelvyn's burdens, she helps to take care of Mr Tan in the day, while Kelvyn is at work.

Kelvyn said that his grandparents have followup appointments for at least four days in a month. Thankfully, his job allows him the flexibility in working hours, even though sometimes he has to work overnight to catch up with his projects.

"It'd be a blessing to be able to sleep for more than four hours each day... I've put my love life on hold for now, because I do not wish to be a burden to anyone," Kelvyn said.

Other forms of support needed

Kelvyn said that he tried to hire domestic helpers before but it did not work out: "My grandmother is not used to having a stranger in the house. Experienced helpers are usually not willing to take up this job, but I'm not comfortable with having inexperienced helpers to take care of my grandparents."



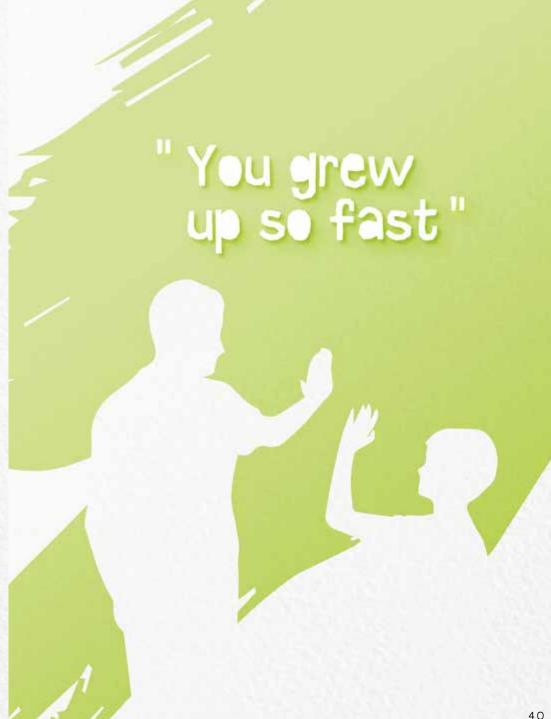
不是亲生, 更胜亲生

一个35岁的上班族,下班后一般会做什么呢?是与同 事朋友外出社交、回家与妻小共享天伦之乐, 还是趁 着年轻多多进修,提升自我?对镇光来说,答案三者皆 非:他下班后杜绝一切社交活动,因为要赶着回家照 顾病弱的外婆和继外公。

镇光因父母离异, 从小便由外婆和没有血缘关系的继 外公一手带大,三人的感情十分深厚,外公更是疼他 如亲生, 还用储蓄供他到海外读大学。如今镇光长大 成人,外公外婆却双双患病:外婆患有轻微失智症, 而外公则由于肾衰竭而需要每天在家进行腹膜透析。 镇光于是毅然扛起照顾二人的重任。除了每天早晚帮 外公洗肾的例行作业外,他还要做家务,带两位老人 去看病等, 有时甚至需要夜里起床好几次, 以确保外 公的洗肾过程顺利。

即使镇光时常为兼顾工作和照料外公外婆而感到焦头 烂额, 连觉也睡不够, 但他却从没抱怨过什么。他说, 就像年幼时的自己依赖外公外婆一样, 如今轮到他作 为他们的依靠了。

毕竟,爱从来不是负担,而是生命的真谛。



My Dad Written by Jing Kang

was overwhelmed as I stood there. Scarlet liquid flowed copiously from my father's arm, ignoring my fervent wishes for their non-existence. It spurted, almost surreally, onto his bedroom's white marble tiles, in sharp, visceral contrast.

"Kang, I am going to need more tissues."

The sound of his voice jolted me back into reality.

"O-okay," I stammered as I ran out of the room. Raw emotion made it hard for me to breathe. I grabbed a box of tissues and looked frantically for our family's first aid kit. Finally finding it, I returned immediately, my feet barely touching the floor.

"Thanks, I'll do it myself," my father said stoically, through clenched teeth. He has always been a proud man, and I knew he wished I wasn't there to see this side of him, a side which he hid exceedingly well.

Having a family history of hypertension, and diabetes, I am often warned that I should eat healthily and lead a healthy lifestyle. While my father was also aware that he has a high risk of getting these chronic illnesses, he chose to ignore all advice. Having a sedentary job did not help; as the years piled on, so did his health complications.

Inevitably, his indifference towards his health led to kidney failure.

Soon, the number of hospital visits increased at a frantic pace. I spent many days and nights at the wards in numerous hospitals, poring over my school notes during the visits as we tried to maintain a semblance of normality. If my father desired company, I would not have known, due to his utmost efforts to avoid worrying us.

Things quickly came to a head. My father had to undergo heart surgery. I remembered nodding mutely as his surgeon briefed me about the medical details. The aortic valve was failing, so they would replace it with a biological substitute. He was to be fitted with a pacemaker. The surgery would have to be in sync with his dialysis. The surgeon concluded by saying he could not make any promises, but he assured us that he was the best in his field in Singapore. More worrying for me, the doctor had commented that my father seemed pessimistic and overly anxious.

My parents did not know much about the procedure, but we all knew how risky it was. It was open heart surgery, after all. I spent the days leading up to it in fear and apprehension, but put on a brave front for my father's sake. Our whole family weaved a facade of regularity, in order to allay my father's anxiety and nervousness.

"You will be fine, Dad," I told him as he was being wheeled to the surgical theatre, "and see you soon. We'll be right outside."

The days following the surgery were not any easier. The brief euphoria after being notified of its success was immediately followed by days of apprehensive waiting at the ICU, since it took that long for my father to regain consciousness. Watching him undergo dialysis while still unconscious post-operation, I idly counted the number of tubes pierced into his body. There were seven. I held onto his hand as I willed for him to wake up.

My father's arm had a large cyst due to lipohypertrophy – a build-up of subcutaneous fat due to repeated insulin injections. It was this cyst that had a burst artery on that day.

As I applied pressure to his arm after he begrudgingly allowed me to bandage his wound, my father tried to make light of the situation.

"Those nurses never get it right. I already told them not to inject in my left arm. See lah, look what happened now."

"Why is the bleeding so severe?" I asked. It took a lot of effort just to slow the arterial bleeding, and the fresh bandages were already soaked through.

"I had to take blood thinners after the operation, and you know I have hypertension," my father replied. Surveying the blood stains that now cover his bedroom floor, he remarked, "It looks like a crime scene in here! I'll get it all cleaned up."

"Just rest on the bed, Dad. I'll handle it," I said, almost in exasperation. "You're supposed to be recuperating right now."

After wiping off the worst of the stains using large wads of tissues, I proceeded to dispose of them and went to fetch a mop.

"Do you know where the mopping solution is placed?" my father called out loudly after me.

"Of course I do," I replied as I rolled my eyes and carried the mop and bucket over.

As I began to remove the faint reddish outlines of the blood splatters, my father looked on wistfully.

"You grew up so fast."

"I know, Dad. I know."



我的父亲

Jing Kang 的父亲患上肾衰竭后, 其它的问题仿佛都接踵而来: 住院的次数突然之间变得非常频繁, 还被检查出心血管衰竭, 需要立刻动手术安装心脏起搏器。 Jing Kang 似乎在一夜之间成长了不少。他知道, 父亲虽然总是在生活中扮演着严肃一家之主的角色, 但面对这个风险不小的手术, 内心依然会感到不安和焦虑, 只是没有说出口, 不想让家人担心罢了。

父亲完成手术躺在病床上,浑身插满管子的模样,令 Jing Kang难受不已,只能紧紧握住他的手,一遍遍为 他、也为自己打气。

出院后,父亲似乎恢复了平日里要强的样子,虽然仍需静养但坚持凡事自己做,哪怕手臂上囊肿的血管破裂,流出一地鲜血,他都不愿麻烦家人清理。只不过,Jing Kang却再也不肯让父亲独自承担一切。他主动清理、照顾父亲,以实际行动告诉对方:爸,我已长大,让我来吧。

I just want my mother to be as healthy and she can be

My experience with kidney failure

Written by Yan Er

could hardly react when I first heard the news of my mother's diagnosis. My life already had all the typical clichés of a Taiwanese drama series, and it seemed that the director had decided to add in more drama to the story.

After 7 years of fighting, my parents were finally getting a divorce. At the time, the anger that I felt was way past boiling point. I was furious at my parents for involving us in their mess. I was anary at my mother for moving out of the house and leaving us with our father despite years of promising that she would never do so. I was angry that I would never have a 'complete' family again and that I would never understand what it would be like to have a cordial gathering with my parents without that awkward tension.

Needless to say, when the reality of my mother's illness sank in, I was without a doubt even angrier. I did not believe in a god specifically, yet I cursed him, "Are you having enough fun with my life yet? Are you done?".

My anger was, however, not the sole feeling I had. Worry also began to fill me, especially after I found out that my mother was not going to start any form of dialysis yet. I vaguely remembered the doctor's estimation of my mother's life expectancy if she did not go on dialysis.

"Two years."

I honestly thought that my mother would die. Knowing that, and being unable to do anything, was disgusting.

Thankfully, my mother decided to start her dialysis not long after, and things were looking up. Eager to get past and move on from all the drama that was going on, I thought, she will live. My mother is a strong person after all. Nothing can beat her. With that in mind, I continued with my way of life, mostly being angry at the whole world.

It was not until one quarrel between us when I truly understood just how much her health had changed. I do not remember if it was something I said out of anger, or the sour topic we were discussing, but suddenly, her hand was on her chest and she was leaning on the table for support.

Images of her being in the hospital the time she got diagnosed flashed in my mind and I was so afraid that she would collapse from the sudden spike in blood pressure. From then on, I resolved to never get my mother angry again. I never want to see that happen again.

Yet, I'm still hardly the model for a filial, understanding daughter. I try, but despite that, my temper flares up ever so often and I forget myself and the resolution I made. I still need to work on that.

Life went on, and the haemodialysis was hardly the perfect solution that I had hoped it would be. I was appalled the first time I saw my mother go through it at the centre. Ridiculously thick needles the size of straws were stuck in her arm that never looked more fragile before. Afterwards, she was stuck there, for four hours three times a week, hooked to a machine that pumped blood in and out of her body. My mother's blood! In tubes! Right in front of me! I had considered that if anything was to happen to any part of the machine, my mother's life would go down with it. That moment, I realised just how vulnerable she had become.

Even then, she barely flinched. She looked nervous, yes, but fine with everything else that was going on. My mother is a strong person after all, I thought.

Of course, life has a way of opening my eyes that were so insistent on being blind to realities. All it took to wrench my eyes wide open was complications arising from a routine procedure that led to my mother's hospitalisation.

There were multiple failures on the doctor's part to find my mother's vein, leaving her hysterical. She was frightened in a way that I have never seen before. I wanted to scream at the nurses, who did not seem be taking her seriously. I wanted to drag the doctors responsible for her trauma out, rip their doctorates apart and yell at them for being the world's greatest losers.

Yet all I could do was hide behind my sister like I had done my whole life, and wait for my aunt to come and take control of the situation.

My mother seemed so strong, and she is, really, yet beneath all that she could be scared too, and I did not realise it. It was so hard for me to imagine my mother, the pillar of support in my family, would be scared and frightened too.

After the nightmare of the haemodialysis, my mother switched to peritoneal dialysis and became significantly happier with life. Gone are the days of having needles pierced into her arm and frequent trips to the hospital. She now has more control over her life again, and all is well. With that, she tries to lead as much a normal and active life as possible, and I am glad to see her settle so well into this method of treatment.

Of course, no treatment is without its side effects and when it occurs, I still get very frustrated, forgetting that my mother is the one suffering these side effects and it is really not her fault. My temper and patience still needs a lot of work when it comes to that, but I am working on it.

"When life gives you lemons, make lemonade," said some overly optimistic person.

I am not a believer of that kind of jazz. Have you ever heard of supply and demand? Life will keep giving you lemons to make drinks if you create a demand for it.

Perhaps such cynicism is not what you are expecting to read in collection of 'experiences with kidney failure', but there you have it, my experience with kidney failure has left me cynical and unhappy.

Characters in TV dramas probably emerge from such life experiences a stronger and wiser person, sparking inspiration in the audience, but I am probably the furthest thing from that kind of person.

While I'm not in the best position to be handing out advice given my obvious flaws and lack of wisdom, at the very least, what I can say about life is that it is imperfect. You can be angry, frustrated, upset, but, no one asked for the world's greatest drama clichés to play out in their life. I sure didn't.

There comes a time where you have to stop, step away from the anger and frustration, and look at what's really important. Something I really ought to do more often.

What's important to me?

Right now, I just want my mother to be as healthy and happy as she can be.



一步一脚印, 谱写新生活

Yan Er的父母经过多年的分分合合,终于正式离婚之际,母亲肾衰竭的确诊书下来了。用Yan Er自嘲的一句话来形容当时的状况,就是"高潮迭起的连续剧"。

当对不公平的命运的愤怒与呐喊退去后, Yan Er的心中只剩下对失去母亲的恐惧。还好, 母亲是名坚强的女性, 她没有因此而放弃生命, 并开始血液透析。Yan Er永远忘不了, 第一次见到吸管般粗的针头扎进母亲手臂里的画面给她带来多大的冲击。

黎明前的黑夜总是最黑暗。母亲无法适应血液透析, 在很长一段时间里都因其副作用而吃尽苦头。她一难 受, Yan Er 的心也跟着抽痛, 母女二人都倍感煎熬。 直到后来, 母亲转为腹膜透析, 情况才逐渐好转。

若问以前的 Yan Er,她会告诉你,人生如戏。但她现在知道,现实往往要比戏剧来得残酷,而人生百态也远比戏剧更为深刻。经历了这一切的她亦懂得,没有什么比家人健康更重要的事了。

family's journey inspired me to become a nurse"

My father, all these years Written by Rizwana

hen I was younger, I did not know anything about kidney diseases or dialysis. I always wondered why my father came home late on some nights, why he visited hospitals frequently and why he was consuming a myriad of medications every day. As a young child, I would even attend Christmas Parties at my father's dialysis centre without understanding that he was actually undergoing dialysis at the centre.

I remembered that he was in the hospital for weeks before he started having to go for dialysis. I was only two years old then, so my memory of that time is fuzzy, but my sister, who is a year older than me, remembers that my father had suddenly fainted at home and was rushed to the hospital. She was traumatised by the incident.

This incident happened during the SARS period when children were not allowed into the Intensive Care Unit and my mother had to leave my sister and I at the service counter or ask the nurses to help keep an eye on us momentarily as she visited my father.

When my father was hospitalised for weeks and we fell into a financial dilemma. He was the sole breadwinner. My mother could not work as she was a long-term visit pass holder and also had her hands full taking care of the family. I remember my mother telling me that she prayed for a kidney donor as my father was in a comatose state and she was afraid that my sister and I would become fatherless if my father did not survive. Thankfully, he managed to pull through.

When my father first started dialysis, my mother, sister and I would accompany him to a private centre and wait outside for hours. Afterwards, we would all go home together as a family just to show him some moral support.

On days when we did not accompany him to the dialysis centre, my sister would constantly call my father on his mobile phone, just to speak to him and cheer him up. There was even once when she dialled the wrong number and called the police station instead.

There were times when my father would come home in pain and he would have to spend the rest of the day in bed. I felt sad seeing him like that, but being a reserved and quiet child, I did not know what to say to him. My father would also cry sometimes; he did not want to go for dialysis because it was very painful

and expensive. Let me tell you – it is the worst feeling in the world to see your parents cry.

I also remember the period of time when my father had difficulty showering on his own because he had a catheter in his chest, and a few months later, he had to go through another operation to have a fistula placed in his left arm. After the operation, he dared not use his left arm as it was too painful.

Our financial situation worsened after my father retired. We had to record all our expenditure and set budgets for everything. As a result, I was determined to do well academically as I felt that education was the only way to improve my family's financial situation. I was blessed with a great teacher in primary five and she helped me a lot, improving my grades for my weakest subject, Mathematics. I did well for PSLE and moved on to secondary school in the express stream.

Around that same time, my father's health worsened. He was in and out of the hospital more often than usual and even had to receive dialysis in the hospital. The medical bills were also piling up. Once, I had to call the ambulance at lam because my father had difficulty breathing. This happened a few times more afterwards.

All these affected my studies. Although I was initially performing well in school, my grades slipped and I went from passing with flying colours to barely passing my subjects.

I even worked part-time during my end-of-year holidays in 2015 to reduce the burden of my parents. I also wanted to save some money for myself because I knew that I wanted to further my studies at a polytechnic, but the tuition fees were beyond my family's gross monthly income.

My family's journey soon inspired me to become a nurse. My parents are grateful for the help of the nurses in the hospitals and dialysis centres, and personally, I was amazed by the nurses' skills to help others in need, not only ensuring that the patients receive the best care, but looking out for the patients' families too.

Although I had a phobia of sharp objects, I took up Red Cross Youth as my Co-Curricular Activity (CCA) in secondary school as I felt that it would be helpful to me in life. In fact, I am still a volunteer of Red Cross. I also help my father to change his dressings, check his glucose levels and help him with his insulin injections.

After going through challenging situations with my

family and overcoming them, I have great respect for my parents. I am also grateful to all the people around us who have helped us, as I do not think we could have done it without them, especially when my father was in his most critical condition.



历经磨难, 心神更坚

在Rizwana朦胧的记忆里,爸爸似乎经常很晚才回家,有时还要去医院,家里也随处可见许多属于父亲的药片。这对于幼小的她来说有很多不解:爸爸为什么要吃苦苦的药?爸爸为什么常常不在家,不能陪我?爸爸为什么看起来很辛苦?随着年纪增长,她意识到,这些问题都指向同一个答案:因为肾衰竭。

因为肾衰竭,父亲要经历无数次的手术和住院,在静脉瘘管手术后手臂疼得无法动弹。因为肾衰竭,父亲的余生都必须洗肾,忍受洗肾带来的皮肉之苦,以及心理上的负担和对家人的愧疚。因为肾衰竭,父亲即使退休后也难以安度晚年,家中经济也越来越吃紧。

但,也是因为肾衰竭,磨练了Rizwana的意志,使她变得更坚强。因为肾衰竭,她深知父母的不易,更懂得珍惜家的温暖。而因为肾衰竭,就此激发了她对抗逆境的决心,并立志要做一名护士,帮助像父亲一样的病人战胜疾病、战胜肾衰竭!



My personal experience with kidney failure

Written by Yuan Ting

ear Reader, I wish I could tell you that what you are about to read will strike inspiration deep in your heart, but I cannot. You are probably thinking, "Confirm another cliché." I can only shrug and say, you are not wrong. Alas, clichés are clichés because our stories are so similar, so true, yet experienced so differently. So maybe, this wouldn't be a clichéd story after all.

As foreshadowed from the quote above, my story begins during the midst of a messy ongoing divorce. The beginnings go so far back that it feels like a lifetime ago. This whole kidney failure ordeal crept up so silently and hit me so suddenly that the only question that stuck with me was, "Exactly how did we end up here?"

I don't remember much. I will tell you what I remember though.

A phone call. Hospital visits. Helplessness. A battered arm. The haemodialysis centre. More hospital visits. Frustration. Surgeries. Even more hospital visits. Growing up. Peritoneal dialysis. Peace.

Stage one: The phone call/denial & bargaining

It all began with a simple phone call that I received early in the morning. Out of the blue, I was told my mum had a ridiculously high blood pressure reading and was in the hospital. My world came to a startling halt. I rushed to the hospital and saw my mum sitting up in bed. I was relieved that she was alive until I was told that she had end-stage renal disease. As ludicrous as it may sound, a wave of panic overwhelmed me and I genuinely thought I was going to lose my mum.

It did not matter anymore. All that resentment I felt from the ongoing divorce seemed so petty. Everything was insignificant against the scale of this affliction.

Stage two: Haemodialysis/acceptance & growth

I will spare the gory details, but haemodialysis is hell for my mum. You see this thick needle inserted into her frail arm and you can literally see pints of her blood coursing through the machine at a rapid pace. It is terrifying. I feel bad that she has to go through all that exhaustion mental and physical exhaustion, yet simultaneously I am divorced from it. I view it as the necessary evil – for me to have yet another day with my mum.

Dialysis came up with one problem after another initially. The flow was interrupted. The vein was no

good. "Back to the hospital, back to the hospital," the nurses would say. My mum hated it.

I will tell you this too. There are certain defining moments in your life that change you at that very point. These will be undoubtedly challenging moments that can send you running unless you choose to face them straight on with a strengthened resolution.

When your mum is crying hysterically in the surgical room, that is a defining moment. You realise there and then that you, the dependant, are now being depended on by whom you once depended on. You grow up. You do things right, you do it well. You do it to assure your mum that "hey, at least this part of your life isn't messed up." You start to take care of her. You start to be more aware. You start to be the adult that she has groomed you to become.

Stage three: Peritoneal dialysis/empathy

My mum switched to peritoneal dialysis eventually and that brought a positive change to our lives. I do not live with my mum, so it is not so often that I get to watch as she prepares her machine for dialysis. Unfailingly, I will hear her announce to the entire house, "I'm going to hook up! I'm going to hook up!" I help every now and then with the heavy lifting. On bad days, I listen to her frustrations on being

"dependent on a machine to live". My patience wears thin sometimes but I remind myself that I too would be equally annoyed if my entire existence depended on a machine.

There is frankly nothing fantastic about my story. "A sickly parent in a broken family" summarises succinctly what the past 7 years have been about. It is most certainly not the easiest thing for anyone to go through, but one can either sit and wallow about the hand one has been dealt with or make the best use of it.

In the story of my life, my mum's kidney failure just happened to be another bump on the road. I do not mean to trivialise kidney failure, but the entire experience just never was that harrowing to me. Of course, my mum will beg to differ.

What I'm trying to say is, should you find yourself one day in a predicament like mine or similar, don't swim against the tide. I leave you with this: You cannot change what was and what did happen, but what you do hereon can change what's to come next. This life is yours to make. Do what you will with it. Do it right, do it well, for you can only do it once.

肾衰竭带来的领悟

某天的清早, Yuan Ting 接到一通毫无预警的来电, 告诉她母亲由于血压过高被送入医院。现在回想起来,那通电话仿佛就是一切的开端。随之而来的,是 母亲肾衰竭的噩耗,是一次次的手术与住院,是对血液透析的难以适应,是强颜欢笑背后的心酸和强忍的 泪水。值得安慰的是,母亲终于从血液透析转为居家的腹膜透析,身体状况没那么糟了,生活也逐渐恢复平静。

一转眼,母亲患上肾衰竭已有7年之久,每天的腹膜透析也成为日常生活中的一部分。作为在母亲漫漫洗肾长路上的陪伴者,Yuan Ting的感触良多。她说,过去既然无法改变,我们所能做的,就是过好属于自己生活的每一天,才是对自己也是对家人最好的爱。



"I do not know what I would do without her"



Stay strong, mum Nurul Syafiqah's story

en-year-old Nurul Syafiqah Roslan took over as the "head of the family" after her father, who suffered from nose cancer, died of pneumonia last August. She takes over the responsibility of taking care of her mother and younger sister as her mother.

Madam Yanti Mazlan, 43, has cancer, high blood pressure, diabetes, kidney failure, a weak heart and a hip replacement operation which caused her to have difficulty in walking.

Every morning, Syafiqah wakes up before 6am to cook breakfast for her mother and younger sister. As Madam Yanti has to take 12 types of medicine daily, Syafiqah helps to sort out her mother's medication every day and helps her mother to the toilet to bathe before going to school with her sister.

After school, Syafiqah rushes home because she worries about her mother being alone at home. She cleans the house, washes the clothes and cooks meals for the family after school every day.

Madam Yanti said that her husband used to do the household chores and cooking, even when he was battling cancer. This allowed her to focus on working and providing for the family. After her husband passed away, Syafiqah took over his role.

Sadly, Madam Yanti was diagnosed Stage 4 Hodgkin's Lymphoma. The chemotherapy weakened her bones and she suffered fractures in the hip bones due to falls and had to undergo hip replacement therapy. This, coupled with kidney failure, rendered her almost immobile.

Today, she is able to shuffle around using a walking aid, but she depends mainly on a wheelchair to move around. She is also no longer able to work because of her health condition.

Madam Yanti said, "I am very grateful for my daughter, Syafiqah. I do not know what I would do without her. She is the light of my life. She takes care of me and her little sister. In fact, she would nag at me if I do not take my medicine. I sometimes feel like she is the mother and I am the child."

Syafiqah's grandmother, Madam Haji Patijah Haji Elias, 66, added sadly, "Syafiqah has to become an adult because she has to take over the responsibility of her father."

Having already lost one parent, Syafiqah's greatest fear is losing her mother too. Her hopes and dreams for her family was expressed succinctly in one poignant sentence: "I hope that my mother will stay healthy and strong and I will always be there for her."



妈妈,有我在

每天早上6点,10岁的莎菲卡便从温暖的被窝中起来,为患有肾衰竭并行动不便的母亲准备早餐,再协助她上厕所和洗漱。和妹妹一起上学前,她还不忘替母亲整理好一天当中要吃的药物。放学后,莎菲卡不像其他同龄孩子一样看电视玩游戏,而是做各种家务活,如洗衣、煮饭等。

10岁, 其实对于许多孩子来说还是在父母怀中撒娇的年纪, 享受美好童年的日子。可由于莎菲卡的父亲去世, 母亲患病, 她便毅然顶替父亲成为家中的"顶梁柱", 照顾母亲和妹妹, 用不属于这个年龄的坚强和勇敢担负起了一切。她说: "只要妈妈能活着在我身边, 再苦再累我也不怕。"

见到女儿如此懂事孝顺,母亲妍蒂深受感动。她坦言,若没有莎菲卡撑起这个家,自己真不知道该怎么办。女儿的努力,不断提醒妍蒂要坚强活下去,不向肾衰竭低头。



Supermum Written by Eddie

hen I was young, I knew nothing about illnesses. I only knew that with every life comes death and at some point in time, we experience the loss of a loved one.

When I was younger, I used to tag along with my mother wherever she went - the wet market, the hospital and her work place. Her high paying job required her to work every day. She woke up as early as 6am to go to work and return home as late as 9pm.

If she received a phone call from work, she had to head down to the office to settle the issue. Her only rest days are limited to the annual family trip overseas. I had never heard her complain about work as much as I do over my school work. In my eyes, my mother is the superwoman in my life and will always be.

As I grew older, I became curious about human health and illnesses. I took up Biology and Food & Nutrition for GCE 'O' Levels. Equipped with some medical knowledge, I remembered looking at my mum's medical report, discovering that she had hypertension.

My mum often complained about pain and fatigue in her leg. I had initially thought that it was caused by her daily work. My mum worked as a "Food and Beverage Manager" and had to oversee all aspects of the stall.

As time went by, the swelling in her feet worsened. She also had frequent attacks of nausea, fatigue, and sometimes, chest pain. Despite all these symptoms, she acted strong.

It did not take long for the doctors to diagnose her with kidney failure, and needed to go for dialysis as the "toxins level" in her blood was above average.

My mum was, however, adamant about not going for dialysis. She did not want to be injected with needles and was fearful of having enlarged veins. I was very worried about her but could not do anything except to monitor her condition.

Instead of heeding the doctor's advice to start dialysis, she visited the Chinese physician, thinking that it could help to delay the need for dialysis. She saw an improvement in her condition in the first few months, but the visits placed a strain on our finances because of the expensive herbs she had to purchase. Unfortunately, the effectiveness of the Chinese physician's treatment did not last.

One fateful day, my mum was woken up by an unusual pain in the middle of the night. She was taken to hospital immediately. The doctor advised her to start dialysis with immediate effect, but she refused to listen to his advice.

It took us a lot of time and many rounds of persuasion before she agreed to the treatment. She was then directed to private dialysis centres for her treatments, which was very expensive.

The first few dialysis sessions were very tough for her as she experienced post-dialysis symptoms such as giddiness and muscle cramps. She had to take time off from work to attend dialysis 3 days per week and it came at a price – a huge cut in pay.

Despite the drawback, she did not work any less. She gave as much as she could at that point of time. Eventually, she resigned from her job because it was taking a toll on her health. Without her income, we struggled to make ends meet.

Eventually she applied to NKF for funding and was accepted. Fortunately, during that period that my mum was unemployed, an NKF social worker from the dialysis centre assisted my mum to secure a part-time job. Although the pay was not as high as that from her previous job, it helped to lighten our financial burden.

Despite all that she gone through, my mum continues to work hard, and that is something I admire her for.

She is my superwoman and she always will be.



我的超人妈妈

母亲在Eddie心目中,一直是一个超人般的存在,仿佛什么事都难不倒她,哪怕是肾衰竭。可是,在母亲第一次开始洗肾时,Eddie目睹她放声哭泣的样子,才明白原来他的超级英雄也会像普通人一样害怕、难过,亦拥有脆弱的一面。

母亲洗肾的头一年最为艰难,她不仅要忍受血液透析的种种副作用,还不得不辞去工作,家里的经济因此受到不小的影响。幸运的是,母亲之后得以从私人洗肾中心转入NKF,洗肾费用下降的同时,她还在NKF的帮助下找到一份兼职,补贴家用。

母亲虽然不再是以前那般无所不能的超人,但从肾衰竭阴霾中走出来的她,在Eddie心中比任何一位超级英雄都要更了不起、更值得敬佩!

Acknowledgement

We wish to express our heartfelt gratitude to our contributors who helped make this book possible for the benefit of kidney patients and their caregivers.



肾 Love 有 Triumphs







