

男性照顧者物語

The Little-Known Role of Male Caregivers

小嫻（左）從小就是個智障兒，17年來都由父母照料，每次到醫院復健，都由父親藍大峰騎機車接送。
Little Mei (left) became afflicted with cerebral palsy after contracting a high fever as a baby. Whenever she needs to go to the hospital for a physical therapy session, her father Lan Dafeng takes her on his motor scooter.

林瑞益照顧失智母親，藍大峰照顧智能障礙的女兒，陳賢照顧中風癱瘓的妻子。照顧者無性別之分，除了母親、女兒、媳婦，父親、丈夫、兒子，也都有可能成為重病家人唯一的依靠。

家是與情感的聚合，也是人性的試煉場。失智、高齡海嘯輪番襲捲而來，家中的照顧者，尤其是一向不善於表達情感的男性，心情誰人知？

久病床前任孝子

當兵退伍是多數男性衝刺事業的開始，但對56歲的新北市市民林瑞益來說，1981年退伍，卻是他擔任照顧者人生的開端。

那一年，林瑞益的父親58歲，母親55歲，父親工作受傷導致雙眼失明，成了第一位需要被照顧的家人。

家裡8個兄弟姊妹，林瑞益排行老五，「大姊、二姊、大哥已婚，二哥不用，就只好我接。」照顧的責任落到林瑞益一人頭上，幸好有母親幫忙，他白天出門幫工廠客戶修理發電機，父親就由母親照顧。

但從1986年開始，父親又接連中風，癱臥在床，林瑞益早上必須提前起床幫父親擦身、換衣服，等媽媽煮好早餐，再由他餵父親吃飯。

這樣的生活維持4年之後，出現劇烈變化。當時已64歲的母親開始健忘，狀況比醫生評估的輕度失智嚴重，合併有大小便失禁。因此，在中風的父親之外，林瑞益還得照顧失智的母親。

林瑞益的工作有時得出差到外地工廠修機器，在其他兄弟姊妹仍不願或無法幫忙之下，他一個人照顧兩老，經常忙不過來。1992年他辭掉工作，只做零星接案，讓自己有較多時間在家。

1996年，有一次他到外地工廠修機器，請兄弟姊妹回家幫忙，他們卻把父親送到安養院暫時照顧。父親在安養院期間突然病危過世，讓林瑞益日後對機構的照顧很不放心。

父親過世後，林瑞益並未恢復正常工作。母親的狀況雖然時好時壞，但失智持續惡化，3年前確診為重度失智時，已認不得人。偏偏這時母親被診斷小腸壞死，於是做了造口，排便後的消毒清潔更需要幫忙。

因此，只要林瑞益醒著，就不會讓母親離開



Lin Ruiyi takes care of his mother, who has dementia. Lan Dafeng looks after his mentally disabled daughter. And Chen Xian takes care of his wife, who is paralyzed from a stroke. Caregivers aren't exclusively one gender. Mothers, daughters, daughters-in-law, fathers, husbands, sons... all can become the sole support for a person with a serious illness or disability.

With a rapidly aging population and growing ranks of dementia patients, the load on caregivers is growing only heavier. Who can say what emotional toll it takes on them? And that's all the more so for the men, who typically aren't as good at expressing their feelings.

A filial son cares for his bedridden mother

For many young men, leaving the military represents a new beginning, the moment when they launch their careers. But for Lin Ruiyi, now aged 56, leaving the military in 1981 meant something else entirely: taking on duties as a caregiver.

That year Lin's father was 58, and his mother was 55. An injury at work left his father blind in both eyes. He became the first person in the family to need a caregiver.

Of the eight siblings, Lin was fifth. "My eldest brother and two sisters were already married, and the next oldest brother just didn't care," Lin recalls. "So it was left up to me." Fortunately, he still had his able-bodied mother to help. During the day, when Lin left for his job of repairing factory generators, his mother would take care of his father.

But in 1986, his father had another stroke that left him paralyzed and bedridden. Lin would get up early to give his father a sponge bath and change his clothes, and after his mother made breakfast, it fell to Lin Ruiyi to feed him.

Four years later Lin's mother, then 64, had grown absentminded. The situation was far more serious than the mild dementia that the doctor had originally diagnosed. What's more, she had become completely incontinent. Consequently, in addition to supporting his paralyzed father, Lin had to take care of his senile mother too.

Lin's work sometimes took him on trips out of town to repair generators. With his siblings unable or unwilling to help out, he had his hands full caring for his elderly parents. In 1992, to be able to spend more time at home, he quit his job and began to work only occasionally as a freelancer.

他的視線，她只要有痰咳不出來或夏天吹電扇著涼，就會發出「响」、「响」聲表達身體不適。

林瑞益高齡88歲的母親目前只能用「嘿」、「好」等單字與人溝通，平常就睡臥床上，或在林瑞益的攙扶下坐在床沿休息。床的旁邊有一張小沙發椅，這裡就是林瑞益休息的地方，10年來，他幾乎都是坐著睡覺。

他的手機鬧鐘設定上午8點、10點、12點，及晚上10點和凌晨共5個時段，提醒他少量多餐餵媽媽吃飯，並幫她化痰、清理造口。他的時間被零碎切割，他說，睡眠就像是「分期付款」。

家裡生活開銷全靠舅舅每月提供台幣3萬元支應。因為沒有其他家人幫他分擔照顧工作，他只能趁居家服務員一周3次、每次4小時前來提供喘息服務時，補眠、出門採買或到郊外散心。

因為單身、沒有家累，林瑞益被兄弟姊妹認定應該擔起照顧的責任。最讓林瑞益氣憤的是，弟弟離婚後，有一段時間回家暫住，兄弟起爭執，弟弟報警，前來的警察竟先斥責林瑞益「不要以為照顧父母就很偉大」。

照顧父母三十多年，林瑞益說，至今還守在母親身邊，就是因為「不捨」。

把拔心中永遠的寶貝

像林瑞益一樣，對家人不捨，是支撐男性照顧者甘於告別職場，留在家裡的主要原因。現年53歲的藍大峰，17年來，照顧只有4歲智商的女兒，除了不捨，也是出於自責。

藍大峰與妻子育有3女，老大、老二是雙胞胎，老么小嫫比姊姊小兩歲。

雙胞胎姊妹早產，出生時體重不足，立刻被送進早產兒加護病房，雖然順利出院，但至3歲前都得密切追蹤，因此藍大峰的注意力都放在她們身上。

雙胞胎2歲時，小嫫出生，夫妻倆看到體重超過3,000公克，鬆了一口氣。原以為三個女兒就此一塊健康長大，沒料到小嫫10月大時高燒不退，2周後惡化成腦性麻痺。命運再次開了藍家天大的玩笑，也讓藍大峰自責疏於照顧小嫫，心裡對她有無限的虧欠。

藍大峰當時的工作是在松山機場維修飛機零

件，家裡再次出狀況，他對上司坦然以告，並尋求諒解，因此雖然3年來經常醫院、機場兩頭跑，但工作還算順利。妻子則辭掉打字員職務，在家當個全職母親。

小嫫日漸長大，但智商停留在4歲階段，除了智能不足，她還有過動和肢體不協調的障礙。2008年藍大峰離開職場，全心投入家庭照顧。

白天，小嫫上啓智學校，放學回家就黏著爸媽。她150公分高、50公斤重，走路橫衝直撞，無法控制力道，藍大峰與太太必須輪流看著，才不會發生意外。有時候，小嫫很「盧」，例如，趁藍大峰轉頭看電視時，衝去拍打電視，試圖吸引「把拔」的注意。

小嫫語言能力有限，無法說出成串句子，最常說的就是「把拔」（爸爸）、「好吃」等單字。日前，她快速吐出一句「媽媽煮得好好吃」和「把拔父親節快樂」，雖然咬字含糊，但已讓藍大峰高興許久。

藍家雙胞胎姊妹唸護校，都說以後會照顧妹妹。小嫫的下一步怎麼走？

「我看不到小嫫的未來，」藍大峰的語氣流露幾許悲哀。

當愛妻倒下…

夫妻結褵一輩子，最怕的，就是另一半發生意外。對76歲、家住台北市文山區的陳賢來說，16年前太太中風倒下的瞬間，猶如天崩地裂。

當時陳賢的兩個女兒還在英國唸書，陳賢一肩扛起照顧的責任。他不明白，不吃肥肉的太太，怎麼會突發腦溢血病變。

陳賢大妻子兩歲，之前從未有過照顧重症病人的經驗。當時，他仍在中壢的郵局上班，一時無法三天兩頭回台北全天候照顧太太。因此太太手術出院後，他先安排她住進社區附近醫院的護理之家。

陳賢知道太太挑嘴，擔心她吃不慣護理之家的伙食，每天親自下廚煮幾道太太喜歡吃的菜，然後向郵局請假，回台北送去餵太太吃。半年之後，他把太太接回家，自己則申請提前退休，全天候陪太太進行中風後的復健。

太太除了身體右半邊癱瘓，語言功能和智力都

In 1996, he once went to a factory out of town to repair its equipment, and asked his brothers and sisters to help out in his absence. They temporarily sent his parents to a nursing home, where his father's condition suddenly took a sharp turn for the worse. He passed away there, and his death left Lin Ruiyi with a deep mistrust of institutional care.

After his father died, Lin didn't return to regular work. Although his mother's condition would vary from one day to the next, her dementia was gradually worsening. Three years ago it entered an advanced stage. She could no longer recognize people. What's more, she was diagnosed with small intestinal ischemia, for which she received a colostomy. Ever since the operation, she has required even more help with cleansing after defecation.

Lin's 88-year-old mother can now only speak in monosyllables such as "hey" and "good." Normally she just sleeps in bed, though sometimes, with the support of her son, she can sit at the edge of the bed. There's a sofa chair next to the bed, which is where Lin rests. For the last decade he's hardly slept anywhere else.

He has five alarms on his watch that are set to ring at eight, ten and 12 in the morning, as well as ten at night and in the wee hours. These are to remind him to feed his mother several small meals, give her medicine to clear her phlegm, and clean her colostomy bag. With his time so fragmented, he says he gets his sleep "on an installment plan."

The household depends on NT\$30,000 of support from Lin's uncle. As no other family member helps him finan-

cially, his only breathers are three four-hour stints each week when he hires a home nursing aid. He uses those hours to catch up on sleep, go shopping or clear his head outside.

Because Lin Ruiyi is single and has no family of his own, his siblings maintain that it is only right that he should take on the caregiving duties. One incident that typifies an attitude that really ticks him off occurred after his younger brother got divorced and returned home to live. The two of them got into an argument and Lin's brother called the police on him. Much to Lin's surprise, the first thing the responding officer did on arriving was to reprimand Lin, saying, "Don't think it's such a big deal that you care for your parents!"

Having taken care of his parents for more than 30 years, Lin says that he stays by his mother's side because "it would feel wrong to leave her."

Forever father's precious little girl

Like Lin, a reluctance to leave family members alone is one of the main reasons male caregivers say they are willing to leave the workforce. For 17 years Lan Dafeng, 53, has been a caregiver to his daughter, who has a mental age of four. For him, self-blame played a role in the decision.

Lan has three daughters. The oldest two are twins, and there is a two-year gap between them and the youngest.

The twins were born premature and underweight, and were immediately put into a neonatal intensive care unit. Although they left the hospital without any serious health issues, they had to be carefully monitored until they were three. Consequently, Lan's attention was focused on them.



56歲的林瑞益（左）未婚，成了兄弟姊妹不願分擔照顧88歲失智母親（右）的藉口。

Lin Ruiyi (left), 56, is unmarried, and his siblings have used his lack of a family as a convenient excuse to evade any responsibility for their 88-year-old mother (right), who has dementia.

明顯退化，生活完全無法自理。幸好兩個女兒如期完成學業，陸續返台，一家人團聚在一起，生活上也多了些照應，照顧工作也有了適度的分工。

譬如，幫太太沐浴、擦澡等比較私密的工作，陳賢做起來難免有些尷尬，由女兒來做，就自然許多。

長期照顧日復一日，照顧者與被照顧者多少都會有情緒。陳賢說，太太受中風後遺症的影響，有時脾氣比較拗，這時，他就讓女兒扮白臉哄媽媽，他則扮黑臉，嚴正拒絕太太無理的要求。

「母女連心，」陳賢說，兩個女兒是他和太太最大的情感支柱。

這麼多年下來，照顧工作漸漸上了軌道，家裡也請了外傭幫忙，但看到太太復健進展有限，以及兩個女兒被耽誤了終身大事，他心裡仍有很大的遺憾。

每當壓力來襲，他就去山上廟裡走走，沉澱思緒。同時，他也參加家庭照顧者關

懷總會的活動，擔任志工，分享自己的經驗給其他照顧者參考。

然而，並非每一個男性照顧者都像陳賢一樣，能夠得到家人的支持與體諒，更多時候反而是誤解與袖手旁觀。照顧工作是每個家庭都可能遇到的艱難課題，男性照顧，更有待社會全體一起補課。 □



陳賢的太太（前）15年前中風，腦傷且半身癱瘓，雖有兩個女兒及外傭分擔照顧工作，但對陳賢（後）而言，精神上的壓力仍是不可承受之重。

Chen Xian's wife (front) had a stroke 15 years ago. She suffered brain damage and is still partially paralyzed. Although her husband has the help of two daughters and a foreign domestic, her condition still places a heavy burden on him.

When the twins were two, Little Mei was born. When Lan and his wife saw that she weighed over three kilos, they heaved a sigh of relief, thinking that their three children would grow up hale and hearty. But at ten months Little Mei contracted a fever that wouldn't break. After two weeks, it worsened to cerebral palsy. Fate had played another cruel joke on Lan's family. Lan blamed himself.

Lan had a job repairing airplane parts at Taipei Songshan Airport. He explained the family crisis to his boss, who was understanding. Although Lan was forced to scurry back and forth between the hospital and his workplace, he managed to get his work done. His wife, meanwhile, quit her job as a typist and became a full-time mom.

Little Mei grew day by day, but her mental faculties stayed at a four-year-old's level. She was also hyperactive and highly uncoordinated. In 2008 Lan left his job and threw himself entirely into caregiving.

During the day Little Mei attends a special education school, and then when she comes home she stays close to her parents. She stands 150 centimeters tall and weighs 50 kilos. She frequently bumps into things. Lan and his wife have to take turns watching her to prevent accidents.

Little Mei has limited language skills, and is usually unable to string together complete sentences. She typically speaks in single words, such as "Papa" or "yummy." Recently, she was able to put together a few longer constructions: "Mama cooks well" and "Happy Father's Day, Pappa." The sentences pleased Lan Dafeng to no end, no matter how garbled they sounded.

The twins are studying at nursing school, and they say that in the future they will be able to care for Little Mei. What's the next step for her? "I can't see her future," says Lan, with a tone that sounds somewhat sorrowful.

When a beloved wife collapses...

Husbands and wives marry for a lifetime, and what they fear most is that something will happen to their spouse. As far as 76-year-old Chen Xian, a resident of Taipei's Wenshan District, is concerned, his life was completely thrown upside down the moment his wife had a stroke 16 years ago.

Chen's two daughters were studying in Britain, and Chen had to take on all the caregiving duties. He didn't understand why his wife, who didn't even like to eat fatty meat, would suddenly suffer a stroke.

Two years older than her, Chen previously had no experience in caring for someone with a serious illness. Back then, he was still working at a Zhongli post office and wasn't able

to spend much time with his wife in the hospital. And so when she was released, he first arranged to have her stay at a nursing facility in a hospital in their neighborhood.

Chen Xian knew that his wife was picky and worried that she wouldn't like the food there, so he would often prepare some food himself, ask for time off from the post office, and then deliver it to his wife in Taipei. After half a year, he brought his wife home from the hospital, applied for early retirement, and began spending his days helping his wife recover.

His wife's right side was paralyzed, and her language and mental abilities had clearly slipped. She could no longer manage things for herself. Fortunately, their two daughters had finished their studies and returned to Taiwan. With the family reunited, things were easier.

For instance, Chen couldn't help but feel embarrassed when helping his wife with certain more private tasks, such as giving her a bath or sponge bathing her. Their daughters were naturally more comfortable with those duties.

When care is provided day after day, the relationship between caregiver and the family member being cared for is bound to become rocky at times. Chen says that since her stroke, his wife acts childish and stubborn at times. At those moments, he gets his daughters to play the good cops and cheekily coax their mother to behave, whereas he plays the bad cop and sternly refuses her demands. "My daughters have a tight bond with their mother," Chen says. The young women are both parents' biggest source of emotional support.

After so many years, the caregiving has become more routine. The family has hired a foreign domestic to help out. But when Chen sees how his wife's recovery has been limited, and how his daughters have postponed establishing families of their own, he is filled with regrets.

Whenever he feels stressed, he takes a stroll to a mountainside temple to settle his emotions. Meanwhile, he has been participating in activities put on by the Taiwan Association of Family Caregivers, sharing his experiences with others.

Yet not every male caregiver has the support and understanding of his family like Chen does. Many more are misunderstood and unsupported. Caregiving is something that every family may one day have to confront. Society needs a better understanding of male caregiving in particular. □

*(Sam Ju/photos by Chuang Kung-ju/
tr. by Jonathan Barnard)*