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澳華療養院基金
Australian Nursing Home Foundation

與癡呆症同行 活出彩虹人生



照顧者手冊

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前言

生老病死，雖說是人生必經過程，但每次看見許多健康活躍的長者，竟患上癡呆症，看著他們記憶和身體日漸衰退，照顧他們的家人疲於奔命，都會不期然問上帝為甚麼會這樣？但透過這次訪問過程，看見照顧者與患者之間那種相濡以沫、不離不棄的高尚情操，才明白甚麼是真正的親情和愛情！在這個冷漠疏離的社會，這種至情更是鳳毛麟角，彌足珍貴。彩虹底下的深藍與深紫，無非為襯托出那璀璨的色彩；原來人生的一些遺憾，是讓生命活得更精彩！

書的第一部分，是六個真實個案分享，由於中國人較忌諱讓人知道家人患上癡呆症，為尊重他們的意向，故文章內都用了假名。期望照顧者在看別人故事的同時，能感受到很多人與你相伴同行，你並不孤單。第二部分是照顧者錦囊，讓照顧者知道癡呆症患者，會有不同的行為轉變，並提供建議對策。第三部分，照顧別人，先從照顧好自己開始，提醒照顧者疏導情緒，參加支援小組，讓別人分擔壓力；第四部分，癡呆症資料指南，除了提供澳洲癡呆症支援機構及網址外，更有華人機構及亞洲的網址，讓不諳英語的讀者，亦可找到支援。

在此特別感謝澳洲健康及老人事務部癡呆症社區資助計劃資助推動關注華裔癡呆症運動，讓華人社區有機會認識癡呆症；更感謝新州阿耳滋海默氏協會，並內西區癡呆症諮詢服務的寶貴意見；以及澳華療養院基金無限量的支持。最後要感謝每位接受訪問的癡呆症患者及照顧者，沒有你們的支持，這本小冊子也不能順利出版。但願每位拿到這本小冊子的照顧者及朋友，都能從中得到幫助。

關注華裔癡呆症運動
社區服務幹事
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簡介

澳洲政府關注癡呆症計劃

澳洲政府關注癡呆症計劃每年撥款多達一億二千萬元，支援癡症患者及其照顧者。癡呆症社區支援資助計劃就是直接由澳洲政府關注癡呆症計劃資助。

支援癡呆症患者

目前澳洲有超過二十萬人患有癡呆症，因為癡呆症而深受困擾的人更不計其數。儘管癡呆症並非老年的自然現象，但凡六十五歲或以上的長者，他們被診斷患上癡呆症的機會，每增長五歲便增加一倍。澳洲政府正視癡呆症的增加並視為優先處理的健康問題，正在擬定最好的方法，以滿足今日及未來的社會的需求。



一) 牽你手，一起走到白頭

詩經云：「執子之手，與子偕老」，每個人結婚時，只想與伴侶開開心心走到白頭，那會想到有天他會患上癡呆症，突然變了性格，像個孩子一樣需要你長期照顧。所以那天當袁太（假名）知道丈夫被診斷患上癡呆症時，真是晴天霹靂！「幾十年來辛勤地工作，都是希望晚年可以舒適自在，和老伴一起到處旅遊，但現在甚麼希望都落空了！」

三年前，袁太與丈夫返中國蘇杭旅行，途中發覺丈夫的行為有些怪異，時常和人爭座位；走到人多的地方，會害怕得突然停下來不敢動；又時常疑神疑鬼地說別人盯著他；同團有個從美國來的男生，說袁先生可能患上老人癡呆症，因為他的父親也有這個病。回澳洲後，袁太帶丈夫去看老人專科，做了腦電圖，最後證實他患上老人癡呆症。「那時真的很徬徨，不知道怎樣做，後來經朋友介紹到澳華療養院基金屬下專為癡呆症患者而設的蘇懷活動中心，在那裡拿到很多資料，聽專題講座，看很多參考書，知道甚麼是癡呆症，也認識了一班和我有同一遭遇的朋友，心裡舒坦了很多。坦白說，直至今今天我仍然接受不到丈夫患上癡呆症，但接受不到又怎樣，要活下去，就只能選擇面對！」

自從袁先生患上癡呆症，除了記憶衰退，性格也變了，變得挑剔、吝嗇、愛批評別人、又容易情緒失控，令照顧他的袁太感到非常勞累。舉例說若是袁先生知道明天和別人有約會，就會變得很緊張，一天問十幾回，令她不勝其煩，現在袁太學懂不到那時那刻不會告



訴他要出外去。為了安撫袁先生，有時袁太也要說些善意的謊話，像袁先生耍脾氣不肯去活動中心時，遇著這情況，袁太一定不能和他硬碰，反而轉個彎說冰箱沒菜，要去市場買菜，但買菜前先去活動中心，那他就會很聽話地穿衣服去。袁先生愛美，每次看見頭上長出一根白髮，就嘆



著要染髮，袁太不理他，有次，他在袁太午睡時，悄悄地走進浴室搞東搞西，袁太沒去理他，後來女兒發覺爸爸頭髮好像有異，袁太去查看，發覺染髮膏原封不動，但半支牙膏卻沒有了，原來袁先生把牙膏當了染髮劑！她看後不禁哈哈大笑，女兒奇怪她怎還笑得出來，「不笑難道要我哭嗎？你爸爸是患有老人癡呆症的！」

袁太知道我要推廣關注老人癡呆症，第一個表示支持，她說澳洲華人社區對癡呆症的認知不足，有次她帶袁先生去教會的老人中心，那裡的人知道袁先生患有老人癡呆症，像怕被傳染似地立即走到另一邊坐。那天袁先生很不開心，邊看電視邊唸唸有詞：「所有人都不理我，他們以為我是傻的嗎！？」袁太感到很心痛，從此不敢再帶他回去那老人中心。

有天，袁先生忽然像清醒些，很困擾地對她說：「不知為甚麼，現在我的腦袋很亂，好像很多東西都記不起來！」袁太很奇怪：「你知道發生甚麼事嗎？」袁先生表情很迷惘，袁太只有安慰他：「你不用怕，我們明白你，我和幾個女兒都會支持你的！」他點點頭應道：「嗯！」幾句簡單的對話，卻讓人深受感動。我想婚姻的意義就在此，開始時候誰知道究竟會是誰生病誰先倒下，但只要不放棄，牽著手，一定可以一起走到白頭。



1 二) 慈烏惜其母，願盡反哺心

踏進專為癡呆症患者而設的實活區蘇懷活動中心，大多看到的都是丈夫或者妻子伴隨著患病的伴侶來參加活動，唯獨Daniel（假名）這個大男人，每星期兩天風雨不改地都帶著母親來到這裡。

「我母親一向很獨立，自從父親於八五年去世後，她都是獨自生活。九一年她移民來澳洲和我一起生活，很快已適應下來，自己學會坐巴士去唐人街，約朋友買東西出外飲茶，都是自己來，不用我費神。直至二零零二年我從日本出差回來，發覺她性格有些轉變，起初還以為是一般人老了都會這樣，不以為然。有天，她突然向我宣佈，說以後不再煮早餐！我覺得很奇怪，向來重視飲食的她，為甚麼抗拒煮早餐？後來我發覺冰箱塞滿很多東西，都是重複買回來的食物，於是勸她不要再買那麼多東西，她沒答話便走開，未幾，我發現她在房間裡啜泣，看見她哭，我心裡也很難過，只有提醒自己，以後說話要更小心。那時我開始懷疑她有病，帶她去看醫生，發現她原來患上癡呆症！」



從事電腦資訊行業的Daniel，那時剛好因為經濟不景，公司要裁員，他便藉此機會轉為兼職工作，以便全時間照顧母親，「起初不知甚麼是癡呆症，照顧她時常會碰壁，後來開始留意這方面的資訊，來到蘇懷活動中心也聽到很多癡呆症講座和拿到有關資料。不過知道並不等於解決問題，怎樣照顧她是最好的，仍要靠自己慢慢去摸索。她現在很依賴我，幾小時不見我便會鬧個不停，每次晚上出去，我會預設讓電腦每十五分鐘出現我的樣子和聲音，跟她說我會晚一點回來，叫她不用擔心，這樣她才不會鬧，不會跑出街外找我。每次和她上街都是挑戰，她總要重複檢查東西，重複上廁所，以前我會很生氣，現在我買了個木結他，每次等她時就彈結他，既

不用和她爭執，又可以紓緩壓力。」

「母親現在一天天地衰退，時常忘記洗頭和洗澡，個人衛生已成為另一挑戰，我又要想辦法對策。有時覺得自己正和時間競賽，所以趁她現在可以走動，帶她去她喜歡去的地方；趁她現在可以享受食物時，帶她去吃她喜歡吃的東西，若她失去這些能力時，再做甚麼已經太遲。有次，我和照顧她的朋友一起帶她去市政廳(Town Hall)飲茶，然後走到海德公園(Hyde Park)及歌劇院(Opera House)散步，再坐船去曼利(Manly)，最後一起坐車回家，就這樣過了一天，在別人眼裡可能覺得很無聊，但我卻很珍惜和她一起相聚的日子，這幾年兼職工作錢可能是賺少了，但我很感謝上天給我這樣的機會。」

即將回復全職工作的Daniel，現正安排人手照顧母親，除了兩天來寶活區蘇懷活動中心外，也為母親安排了高齡家居服務，讓工作人員上門幫忙清潔和煮餐，其餘時間，他打算請人來看顧母親，「現在這些照顧者跟她都很熟稔，所以我出外工作也比較放心。我母親說過不想入老人院，所以我們幾兄弟商量過，寧願多花些錢，也讓她安心住在家裡。當然照顧她可能會愈來愈困難，但我只想盡力而為，就作為兒子對母親的一點回報！」



Daniel現在很會逗母親開心，兩母子似乎已走出默契來，「每次我扮不想付款卻充闊綽的人，裝作找錢包，邊找邊說有有有時，她便會哈哈笑個不停，看到她笑，看到她心情好，我也會很開心！」難怪每次走過蘇懷中心，都聽到Daniel母親開朗的笑聲，能有這樣孝順的兒子，確實是母親的福氣。

三) 一個護士學校校長的自白： 「為甚麼我會患上癡呆症？」

認識趙太（假名），是因為她打電話來報名參加敝機構主辦的癡呆症講座。細問下，才知道她是早期癡呆症患者，並服食延緩癡呆症藥物將近一年，但趙太仍一再問：「會不會是醫生誤診？我只是記憶衰退，而不是患上癡呆症？」隔著電話，仍可以感受到她對癡呆症這個稱號非常抗拒。



和趙太第一次見面，就感到她獨有的學養氣質，單看外表，一點不像年過七十。生於上海的趙太，唸完中學再進護士學校學習，並在醫院工作，是醫生很信賴的助手。後來趙太再進夜間醫學院進修四年醫學課程，之後除了在醫院從事護理工作外，也在護士學校任教，最後擢升為護士學校校長，並被北京中央衛生部指派擔任編寫護理教科書，如此聰明能幹，難怪當她被診斷患上癡呆症時，她的反應是：「我不服氣！」

「我辛勤地工作了幾十年，每一天都很認真地生活，不像別人遊戲人間，工作讓我很有成就感，我的學生現在很多已是有名的醫生，他們讓我感到很自豪。六十歲我決定退休，之後隨女兒移民來澳洲，以為可以好好地享受生活，想不到卻患上這個病！」

趙太年青時，記憶力很好，不用電話簿，電話號碼都是用腦記下來的。去年，發覺電話號碼記不牢，英文地址有時也寫不出來，電話費帳單交了再交，但物業管理費卻忘了繳交，結果要罰款，她開始奇怪，為甚麼會變得這麼糊塗，後來有人介紹她去看老人專科，醫生看她的腦部素描，說腦部有些萎縮，診斷她患上癡呆症，並著她服食延緩癡呆症藥物。「我很矛盾，一方面覺得自己很幸運，可以有藥物治療，另一方面，我又擔心我只是早期患者，是否需要服藥？服藥後會否更嚴重？可是，我又希望可以快些好起來，擔心若果藥物的份量不夠，會不會沒有效？真的很矛盾！」

每次見趙太，她丈夫趙先生都會體貼地陪在一旁，原來趙先生在中國是外科醫生，二人當年在醫院裡認識邂逅，然後結婚。問他當年在醫院時，有沒有看見癡呆症病人？「以前中國大陸不知道也不注意這個病，很多病人到了嚴重時才住院，我也有朋友患這病，他們都是醫生，病情發展得很快，突然一下子不認得人，大小便失禁，後來得了併發症，幾年就去世！」現在趙太得了癡呆症，問趙先生會不會特別照顧她？「慶幸太太是早期患者，自她服藥後，病情已趨穩定，空白時候比較少。現在還是她煮飯燒菜，仍是她照顧我呢！」

現在趙太身邊都有本記事簿，每天把要做的事情都記下來；堅持電話不肯輸入簡易撥號，仍努力記著家人的電話號碼；趙太心臟不好，每天要吃八種藥，每次吃藥時，她都把每隻藥的名稱唸一遍；用盡所有方法，就是不讓自己失卻記憶。「參加完你們的講座，讓我安心許多，因為感覺有人關心。我現在去蘇懷活動中心，認識一些癡呆症患者，大家分享感受，交流保持健康的方法。現在知道很多聰明人，也會患上這個病（即使聰明如諾貝爾得主「光纖之父」高錕，也患有癡呆症），既然命中注定我有這個病，要避也避不開，我很幸運可以及早被診斷和治療，只希望一直努力保持在這個階段，不要太快惡化，已經心滿意足了！」



1 四) 鶼鶼情深，相濡以沫

所謂「夫妻本是同林鳥，大難臨頭各自飛。」現今世代，即使沒有大難，夫妻也動不動喊離婚。能夠患難與共，相依相守六十載，就算妻子患上癡呆症，仍然不離不棄地守在她身邊，無微不至地照顧她，這種鶼鶼情深，相濡以沫之情，實在世間罕見。



陸先生（假名）憶述當年和妻子邂逅，可說是一見鍾情。「那年清明回鄉祭祖，順道騎單車探同事，看見他家外幾個鄰居女孩坐在門外乘涼，我第一眼看見她便喜歡她，於是悄悄向同事打探她是誰家姑娘，後來我正式到她家裡向她父親提親，然後我們很快便訂了親。雖然是已訂親，但她性格很害羞，每次約她出外看電影，她不肯拖手不肯並肩走，總愛在後面跟著我走，這習慣直到現在都一樣。」

陸先生四八年已移民來澳洲，起初人生路不熟，做過雜貨店、餐館、外賣店、學打麵、做點心，可惜都失敗，生意沒有起色，陸太只有去洗衣工場打工，生活雖然艱苦，但夫婦二人從不放棄，拼手抵足，最後嘗試做河粉，「做河粉要半夜開工，我和妻子一直工作到早上六點，九點開始送貨到各燒臘店，雖然辛苦，但因當時沒有競爭對手，總算闖出一條路來，後來我向星加坡購入悉尼第一部整河粉機，開始打正招牌，獨立包裝，看起來比較衛生，亦讓顧客有信心。」夫婦同心合力，甘苦與共，終於在澳洲安居樂業。二人兒女成群，各有所成，陸先生決定退休，與老伴安享晚年，想不到陸太此時卻患上癡呆症。

八年前，陸太遇上車禍，之後神情變得呆滯，記憶力減退，女兒帶她看醫生，做過腦部素描，看不出有問題，只說她年紀大，記憶力衰退。零八年陸太患上帕金森症，手腳不受控地顫動，需要吃藥控制；有次，陸先生參加澳華療養院基金舉辦的癡呆症講座後，開始



懷疑太太患上癡呆症，於是帶陸太去看老人專科，證實她患上癡呆症。

「以前她很獨立，來澳洲後學會英文，比我更快拿到車牌，去那裡也自己去。但自患病後，她已不能照顧自己，早上煮麥皮，就算我在旁提示，只要一個不留神，她就把麥皮燒焦；每天吃藥都要我給她；她也不會洗澡，乾淨的衣服拿給她也不會換；我不介意服侍她，但最尷尬是出外，我也不能跟著她上廁所；她現在性格變得很倚賴，一步也不能離開我，甚至我上廁所，她也要偷看我，證實我真的在洗手間內，才可以放心，所以我連洗澡也不敢鎖門。現在我最擔心是萬一我比她早走一步，她一個人怎樣生活下去！」每次說到這裡，陸先生便會哽咽不已。

陸先生說現在每天都祈禱，希望上帝醫治妻子，也讓他有健康身體，可以繼續照顧她。「年底位於好市圍市錢梁秀容療養院建成後，希望我能和太太一起入住，太太入住高度護理的癡呆症院舍，而我可入住低度護理的院舍；現在我年紀大，照顧她有時也有點力不從心，若讓她一人入住，我又不放心，所以最理想就是可以陪她一起住進去。」說甚麼情是何物生死相許都是虛假，能相依相扶到終老，才是至情。

1 五) 天意憐幽草，人間重晚情



八月二日至八月八日是澳洲全國的「失蹤人士周」，紐省警方透露現有失蹤人口一萬一千人，其中百分之十的失蹤者是患有老人癡呆症*。隨著人口老化，因為癡呆症或喪失記憶以致人間消失，已成為社會人士愈來愈關注的問題。

曾經照顧過癡呆症患者的家人，很多都經歷過親人走失那種慌亂失措、彷徨無助的感受。

那次，潘太（假名）和患有癡呆症的丈夫一起上街，經過一家商店，她進去買東西，囑咐丈夫在門外等，那知買完東西出來，卻不見了丈夫，「那時心裡真的很慌，在那條大街上來來回回地找他，像瘋了一樣，不停大聲呼喚他的名字，但都不見他，找了一個多小時，實在沒有辦法，心裡想他會不會自己先回家，於是跑回家，但打開門，一個人也沒有！」

那時潘太的兒子不在澳洲，她實在求助無門，只好報警求助，等了十五分鐘，警察還沒來，「等待的每一分鐘都如坐針氈，我像熱鍋上的螞蟻，實在沒法再等下去，於是找鄰居代我守在家裡等警察，自己又跑回那條大街去找他，街上每個角落每個罅隙都不放過；最後，感謝上天，終於讓我發現他的身影，原來他正在對面馬路徘徊！等不及所有車子停下來，我已跑過去一手抱住他，激動得眼淚都流出來，但他根本不明白，還埋怨我去了那裡，要他站在這裡等那麼久，我有理也說不清。能找回他，我已經很幸運！」

潘先生自從患上癡呆症後，人也變得敏感，潘太跟著他出外，他會不高興：「你為甚麼跟著我，你以為我是傻的嗎？」潘太無奈，只能悄悄尾隨他，然後扮在街上偶遇，再與他一起回家。有次有個好心的鄰居見狀，自願請纓開車幫她悄悄跟著潘先生，鄰居感同身受地歎喟：「錢丟失了還可以賺回來，人丟失可能永遠也找不到！」

從事機械工程的潘太，一直都是女強人，移民到澳洲，本想在事業上大展拳腳，更上一層樓，但因丈夫患上癡呆症，一切都變成泡影。「事業與丈夫，我會毫不猶豫選擇丈夫，畢竟一起生活了幾十年的老伴，要我放棄他，我實在做不到！」

潘先生喜歡坐船，潘太太差不多每天都帶他去達令港（Darling Harbour）坐船去曼利（Manly），「因為坐船最安全，他不會走失，看見他很開心地欣賞兩旁風景，我也可以放心地做自己喜歡的事，例如讀書看報，或者玩玩讀數（Sudoku），訓練自己的大腦，避免自己也患上癡呆症，這是我一天最放鬆的時間。」潘太說年輕時夫婦兩人都忙於工作，沒有時間拍拖，現在卻天天去拍拖；以前不想防礙大家，所以分房睡，現在潘先生每晚一定要她先上床才可以安心睡，「自他患病後，變得很膽小怕鬼，每分每秒都要我在身邊，也不知道這究竟是祝福還是詛咒。照顧一個小孩，可以看到他天天進步；但照顧一個癡呆症患者，永遠不會看見這種回報，有時也會很沮喪；工作有下班時間，但照顧癡呆症患者，每天二十四小時無休，完全沒有自由，沒有自己。」

「不過，換個角度想，幸好患病是我先生，我還可以照顧他，若有病的是我，他一定不懂照顧我，那時更加淒涼，想到這裡我就會很感謝上天！現在我人生的意義，就是全心全意地照顧他，兩個人總比一個人好，若有天他不在，沒有人讓我去掛繫，我一定會感到很失落很孤獨，想到這裡，我就覺得現在已經很幸福了！」



* 資料來源: www.missingpersons.gov.au

1 六) 誰憐寸草心，報得三春暉

現今社會物質豐富，但父母和子女的關係卻日益疏離，子女回家就關在房裡打機打電腦，父母一開口，就覺得煩厭。究竟還有幾多子女，願意照顧年紀老邁的父母？肯花時間陪他們去看醫生、上茶樓？在父母患上癡呆症，仍對他們不離不棄，就像當初父母愛我們一樣？

從別人口中聽說Daisy(假名)的故事，就覺得不可思議。Daisy的父親早年患上癡呆症；幾年前，她丈夫又遇上嚴重車禍，需要她貼身照顧。其實她大有借口可以拒絕再去照顧父親，但Daisy卻甘之如飴地扛起照顧父親責任，因為父親一直是她心裡最敬佩的人。

Daisy的父親是內蒙古著名的醫生，年青時曾往日本習醫，回國後在內蒙古自治區第一間醫院當院長。「爸爸醉心醫學，以救人為他的人生目標，無論夏天刮風沙，還是冬天零下四十度，日間還是夜深，即使春節，做滿一枱餃子，只要有人敲門求醫，他就騎馬跟著人家去，那年代內蒙古交通和通訊設備都很落後，既沒有汽車，只能騎馬；也沒有電話，很多時候一去就幾天，音訊全無，媽媽總是又擔心又生氣。」



文革時Daisy的父親被誣告為日本特務，被抓進牛棚，連續四十天不准他睡覺地嚴刑拷問，身體也給鬥垮。儘管苦難重重，但從沒有動搖他作為醫生的熱誠。「爸爸一生救人無數，他治病從來不計錢，他知道有些人真的很窮，就自掏腰包先替人付帳，當移民來澳洲時，收不到的爛帳超過二萬元人民幣，而那時買一幢漂亮的樓房才不過八千元！」



移民後Daisy一家和父母同住，兩老與女婿孫兒相處融洽。零四年，一天Daisy父親忽然對她說，他診斷自己患上了癡呆症，當時Daisy並不相信，因為家庭醫生也看不出來，但父親堅持自己的診斷，最後Daisy只好帶他去看專科醫生，做不同的測試，最後證實他的診斷正確。Daisy

父親接受治療，最初服藥後的反應還不錯，但零五年，因為他心臟出現問題，需要做心臟起駁器手術（pacemaker），所以停了服藥，記憶開始衰退。零七年，Daisy父親在家跌倒三次，反覆住院，自理能力開始有困難。「爸爸是我一生最敬愛的人，他對人太好了，我實在捨不得把他送進療養院；他性格喜歡活動，我常帶他出外吃飯，買東西，但自丈夫遇上車禍後，為了照顧他，我也心力交瘁；幸好找到澳華療養院基金的高齡家居照顧服務（CACP）上門幫忙照顧父親，那裡的負責人更介紹他們到蘇懷活動中心，爸爸很喜歡到那裡參加活動，看見他開心我也開心，你們確實幫了我很大的忙。」

Daisy一家是敬虔的教徒，每星期仍堅持和父母一起去教堂敬拜，「起初很擔心爸爸會發脾氣，沒耐性，但很奇怪，每星期天的敬拜，他坐得特別安靜，連洗手間也不用去。其實我很感謝上帝，零七年丈夫遇上嚴重車禍，與大貨車相撞，他的車全被壓扁，丈夫斷了十三條肋骨，手也斷了，但仍能奇蹟地生存下來；爸爸雖然患上癡呆症，但因為有很多人幫忙，仍能和我們一起住，讓我可以照顧他，我相信上帝仍然聽我的禱告！」很多人都視父母是包袱，但Daisy卻感謝上天能讓她背上這甜蜜的包袱。就因為還有這些人在身邊，讓我們相信世間仍有血濃於水的親情。

由於癡呆症會影響患者大腦的記憶、情緒及表現，令患者行為出現異常。作為照顧者，你必須明白這些行為是癡呆症患者常有的徵狀。在這章中，將集中講述癡呆症患者常有的異常行為，並提議一些對應的策略，以供照顧者參考。

| 異常行徑 | 徵狀 / 原因 | 對策 |
|-----------|--|--|
| 不斷重複及焦躁不安 | <ul style="list-style-type: none"> - 患者由於記憶衰退，缺乏安全感，時常重複同一句子，或問同一問題，或不停踱步及說話； - 可能患者身體有其他問題（如：尿道感染，便秘及其他疾病）引致患者焦躁不安或脾氣暴躁 - 抑鬱症的徵狀 | <ul style="list-style-type: none"> - 確認患者的不安感覺，加以安慰及輔導； - 安排一些簡單而重複的工作如摺衣及洗菜等，轉移其注意力； - 切勿提醒患者已重複發問，對患者的問題予以相同的答案，不要隨意說謊； - 為患者簡化工序，培養固定生活習慣及避免生活環境有太大的轉變； - 避免與患者爭拗、理論； - 當患者情緒激動時，應盡量使他心情平伏； |
| 幻覺及幻聽 | <ul style="list-style-type: none"> - 癡呆症患者常會看見一些東西，實際上卻不存在； - 幻聽亦是患者常見的現象； - 患者有時會感覺被人監視或攻擊，但並不是真有其事； | <ul style="list-style-type: none"> - 及早找醫生找出引致幻覺的成因，縱使難以找出成因，但某些精神藥物可以控制及減少幻覺及幻聽發生； - 切勿與患者爭拗，或分辨現實的真偽，要明白患者已失去自控的能力； - 向患者解釋他的感受，嘗試安慰患者，並引開他的注意力 |
| 遊蕩 | <ul style="list-style-type: none"> - 患者因為記憶衰退，原先擬定去的地方，卻因忘記而在街上遊蕩 - 若搬家或置身新環境，更容易出現混亂和遊蕩的情況 - 患者若情緒出現焦慮不安或混亂時，亦會出外遊蕩，有時甚至愈走愈遠，以致迷路； | <ul style="list-style-type: none"> - 為患者配備寫上家人姓名和電話號碼的手鐲或名牌，讓患者迷路時，能盡快與家人聯絡； - 記錄患者每天是否有特定時間遊蕩，為他在這段時間安排活動消耗多餘體力； - 在不熟悉的環境下，加倍留意患者行為及適應能力； - 將患者情況預告與鄰居或附近商店職員，若發現患者遊蕩，可盡早與家人聯絡； |

| | | |
|----------------|--|--|
| <p>抑鬱</p> | <ul style="list-style-type: none"> - 很多癡呆症患者都有抑鬱症，可能因為難與別人溝通，亦可能是服藥後的副作用 - 缺乏動力，連過去喜歡的活動都沒興趣參與 - 沒有食慾或失眠； - 情緒化，易發脾氣及激動； | <ul style="list-style-type: none"> - 必須與家庭醫生商議，有些抗抑鬱藥可幫助患者減輕症狀； - 留意那些活動適合患者，鼓勵患者繼續參與； - 協助維持患者的社交生活，鼓勵患者交朋結友； - 避免讓患者置身嘈雜地方，避免讓患者感覺不安全或受驚； - 耐心聆聽患者心聲，並向患者灌輸積極思想 |
| <p>失禁</p> | <ul style="list-style-type: none"> - 失禁可能是由於忘記上洗手間，或趕不上洗手間； - 脫衣服方面有困難； - 晚間找不到路向； - 肚瀉及便秘； | <ul style="list-style-type: none"> - 定時帶患者上洗手間；臨睡前或半夜叫醒患者上洗手間； - 晚間適量減少飲流質飲品； - 在床邊放置尿椅方便患者晚間使用，適當照明或螢光指示； - 注意患者飲食，避免產生便秘； - 鼓勵患者多做運動，避免產生便秘； |
| <p>不適當的性舉動</p> | <ul style="list-style-type: none"> - 包括在眾人面前脫衣服、露體及狎玩性器官； - 這些舉動可能與性無關，患者可能覺得這樣比較舒適； - 患者可能以為處身於浴室； | <ul style="list-style-type: none"> - 記錄這些舉動的次數，並嘗試找出原因； - 嘗試叫患者做別的事情，以引開他的注意力； - 瞭解患者是否衣服太厚或感覺不舒服，或患者有需要上洗手間； - 切勿大聲責備，嘗試說服患者不要在公眾場合做不適當行為； |
| <p>匿藏物品</p> | <ul style="list-style-type: none"> - 患者缺乏安全感，擔心被人偷竊，故常把物品收藏，但卻忘記藏在甚麼地方，然後懷疑別人偷去他的東西； - 患者可能感覺孤單，或受到忽視，希望得到別人注意關懷； | <ul style="list-style-type: none"> - 瞭解病人習慣將物品收藏在哪裡，以便替他找出來； - 準備一個裝滿物品的抽屜讓患者來整理，以滿足患者忙個不停的需求； - 儘量讓患者處身於熟悉的環境裡，陌生的環境可能讓加劇患者匿藏物品的問題； |

照顧癡呆症患者是很艱巨的工作，因為一般的癡呆症患者都很依賴照顧者，時常會令照顧者感到筋疲力竭，心力交瘁。照顧者很多時候會變得很情緒化，有時會覺得很憤怒，或無助，或內疚，甚至沮喪等，這是照顧者正常的心路歷程。在澳洲現有超過二十萬癡呆症患者，照顧者更是不計其數，所以在這條崎嶇的路上，你絕對不是孤單一人！

疏導情緒

照顧者也是人，在漫長照顧患者的日子裡，你要容許和接納自己可能會出現情緒起落。照顧者許多時會有思想矛盾，角色混淆。每當看見患者連最簡單的事情都做不到，就如穿衣服或扣安全帶等，有時會不能自控地生氣，甚至謾罵，但當冷靜下來，知道這是患者的徵狀，又會為剛才曾有過的怒氣而感到內疚，每當回想到患者從前健康能幹時，又會感到很傷心，甚至因不能幫助患者而感到無助和沮喪，這些情況可能會重複地發生。

首先，當你出現情緒低落時，你要知道警號已經響起，你需要別人幫助。如果你有朋友明白你的情況，你可以先找他傾訴，以舒緩情緒。你也可以找一些同路人，如癡呆症照顧者支援小組裡的朋友，因為他們也面對同樣的問題，一定可以明白你的感受。

在澳洲有特別為照顧者而設的支援機構，你可以致電1800 242 636，找出就近你所住該區的支援機構，他們有豐富的經驗和最新資料可協助照顧者。

安排休息時間

每個人都需要休息。平常人五天工作後，都需要周末休息，更何況是癡呆症的照顧者。記著，休息並不是要你逃避照顧的責任，而是讓你有機會充電，更有力量走前面的路。

你可以利用聯邦照顧者暫息照護服務，選擇不同的休息方法。你可以休息幾小時或一天，利用這些時間去做自己喜歡做的事情，例如做運動、看電影，和朋友閒談聊天，以鬆弛情緒；亦可以計劃放一個長假，到外地或本地旅行，讓身心舒暢。

照顧者選擇休息，對癡呆症患者亦有好處，讓患者藉此機會，可與其他人見面和結識新的朋友，亦可讓他們習慣被其他人提供支援和照顧。

凡欲諮詢有關暫息服務的詳情，可致電聯邦照顧者暫息照護服務中心，電話：1800 052 222。

減壓方法

當你的情緒感到受壓時，首先不要否定這感覺，而是要承認和面對。不同人選擇不同的減壓方法，現提供以下一些資料可供參考：

- * 聽輕音樂，調息呼吸，利用默想或瑜珈等方法釋放壓力
- * 與朋友、親人、其他照顧者或輔導員分享感受
- * 每天定時做帶氧運動三十分鐘
- * 若有機會多些學習有關癡呆症的知識，當患者行為有所轉變時，較容易接受和明白
- * 嘗試找別人分擔照顧者的工作，讓自己可以休息
- * 建立自己的支援網絡，以便隨時可以找到支援自己的人
- * 關注自己的身心健康，定期休息
- * 當感到壓力難以承受時，要向別人求助

照顧者支援小組

照顧癡呆症患者的感受，一般人是不容易明白，除非大家都面對同一困境，家裡都有癡呆症患者需要照顧，相同的感受很容易找到共鳴，所以新州阿耳滋海默氏協會向來很鼓勵照顧者建立支援小組，以便互相分享和彼此支援。

新州阿耳滋海默氏協會定期為照顧者或癡呆症家人舉行有關‘記憶衰退’(Living with Memory Loss Program)課程，讓他們學習更多有關癡呆症的知識，課程後照顧者亦可組成支援小組，讓照顧者分享照顧的經驗和感受。當然，照顧者可隨意選擇同一文化和語言背景的支援小組。

如欲查詢有關記憶衰退課程，可致電全國癡呆症熱線1800 100 500或癡呆症華語熱線1800 300 386（逢星期四早上九時至下午一時），或瀏覽阿耳滋海默氏協會網址：www.alzheimers.org.au

4 第四章 參考資料及支援服務

1. 澳洲阿耳滋海默氏協會

澳洲阿耳滋海默氏協會為癡呆症患者、家人及照顧者提供豐富的資料及各式的支援服務，包括：

- * 中文單張詳細介紹有關癡呆症（包括何謂癡呆症、癡呆症的診斷、行為變化及暫息服務等）
- * 為癡呆症患者及照顧者安排支援小組
- * 個人輔導服務
- * 專為癡呆症患者及家人而設的圖書館，內有癡呆症書籍及錄影帶可供外借參考
- * 癡呆症全國電話熱線：1800 100 500
- * 癡呆症華語電話熱線：1800 300 386（逢星期四上午九時至下午一時，公眾假期除外）

2. 澳洲照顧者

澳洲照顧者服務樂意為照顧者提供支援服務。澳洲每州每區都設有聯邦照顧者資源中心，設有十種不同語言，以便隨時支援照顧者。凡欲與澳洲照顧者服務聯絡，可致電：1800 242 636

3. 聯邦護理資訊中心

聯邦護理資訊中心為照顧者提供資訊服務，包括不同的種類的社區護理服務及其收費，聯絡電話：1800 052 222

4. 癡呆症行為管理諮詢服務

癡呆症行為管理諮詢服務是一項全國性的電話諮詢服務，為癡呆症患者的家人及照顧者提供每星期七天二十四小時的電話查詢服務，讓照顧者更了解癡呆症患者的行為變化，查詢電話：1800 699 799



| Country 國家 | Name of Association 機構名稱 | Language 語言 | Webs 網址 |
|------------------|--|----------------|------------|
| Australia 澳洲 | Department of Health and Ageing | English | www. |
| | Alzheimer's Australia National Dementia Helpline | English | www. |
| | Commonwealth Respite and Carelink Centre | English | www. |
| | HealthInsite | English | www. |
| | Carers Australia | English | www. |
| | Centrelink (financial assistance for carers phone) | English | www. |
| | Dementia Collaborative Research Centres | English | www. |
| HongKong 香港 | Ginkgo 癡呆(失智)症網上資源中心 | English 中文 | www. |
| | Hong Kong Alzheimer's Disease Association 香港老年癡呆症協會 | English 中文 | www. |
| | Jockey Club Centre for Positive Ageing 賽馬會耆智園 | English 中文 | www. |
| | Mingpaohealth.com 明報健康網 | 中文 | www. |
| | Resource Centre on Healthy Ageing 健康耆年資源中心 | English 中文 | www. |
| | Brian Fitness Gymnasium 大腦健身室 | English 中文 | www. |
| Singapore 新加坡 | The Alzheimer's Disease Association (ADA) Singapore | English 中文 | www. |

| ite | Information Line 電話 |
|---|---|
| health.gov.au/internet/main/publishing.nsf/content/dementia | 1800 500 853 |
| alzheimers.org.au | 1800 100 500 1800 300 386 (華語熱線, 逢星期四上午9時至下午1時) |
| commcarelink.health.gov.au | 1800 052 222 |
| healthinsite.gov.au/topics/Dementia | |
| carersaustralia.com.au | 1800 242 636 |
| centrelink.gov.au | 13 27 17 |
| dementia.unsw.edu.au | |
| ginkgogroup.org | (852)2766 4369 |
| hkada.org.hk | (852)2338 1120 |
| jccpahk.com | (852)2636 6323 |
| mingpaohealth.com | |
| healthyageing.sphpc.cuhk.edu.hk | |
| loveyourbrain.org.hk | |
| alzheimers.org.sg | |

4. Dementia Behaviour Management Advisory Service (DBMAS)

Provides information for people who are concerned about the behaviour of a person with Alzheimer's Disease. A 24 hour toll free helpline is available: 1800 699 799



4 Section 4 Resources and Support

1. Alzheimer's Australia

Alzheimer's Australia provides a range of resources and support services for people with dementia, carers and families, including:

- information fact sheets (including Chinese version fact sheet: what is dementia? diagnosing dementia, changed behaviours and taking a break, etc)
- support groups for people with dementia and carers
- counselling services
- library of books and videos
- National Dementia Helpline 1800 100 500
- Chinese Dementia Helpline 1800 300 368
(every Thursday 9am-1pm except public holidays)

2. Carers Australia

For assistance with caring, Carers Australia provides information about support services for carers. Carers support kits are available in 10 languages, and can be ordered by contacting Carers Australia on 1800 242 636.

3. Commonwealth Respite and Carelink Services

Commonwealth Respite and Carelink Centres provide information and guidance about community care services available in the local community. Call 1800 052 222.

might become essential in the future.

For information about respite services you can call Commonwealth Respite and Carelink Centre on 1800 052 222

Stress relief

You need to recognise that you are in stress and face it. There are different ways to de-stress and below are some suggestions:

- * Listen to light music, use breathing techniques, meditation or yoga to relieve your stress;
- * Share you feelings with friends, relatives or other carers;
- * Do 30 minutes of exercise every day;
- * Learn more about dementia and understand its symptoms;
- * Share your workload with other people and take rests;
- * Build up your own support network;
- * Look after your own health; and
- * Seek assistance whenever necessary.

Carers support group

The NSW Alzheimer’s Association is eager to help carers to form their own support group. It is only those carers who are faced with similar problems in caring for someone with dementia who can understand and sympathize with one another. They can share their experience and support one another in these groups. The Association regularly organizes “Living with a Memory Loss Program” for carers to obtain more information on dementia. Carers can form their own support group according to their language and cultural needs.

To get more information on the “Living with Memory Loss Program” please call the nationwide Dementia hotline at 1800 100 500 or the Dementia Chinese hotline at 1800 300 386 (every Thursday from 9 am to 1 pm). Or you can visit the Alzheimer’s Association’s website: www.alzheimers.org.au.

3 Section 3 Caring for Yourself First, Then Your Loved One

It is never an easy task to take care of someone with dementia. All dementia sufferers depend fully on their carers and this can cause immense fatigue. On many occasions carers find themselves becoming emotional, angry, helpless, regretful or even in total despair. With over 200,000 people suffering from dementia in Australia and their numerous carers, you are definitely not alone in this task.

Your feelings

Carers are normal people. You have ups and downs like all other normal people. You will become angry when the person you care for cannot do the simplest of things such as getting dressed or fastening their seatbelt. However you may later regret having expressed your anger at them. You are sad at their deteriorating conditions. Many times you may find yourself helpless and in despair for not being able to help them. You are confused in the different roles you play and do not know the way out.

Having emotional problems is the first sign that you need help yourself. You can tell your problems to a friend who knows you well. You can also talk to other carers who are in similar situations from the Dementia Carers Support Group. They are sure to understand you and can offer some support. There are support organisations in Australia which can offer carers some valuable experiences and the most updated information. You can call Carers Australia on 1800 242 636 to find out your nearest support organisation.

Taking a break

All people need rest and leisure. Most people only work five days a week and use the weekends for rest. There is no difference for a carer. You need rest to recuperate so that you can continue with your heavy workload.

The Commonwealth Respite and Carelink Centre offers various forms of respite for carers. You can take a few hours break or a whole day to do things that you like such as sports, shopping or going to a movie. You can even take a long local holiday or overseas trip to relax yourself completely.

When the carer chooses to take a rest it is also good for the people with dementia who they care for. They have a chance to meet new people and make new friends. They can learn to be looked after by some other people which

| | | |
|--------------------------------|--|---|
| Depression | <ul style="list-style-type: none"> * Many patients with dementia also suffer from depression. It may be due to difficulty in communication or a reaction to medication. * Lack of energy and loss of interest in the activities that they used to enjoy. * Loss of appetite or insomnia. * Emotional and easily agitated | <ul style="list-style-type: none"> * Must discuss with family doctor as there are anti-depressants which may help patients to alleviate some of their symptoms. * Encourage patients to participate in the activities they like. * Encourage patients to keep up with their social life and make new friends. * Avoid taking patients to noisy places and do not scare them. * Listen patiently and help them to think positively. |
| Incontinence | <ul style="list-style-type: none"> * Incontinence may be a result of forgetting to go to the toilet or just not going in time. * Difficulty in getting undressed. * Cannot find the way to toilet at night. * Diarrhea | <ul style="list-style-type: none"> * Toilet patients regularly and before going to bed and in the middle of night. * Offer less fluid at night. * Put a commode chair at the patient's bedside with adequate lighting. * Feed appropriately to prevent constipation. * Encourage patient to do more exercise to prevent constipation |
| Inappropriate sexual behaviour | <ul style="list-style-type: none"> * Undressing in public and playing with sexual organs. * Patients may not have a sexual motive. They just feel like doing it. * Patients may think that they are in the washroom. | <ul style="list-style-type: none"> * Record the number of these inappropriate behaviours and try to find out the cause of them. * Try to divert the patient to do other things. * Find out if the patient is wearing too many clothes or there is an urge to go to the toilet. * Try to persuade the patient not to do these inappropriate behaviours. Do not reprimand them. |
| Hiding Items | <ul style="list-style-type: none"> * Dementia patients feel insecure. Harboring fears that their things might be stolen, they always hide them away, but forget where they are kept and complain that they have been stolen. * Dementia patients might feel lonely, ignored. They hope to receive care and concern from others. | <ul style="list-style-type: none"> * Find out where dementia patients usually keep their stuff. * Completely fill a drawer for them to take care of so as to meet their needs in being always occupied. * Always try to let dementia patients stay in a familiar place. An unfamiliar environment might intensify their desire to hide things. |

2 Section 2 Tips for Carers

As dementia affects a patient's memory, emotions and performance, they tend to demonstrate some abnormal behaviours. As a carer, you should understand these behaviour and keep your own composure. This section will categorise some of these behaviours and offer some strategies for remedies.

| Abnormal behaviours | Symptoms/Causes | Strategies |
|---------------------------------|--|---|
| Repetitive, Agitated and Uneasy | <ul style="list-style-type: none"> * Due to memory loss and lack of a sense of security, tends to repeat the same sentence, ask the same question or keep on walking and talking * Maybe affected by other diseases such as urinary tract infection or constipation which cause them to be uneasy or agitated. * Displays symptoms of depression. | <ul style="list-style-type: none"> * Acknowledge the patient's feelings of uneasiness and give comfort and counselling. * Arrange for the patient to do some simple and repetitive tasks like folding clothes to divert their attention. * Simplify the task procedures for the patient, help them develop a daily routine and avoid abrupt changes in their environment. * Avoid any arguments with the patient. * Divert their attention if the patient gets agitated then calm them down. |
| Hallucinations | <ul style="list-style-type: none"> * Often have hallucinations. * They feel that they are being watched or attacked. | <ul style="list-style-type: none"> * Seek medical advice to find out the cause of these hallucinations and use medications to control the symptoms. * Do not argue with the patient or try to convince them that these are only hallucinations. * Comfort the patient, divert their attention and try to explain their feelings. |
| Wandering | <ul style="list-style-type: none"> * Due to not remembering where they first intended to go, the patient is found wandering in the street. * Moving house or a new environment are catalysts for getting confused and wandering. * Stress and confusion are also causes for wandering until they finally get lost. | <ul style="list-style-type: none"> * Let the patient carry a bracelet or a tag with their name and contact number. In case of being losts these will help others to contact their families. * Record the times of wandering to look for any pattern. Arrange activities for them in their wandering time. * Pay special attention on the patient's behaviour and adaptability when they are in a new environment. * Inform neighbours and neighbourhood shop assistants about the patient's conditions so that they can inform families in case of wandering. |

time, a nice house was only \$8,000 RMB”.

After migrating here, her parents lived with Daisy’s family and got along tremendously well with their son-in-law. In 2004, her father told her that he had diagnosed himself as having dementia. At that time, Daisy did not believe him and took him to see the family doctor but did not get a diagnosis. Her father insisted on his own diagnosis and finally, after seeing a specialist followed by a number of tests, it was confirmed that he had dementia. In the beginning, her father responded well to medication, but because of his heart problem and having to have a pacemaker inserted, the medication was stopped and his memory then began to deteriorate. In 2007, her father had three falls at home and was hospitalised every time; self-care had become a problem. “Dad has always enjoy going out, I would take him to restaurants, shopping, to meet friends and strolling on the beach. But since my husband had the car accident, I could not split my time up to look after him as well. Trying to accommodate their needs, I became very exhausted. It was not until I got domestic help through a CACP (Community Aged Care Package) that I was advised to enrol my dad at an Activity Centre. Dad enjoys his visits there very much, especially when he brings home prizes that he occasionally wins whilst he’s there”.

Daisy and her family are Christians and insist on bringing her parents to church. “In the beginning, I was worried that dad might lose his temper and be impatient, but surprisingly every time we were in church, he remained unusually calm during the service and wouldn’t even ask to go to the toilet.” says Daisy. “I truly thank God for everything. My husband miraculously survived the car crash in 2007 with 13 broken ribs and a broken hand during the head-on collision with a semi-trailer and his car was a total write-off and although dad is suffering from dementia, he can still live with us and be cared for by us because of all the help we are getting from so many people.

Many people treat their parents as burdens, but Daisy on the other hand, thanks God for letting her have the strength and courage to carry these precious burdens.

It is individuals like Daisy, who give us the meaning of what a true family is.

In today's materialistic society, relationships between parents and children are growing further apart to the extent that the majority of children retreat to their rooms to use the computer as soon as they get home. The children would be offended if the parents were to comment on this. One wonders how many children will still want to care for their parents when they get old, accompanying them to doctors' appointments, having yum cha with them and looking after them even if they have been diagnosed with dementia.

Therefore, it was quite a unique, but incredible experience, to be told about Daisy's (alias) story. Following a serious car accident, her husband was in dire need of personal care from her. Daisy could easily have used this as an excuse to send her father to a nursing home, but she chose to take over the responsibility of caring for her dementia suffering father because of the admiration she has for him.

Daisy's father was a well known doctor in Mongolia after practising his medicine in Japan during his younger days. On returning home, he became the Head of the first hospital ever built in the self-governing Mongolia. "Dad takes his medical profession seriously and believes he was there to help save people from illness. If there was a knock on the door with someone asking for help, he would pack his medicine case, ride on horseback and leave immediately. He would drop everything he was doing and travel through sand storms in summer and -40 degrees in winter, whether it was in the middle of the day or the deep of the night and even during New Year celebrations.. During those years, there were no cars or any other form of transportation except horses and it would be days before his return. Without the convenience of telephones, mum was worried and upset and complained about how dad could care so much about others and forget his own family and children".

At the time of the cultural revolution, her father was arrested and accused of being a spy for the Japanese. He was held in a cowshed for over a year and during that time, for a stretch of 40 days, he was severely beaten and deprived of sleep. His health was completely ruined.

Daisy, a trained paediatrician had to give up her specialty for the sake of migrating to Australia. "Dad has helped treat many people during his life and never would he care about making money, he would pay for people who were struggling. It was on preparation to migrate to Australia that he realised the bad debt accumulated during his practise was over \$20,000 RMB and at that



A professional in her working life, Mrs. Poon was going to continue working after migrating to Australia, but with her husband's illness, she had no choice but to stop work. They never got the chance to enjoy each other's company while busy working, now it is 'dating' every day.

"When you look after a child, you can see the child growing up, but caring for a person with dementia, it never happens, I feel somewhat depressed and upset. You can rest at least when you finish work, but it's 24 hours work without rest when caring for someone with this illness, no freedom and no time for self. On the other hand, I am glad that it is my husband who has the illness, I can still look after him. If it was me who was sick, he would not know how to care for me and it would be very sad. I thank God when I think of this. Now I feel fulfilled while my full attention is given to caring for my husband, two of us are better than one. If he's not here one day, I will have no one to care for, I will feel very lost and lonely. When I think about this, I feel I am actually blessed!"

* Information come from www.missingpersons.gov.au

In Australia, [Missing Persons Week] falls between August 2 – 8 every year.

According to NSW Police, currently there are over 11,000 missing persons in the state and 10% of them are Dementia sufferers.* As the population grows old, people that had gone missing because of dementia and loss of memory have become a huge concern within society.

Many carers of people with dementia would have experienced the awful panicky feeling of losing someone. Take, for example, Mrs. Poon (alias), who could not find her husband (dementia sufferer) when she came out of a shop. She frantically searched and screamed out for her husband in the street and even went home looking for him without success, and finally she called the Police for help. Fifteen minutes later, she found him wandering and was so overwhelmed she cried and ran to hug him while he complained about waiting for her all that time. “I consider myself lucky that he was found, there’s this friend of mine who looked for his missing relative for three days and when found, the relative was already dead”.





Australia. She even got her driver's licence before me and was going everywhere on her own. Now that she's got dementia, she cannot even look after herself. She will not shower, will not change into the fresh clothes provided for her and needs me to give her daily medications. I don't mind caring for her, but when we go out I can't take her to the toilet. She has become very dependent on me and watches me to make sure I have not left her even when I go to the toilet or have a shower. My worst nightmare is – 'What happens if I die before her, what is she going to do?' Mr. Luk weeps every time he talks about this.

Mr. Luk prays every day for God's help in treating his wife and to keep him healthy so that he can continue caring for her. "It is my wish that my wife will be admitted to a high dementia care service and there will be a low aged care service for me. It has become much more difficult for me to care for my wife because of my age and it would be ideal if both of us could be admitted at the same time as I would worry so much if she was going in alone".

[Birds of a feather flock together – (follow by) - till great catastrophe falls – fly their separate ways]..... as the Chinese proverb depicts Nowadays, couples spilt up under the slightest discontentment.

It is considered rare when a couple manages to stay together for over 60 years, even after the wife has been diagnosed with dementia. He would care for her,



be there for her and unconditionally love her. That's the story of Mr. & Mrs. Luk (alias).

It was love at first sight when Mr. Luk set eyes on his wife. He introduced himself and asked for her hand in marriage from her father. While dating, Mrs. Luk was shy, would not hold hands and walked a few steps behind him....

these habits are still evident now.

On migrating to Australia in 1948, Mr. & Mrs. Luk worked hard through many challenges and hardship to build their foundations. After many labouring jobs, they finally found their livelihood through making 'flat noodles' and brought their first professional noodle making machine from Singapore. From then on, life became better and their children grew up and were successful in their own right. When Mr. Luk thought they could relax and enjoy each other's company, Mrs. Luk was diagnosed with dementia.

Eight years ago, following a car accident, Mrs. Luk was found to be slow and her memory was declining. An MRI scan was performed and nothing out of the ordinary was found and she was told that bad memory goes with old age. Mr. Luk became suspicious that Mrs. Luk might have dementia only after an information session on the subject and it was later confirmed by a geriatrician that this was a reality.

“She has always been independent and learnt English when she arrived in

moments have become less frequent.

A notebook now accompanies Mrs. Chiu wherever she goes. She writes down ‘things to do’ on a daily basis. She still tries to remember all telephone numbers by heart and the names of all of the eight medications she takes for her heart condition. She refuses to let her memory go.



“After attending a seminar, I am much more at ease as I feel there are people who care. When I go to the Activity Centre and meet with other dementia sufferers, we share our feelings and exchange ways of keeping healthy. Now, I realise there are a lot of clever people that have the same illness. It is fate that I have this illness and I have to face it. I am glad that I was diagnosed at an early stage and hopefully I can work hard at slowing its progression and would be very grateful if the illness does not get worse too soon.

Story 3 “Why Me? Why Dementia?” Emotional Struggles of a Former Nursing School Principal

We came to know Mrs. Chiu (alias) when she enquired about a seminar on dementia.

When we first met, she looked much younger than her 70 years. After graduating as a nurse in Shanghai, she worked as an assistant to doctors in hospitals, taught nursing and later became the head of a nursing school. It’s no wonder that her response was “I am not willing to accept that I have Dementia” when diagnosed.

When Mrs. Chiu (alias) was young, she had an excellent memory. It was only last year that it became quite obvious that she was becoming more and more forgetful. After seeing a specialist and having an MRI scan on her brain with a diagnosis of dementia, she was put on a medication to slow down the progression of the illness. “My feelings are contradictory, on one hand I am lucky that my illness can be controlled with medication, on the other I am thinking – what if my illness is only at its early stage – maybe I don’t need to be medicated; but if I don’t – will it get worse?” Mrs. Chiu says.

Mrs. Chiu’s husband, who is always by her side, told us that when he was a surgeon in China, many of his friends (doctors) had dementia. This condition can go downhill within a very short period of time, from not recognising familiar faces to incontinence and finally death. Mr. Chiu said that since Mrs. Chiu started on the medication, her condition has stabilised and ‘blank’



got everything over and over again and go to the toilet repeatedly. I used to get upset, but now I've bought myself a wooden guitar and will play it while waiting for her. It is quite a soothing thing to do and stops us from arguing”.

“Watching mum's condition declining, with her forgetting to shower and wash her hair, has now become another challenge. Whilst thinking of a new way to deal with this, I realise that I am running against time and that's why I take her to places while she is still mobile and to restaurants so that she can enjoy the food she likes before it's too late”. Daniel says, “Recently, with her other carer, we went to Town Hall for yum cha, then walked to Hyde Park and strolled down to the Opera House, then took the ferry to Manly. People might think that all this is very boring, but I am treasure every moment I spend with mum. I might not be making great money working as a casual, but I feel very blessed and thank God for the opportunity to be with mum.”

Daniel, who will be resuming full time work, is arranging for appropriate care for his mum. Other than her attending a Day & Activity Centre twice a week, he has also organised for an Aged Care Home Service to do domestic tasks and cook for his mum. He is also looking for carers who will spend the other times with his mum when he is not around. “I know these carers/helpers very well and when I am away working, I feel much more relaxed. Mum said she does not want to go to a nursing home and between us brothers, we have decided to keep her happy at home even if we need to spend more money. We know that looking after mum will become more and more difficult, but I just want to do my utmost in returning everything she has done for me!”

Daniel now knows exactly what to do to make his mother happy, “I'd pretend to be a wealthy man who never wants to pay, I'd go through my pockets pretending to look for money. Mum finds this hilarious and would laugh out loud every time. When I see her happy, I also feel happy. It is obviously a blessing to have a son like Daniel.



One would expect to see a husband accompanying wife or vice-versa when entering a Day Care & Activity Centre, except in the case of Daniel (alias) who, accompanies his mother twice a week, rain or shine.

“Mum has always been independent and lived on her own when dad died in 1985 until she moved to Australia to live with me in 1991. It didn’t take long for her to adapt to her new life and in no time, she was taking herself to Chinatown by bus and meeting up with friends for shopping and yum cha”, says Daniel. “It was in 2002, when I returned from a business trip to Japan, that I noticed a change in her personality and thought it might just be old age causing her memory to decline. I didn’t think any more about it. But it became more unusual when all of a sudden she announced that she would no longer cook breakfast. This, from someone who cares about food and nutrition and is refusing to have breakfast?” continued Daniel. “The situation became worse when I found that mum was filling up the fridge with identical things. When I queried this, she went silent and I was quite stunned when I found her weeping in her room. Seeing her like this made me very sad and I had to remind myself to be very cautious when talking to her. By then, I was suspecting that she might be sick and took her to the doctor who confirmed that mum is suffering from dementia.”

“Around the same time, I was made redundant by the IT firm I was working with due to the global financial crisis. I took the opportunity to take up casual work with the view to caring for my mum full time. In the beginning I had no idea what dementia was and caring for mum was a challenge. It wasn’t until I did some research into this illness and attended many seminars that I understood more about dementia. But ‘understanding’ does not mean ‘solving’ the problem - how best to look after mum is still trial and error. Now mum is very dependent on me and throws tantrums if I am not with her for several hours. I now set my computer to show my face every 15 minutes to tell her not to worry and that I am just running a bit late. This has stopped her from throwing tantrums and from running in to the streets looking for me. It is also very challenging when getting her ready to go out, she will make sure she’s

Activity Centre, she would say that there was no food in the fridge and they need to go shopping but need to stop by the Centre first. This way Mr. Yuen will listen and get ready.

Mr. Yuen tried to dye his hair one day and sneaked into the bathroom while Mrs. Yuen was having a nap. Some time later, their daughter told her that Mr. Yuen's hair looked a bit odd. Mrs. Yuen then found the tube of toothpaste almost empty rather than the hair dye and thought it was hilarious. Her daughter asked how she could still find this funny and Mrs. Yuen answered, "What can I do but see the funny side of this, your father has dementia".

When Mrs. Yuen realized there was work being done to promote caring for people with dementia, she was one of the first to support this work, as dementia is not very well understood in the Chinese Community



One day, Mr. Yuen was suddenly quite alert and asked "Why am I so confused, I can't remember a lot of things" and when Mrs. Yuen

asked him if he knew what had happened he looked quite lost again. With that, Mrs. Yuen comforted him and said, "Don't worry, we understand what you are going through and our daughters and I will be here to support you!" Mr. Yuen nodded. Everyone there at the Day Centre was so deeply touched by these few simple, but meaningful words.

To me, the real meaning of 'marriage' lies here, who can predict which one will be sick before the other. As long as we don't give up and hold each other's hand we will be together until the end!

Section 1 Stories

Story 1 Together we go, along This Uneven Road

When two people get married, they tend to look into the future and dream of all the happy times they will share while growing old together. No one would ever think that their soul mate's personality would change suddenly with a diagnosis of dementia, becoming needy like a child and having to be cared for 24/7. Mrs. Yuen (alias) was grief-stricken when she found out about her husband's illness. "After years of hard work, hopes of enjoying our life and travelling together have gone down the drain".

Three years ago while Mrs. Yuen was travelling in China with her husband, she noticed that he was acting strangely. He was frequently fighting with people for seats, became paranoid in crowds and would stop dead in his tracks and suspiciously say that people were watching him. One of the American travellers in their group suggested that Mr. Yuen might be suffering from dementia and upon returning to Australia, Mrs. Yuen took her husband to see a geriatrician. After having an MRI scan of the brain, it was confirmed that he did, in fact, have dementia.

"I was beside myself and did not know what to do, until a friend recommended a Chinese Activity Centre for people with dementia. We were able to gain more information on the subject as there is much literature and many seminars to attend that provide a better understanding of Dementia. I also met people in similar circumstances and felt much better. Frankly, up till now, I still cannot accept that my husband has dementia, but what can I do, I still have to live with it and face it, this isn't a matter of choice", Mrs. Yuen said.

It is very tiring caring for her husband who has dementia. As well as the decline in Mr. Yuen's memory, changes in his character have become quite profound. He became judgmental, selfish, loved to criticize and quick to have an emotional outburst. One example is that if Mr. Yuen is aware of an appointment on Saturday, he becomes very anxious and repeatedly asks her every day about it until Mrs. Yuen becomes very tired of this behaviour. Now she has learnt to keep things to herself until the very last minute to let Mr. Yuen know and sometimes even telling a white lie to make things easier. She has to think fast as direct conflict will get her nowhere. If they were to attend the

Introduction

The Australian Government Dementia Initiative

The Australian Government's Dementia Initiative provides funding of more than \$120 million each year to support people with dementia and their carers.

The Dementia Community Support Grants Program is funded under the Dementia Initiative.

Supporting people living with dementia

It is estimated that around 200,000 people currently have dementia. As Australia's population ages, more people are likely to be affected.

Dementia is not a natural part of ageing. After the age of 65, however, the likelihood of being diagnosed with dementia doubles every five years.

The Australian Government recognises the growing importance of dementia as a health priority and is looking at how it can best meet the needs of the community today and into the future.

Foreword

Although issues such as life and death, or human sickness are all part of our daily lives, each time I encounter patients who are suffering from dementia; with their minds and bodies gradually deteriorating, and notice their family members who are exhausted by taking care of them, I ask myself ‘Why does this happen?’ However, through a series of case interviews, I was moved by the close relationship between the carers and the patients. The bonding between the carers and the patients shows me once again the true meaning of love and family. It is quite a rare and precious experience, especially nowadays in our cold and distant society. The dark blue hue beneath the rainbow accentuates its dazzling colours – indeed regrets in our lives are there for us to live a fuller life.

This handbook begins with six real-life family cases. Under the Chinese culture, many families still count dementia as a taboo. To protect the interviewees and their family’s privacy, all cases and related interviewees are kept anonymous. As these stories unfold one episode after another, we hope the carers can find some comfort and ease during the reading process – they are not all alone in facing the problem of dementia.

The second part shares tips with carers through a close study of the behaviour changes of people with dementia, which includes advice for handling changes.

The third part of the handbook is dedicated to emotional support for carers. In order to take care of dementia patients, carers need to take good care of themselves as well.

The fourth part centres on useful information and guidelines on dementia: local websites on support groups for dementia patients and carers plus websites on Asian and Chinese community support centres. The latter will provide handy and culturally-appropriate information for Chinese-background clients.

In closing, I would like to thank the Australian Department of Health and Ageing Dementia Community Grants Program for their funding for the Chinese Dementia Awareness campaign. Without their support, the Chinese Community would not have the opportunity to be aware of Dementia. Thanks also go to Alzheimer’s Australia and Inner West Advisory Service (SSWAHS). My gratitude also goes to Australian Nursing Home Foundation for their unlimited support. I’d like to extend my heartfelt thanks to people with dementia and their carers for their stories. Without their support and patience, this handbook would not have been a success. It is also my sincere hope that handbook will be an invaluable resource for carers and friends of people with dementia.

Rebekah Kwan

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Chinese Dementia Awareness Program

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Living with Dementia



Carers Handbook

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