



IPF 護理者 的歷程

為您照顧您罹患特發性肺纖維化 (IPF)
的至親提供的貼心小貼士

簡介

照護 IPF 患者是一項重要且有意義的工作，但同時也充滿挑戰。作為護理者，意味著您要以熱情和善意照顧他人的健康和福祉。這也意味著您要關照您自己的情緒和身體需求。

本手冊將提供滿足這兩者需要的訣竅。

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關於 IPF 的 關鍵事實

定義特發性肺纖維化（即 IPF）



特發性
(Idiopathic)
是指疾病成因未知



肺部
(Pulmonary)
與肺部有關



纖維化
(Fibrosis)
指疤痕

換言之，某些未知來源的物質導致肺部產生疤痕。

您需要知道關於 IPF 的四件事情：

1

進展性:

IPF 會隨時間惡化。

2

無法預測性:

不同的人 IPF 惡化的速度不同。有些人會保持病情穩定，而其他人可能在沒有預警的情況下病情會快速惡化。

3

永久性:

IPF 會導致對肺部不可逆的損傷。

4

限制性:

瘢痕會使肺部難以擴張從而導致肺部無法吸入足夠的氧氣。

您作為護理者的 關鍵

作為支持者

作為 IPF 患者的護理者，您可在幾個關鍵領域為他們提供綜合照護。

- 因為您最了解您的摯愛，所以您是患者的最佳代言人，可以代其詢問困難的問題
- 您的一項工作是在適當的時機尋求適當的護理

鼓勵患者的獨立並維護患者的尊嚴

雖然這是一種很微妙的平衡，但是您還是要盡量讓患者保持獨立，即使您想要幫助您的摯愛。這對你們雙方都好。

給予鼓勵。

鼓勵患者任何微小的保持獨立性的努力

給予耐心。

讓您的摯愛自行完成事情，即使您可以更快地做完

尊重患者。

不要像對待孩子一樣對待您的摯愛



您的摯愛應該參與和她/他的護理有關的一切決定。尊重患者，並協助他們盡可能維護他們的自身控制感和隱私。



**仔細傾聽並關注您摯愛的
擔憂和顧慮**



**依照其意願協助他們；
包括其私人的事情，例如
穿衣和沐浴。除非患者要求，
請勿主動協助。**



理解您的患者。
請記住，患有進行性疾病的患者都會時時感到沮喪和無助。

情感支持和日常護理

保持聯絡

雖然您現在可能是患者/護理者的關係，但是如果您也是患者的妻子或是患者的丈夫，請您務必堅持做好您配偶的角色。

確保雙方皆未被孤立

關注讓彼此皆感到快樂的小事

如果您的摯愛因其疾病感到害怕或憂鬱，請提供情感支持

請記住:



將患者的所有醫生以及用藥清單保存在您便於找到的地方，例如貼在冰箱上，或存在您的手機內。

監測患者的病情

對您或您的摯愛來說，每天記錄病情會很有幫助。注意任何令人擔心的變化，並及時與其他醫療保健團隊聯繫。而且，您和您的摯愛都必須知道何時該致電醫生，其中包括：

- 呼吸困難加重時
- 咳嗽或胸痛加重時
- 鼻涕或痰帶血、有臭味或呈綠色或黃色時
- 腳踝或腳部腫脹
- 疲倦感加重
- 發燒
- 食慾不振
- 肌肉痙攣或無力
- 呼吸困難／急促造成睡眠中斷

管理患者的作息時間

另一個重要的護理層面是幫助安排您摯愛的每日作息時間：

- 確保患者按指示醫囑服用藥物
- 在藥物用罄之前補充處方藥物
- 協助安排醫療約診
- 安排到醫生診所和實驗室就診的交通

姑息護理

姑息護理是指對像 IPF 一類進行性疾病的相關症狀和心理壓力所進行的治療和護理。

姑息護理的目標不同於臨終關懷，是為了改善或維持患者的生活品質。

姑息護理的一些例子包括：



用藥以協助解決特定症狀



氧氣治療以緩解氣短／呼吸急促並改善睡眠



其他干預方式以幫助患者減輕壓力、憂鬱和疼痛

姑息護理是 IPF 支持療法的關鍵部分，可被您的醫生和保險公司視為「**例行醫療管理**」。



IPF 病情的發展可能增加氧氣的使用

隨著呼吸困難且氧氣使用增加，**您的摯愛可能**需要更高層級的照護。

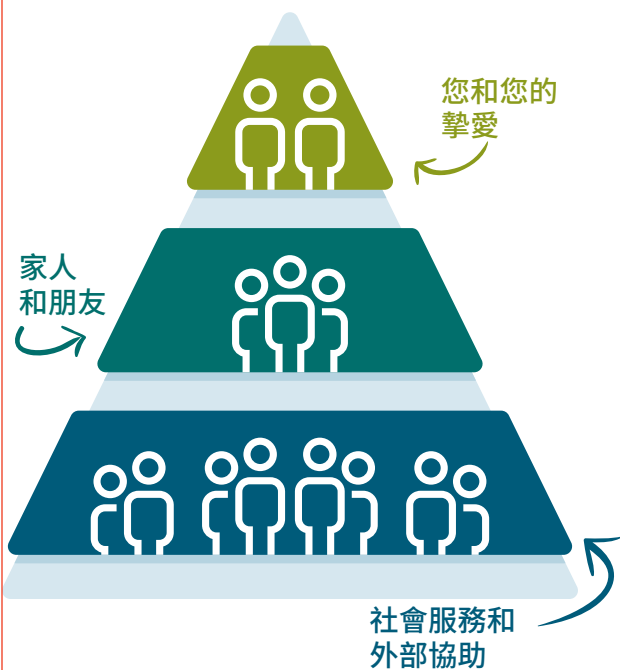
- 您的摯愛在疾病「早期」可能無須補充氧氣
- 隨著病情的發展，您的摯愛可能在活動時需要氧氣（但在休息時不需要）
- 最終您的摯愛在活動期間、休息時或睡眠中可能需要持續使用氧氣
- 如果您的摯愛需要高流速氧氣或者可攜式濃縮氧氣輸送系統不再滿足需要，他們可能需要更高級別的氧氣補充

氧氣: 考量重點

- 指導文件建議一旦血氧濃度降至 88% 或更低時即開始接受氧氣治療。若血氧濃度在 88% 以上，聯邦醫療保險 (Medicare) 及其他保險公司將不會承保氧氣治療，因此應確認低血氧濃度並記錄
- 用氧應有醫生的書面處方
- 氧氣處方也可通過步行測試決定

獲得 您需要的支援

一般而言，護理人員得到外界的幫助時，他們的壓力會減少。試圖親力親為承擔所有的照顧事項對護理者和被護理者都不是最好的情況。因此，請護理者不吝於尋求協助。



把照護想成是金字塔。

您和您的摯愛最重要，位在頂端。下一級是希望幫助您的家人和朋友。第三級是社會服務和外部協助。

護理決定可能是艱難的

您最重要的角色之一就是對您摯愛的健康相關事宜做決定。請您盡可能地讓您的摯愛參與決策。雖然參考醫生和家人的意見會有幫助，但最終，您應該做出符合摯愛意願的決策。

分小步解決事情會更容易。有時候我們把大事情或是很艱難的決定分步驟有條理地解決會對我們有幫助：

步驟 1

確定特定目標

步驟 2

取得資訊

步驟 3

尋找替代方案

步驟 4

制定計劃

步驟 5

留一段時間看您的決定是否可行

步驟 6

評估效果是否良好

要求家人和朋友協助

當您需要休息時，請家人或朋友替代您會有以下好處：

- 您的摯愛將會更加自在，因為照顧他們的是其認識的人
- 將患者留給您認識的人照顧您會比較放心
- 朋友和家人可能更熟悉患者的日常起居和偏好
- 您可以省去安排外部照護的費用和困難

與其他友善的人在一起可以幫助您的摯愛減少被孤立的感覺

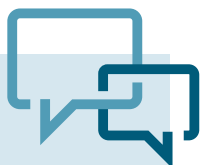




如何尋求您需要的協助

做好準備。

當人們詢問他們如何協助時，
您可以提供清單



具體說明。

「您能否在週一陪我爸爸去呼
吸治療的約診？」

態度誠懇。

「我真的很感激您為我媽媽採
買日常用品。」

提供選擇。

「我需要去取 Bob 叔叔的處
方箋。您是否可以幫我去取
藥，或者我去取藥的時候您
可以陪著 Bob 叔叔？」

社會服務和外部協助

居家醫護助理員

居家醫護助理員 (HHA) 受過訓練，能夠居家護理患者，並提供日常照護，例如：



| 清洗和穿衣



| 準備三餐



| 幫助您的摯愛如廁



| 簡單的家務服務

大部分 HHA 都在居家照護的機構登記且受僱於這些機構，並接受培訓。一定要確認居家護理機構和 HHA 有註冊記錄。若您沒有通過代理機構雇用 HHA，請檢查 HHA 是否有完整的保險，並是否可提供推薦人給您。

考量您需要 HHA 的頻率，以及每次需要的服務時間應為多久。例如，您的摯愛每天早上可能需要居家協助，一週幾次，是否有時候需要過夜服務等。

支付居家醫護助理員費用

- 聯邦醫療保險 (Medicare) 有時會承保出院後或復健出院後數週的 HHA 費用
- 您所在州的老人部門可能可以支付長期照護
- 否則可能需要使用私人資金



請記住:

可能會有福利協助支付這些服務費用。

其他類型的 專業協助



喘息服務

喘息服務為一項短期全職照護，可讓您從日復一日的照護中得到喘息機會。當您沒空時，家裡通常是讓摯愛感覺最舒適的地方。通常，最簡單的解決方案是請您的 HHA 提供喘息服務。

您可能可以取得免費服務，例如交通、居家照護與維護，以及家庭支援。您可以聯繫當地的政府辦公室、志願者組織和老人服務機構，瞭解您的社區可能提供哪些免費服務和幫助。



成人日間照護

成人日間照護中心提供**居家以外的監護**，所以您的摯愛可與更多的人互動、結交新朋友、參與活動，從而比較不會感覺被孤立。



住宿全托照護

另一個選項是讓您照顧的患者短期居住在**安養設施**或專業護理機構中。這樣您的患者隨時可以得到及時的護理和幫助，您也可以放心。

護理者的 支援團體

這是瞭解更多有關 IPF 的資訊，尋求建議，並找到資源的有用途徑

雖然護理 IPF 患者可以讓您感到滿足和有成就感，但是也可能消耗您的體力和心力。此外，這是一個通常很孤獨且孤立的角色。護理者的支持團體可以：

- 協助確認並驗證您的經驗
- 幫助您聯繫有相似護理經歷的其他人
- 讓您能夠分享關於照護 IPF 患者的（正面和負面）感受

面對面、電話或線上會面



尋找支援團體

線上搜尋當地團體

肺纖維化基金會 (pulmonaryfibrosis.org)
根據不同的州分別列出了 IPF 支持小組

Inspire.com 有「照顧肺纖維化」社羣

聯絡其他國內組織（請參閱第 32 頁所列的機構），與當地社團聯絡

請您的醫療專業人員或當地社會服務部門
建議團體

精神和宗教組織有以信仰為主的支援計劃

照顧您自己

保留「私人」時間

當您照顧某人時，您可能認為您的自身需求並非最優先。或者，您可能會覺得自己已經完全浸入至護理者的角色中，而這個角色不再讓您擁有任何自我的時間。**令人驚訝的是，相反的方法才更有效。**

照顧您自己的需求和想法，可以提供您繼續護理 IPF 患者所需要的動力。以下是您可以自我調適的一些方式。

自我調整。

- 雖然看起來可能很明顯，但其實您很容易過度疲倦。若您過度疲倦，您很有可能做出不明智的決定或對其他人發洩您的沮喪

花時間參加您覺得能放鬆自己的活動或愛好。

- 高品質的獨處時間可幫助您感覺煥然一新
- 冥想和瑜珈可幫助您找到情緒平衡
- 每日運動將有助於您保持良好的身心狀態



提醒自己休息和充電

請勿一切都自己做

請家人和朋友幫助各種工作，如準備餐點

如有需要，僱用居家醫護助理員

度假時使用護理之家或安養設施服務
護理患者

鼓勵患者參與成人日間照護

對於全職照護，護理之家或安養院可能是
患者的最佳選擇

每個人都會經歷 生命逝去的悲傷

悲傷是一種感受，並且因人而異。當您得知自己的摯愛罹患 IPF 時，您可能會感到特別難過；之後當您意識到您和您的摯愛可能正在渡過她/他生命中的最後時光，尤其是生日和節日的時候，您可能會更加悲傷。這種悲傷的情緒對您和您的患者都很正常。

雖然您無法避免憂傷的情緒，但是以下這些建議可能有助於讓您感覺好一些：

獨處會有幫助

有時您可能會感到極度悲傷。您可能想獨自一人或哭，或睡，或散散步，或靜靜地坐一會。這種時候請您不要感覺愧疚。

造訪家人和朋友

接受邀請，並與您喜歡和在意的人待在一起。如果您感到沮喪，請您向您親密的人訴說或尋求幫助。

充分休息

照顧重病患者會讓您疲累。您要給自己時間休息和恢復自己的體力和心力。

作息規律

雖然您的生活因為照護 IPF 患者已產生變化，但是仍請您試著保持有規律的作息、健康飲食、堅持運動和有規律的睡眠。

知道自己何時需要幫助

若您感覺極度抑鬱或焦慮，您可能需要尋求專業治療師的協助。

為未來做 準備

生前遺囑

許多成人都有生前遺囑或預設醫療指示，詳細說明在其無法正常溝通時其希望接受的醫療照護方式

您所在州的立法可能定義生前遺囑生效日期，以及可能限制使用相關的醫療干預方式

請務必與律師討論您所在州的前遺囑的相關法律

POLST 表格

- POLST 是「維持生命治療醫囑 (Physician Orders for Life-Sustaining Treatment)」的縮寫
- 這是一份簡短的文件，在緊急情況下向醫療保健提供者提供醫囑
- 不同州有不同的 POLST 表格，但其中的重要資訊相似
- POLST 表格必須由主治醫生或其他醫生簽署，方可合法有效



永久生存信託授權書 (Power of Attorney, POA)

- 務必請您的摯愛考慮簽署永久生存信託授權書文件或選擇醫療照護代理人。當您的摯愛不再能自主做出醫療決策時，此人會代其做出醫療決策
- 大多數人會指定一位密友、家庭成員、牧師或律師做為自己的醫療照護代理人。
- 指定人員應能夠支持您摯愛的決定，瞭解其治療選擇，並知道他們的意願



請記住:

鼓勵您的摯愛與律師及其醫生討論所有這些文件。

談論 生命終止規劃

這是重要的對話

建立生命終止或預立醫療自主計劃可能很困難，因為這意味著承認您摯愛的健康正在惡化。**但是，清楚了解您摯愛的意願也能讓雙方都感到安心。**如果發生緊急事件，您不用去猜想您摯愛的選擇。

- 因為這些對話可能很困難，有些人覺得改成「如果」的假設問句會更容易破冰（例如，「如果其他人需要代表您發言，該怎麼辦？」）
- 您會想與您的摯愛和其醫生討論惡化症狀如何顯示 IPF 惡化，以及如何影響治療計畫
- 確保您的摯愛理解他們始終可以修改其計劃，但是他們要務必先制定好初步計劃

以書面方式為證

預立醫療自主計劃應以書面形式提供並包含以下要點:

如果患者病重，請指定一人代表她/他全權做決定

決定在緊急情況下該怎麼做

可接受的治療選擇和醫療干預

使用呼吸器、復甦裝置或餵食管的時間限制

建立 預立醫療自主計劃

完整合法的預立醫療自主計劃應包含以下功能：

指定醫療保健代理人
(即已獲得決策權限的人士)

列出常規和緊急醫療救助時可接受的治療和醫療干預

可提供給在您摯愛的家中、護理之家或醫院的任何護理者

請律師審查

預立醫療自主計劃應由律師審查，以確保遵守您摯愛的意願，且文件合法並具有約束力。律師也能視您摯愛的需求，提供遺囑、壽險保單以及其他財務事項的協助。

安寧照護 / 臨終關懷

隨著 IPF 惡化，您的摯愛可能想進入安寧照護，以接受生命終止舒緩醫療照護和對患者和其家人的支持。大部分時間安寧照護會在患者家裡，但住院安寧照護也可作為一種選擇。

聯邦醫療保險為多數 IPF 患者提供安寧照護作為關鍵福利。州醫療輔助計劃 (Medicaid) 與大部分私人健康保險計畫也會在不同範圍內承保安寧福利。



請記住:

有關承保範圍，請諮詢您的保險公司。

實用資源

線上支援

美國退休人員協會(AARP)*

aarp.org/caregiving

美國肺臟協會*

Lung.org

呼吸急促 IPF

BreathlessIPF.com

關愛橋樑*†

caringbridge.org

護理者聯盟

caregiver.org

Inspire.com (關懷 PF 社羣) *

Inspire.com

Lotsa 幫手*†

lotsahelpinghands.com

Lungs and You™

lungsandyou.com

肺纖維化基金會 (PFF)*

Pulmonaryfibrosis.org ; 1-888-733-6741

肺纖維化醫生*

pulmonaryfibrosismd.com

VA 護理者支援組織

www.caregiver.va.gov





智能應用程式

Carezone*

提供被護理者的照護資料。包括一份您和家人/朋友共享的任務清單和期刊。也可提供藥物追蹤和檔案共用服務。**免費供 iPhone、iPad、Android 系統使用**；carezone.com



Cozi*

管理家庭時間表、組織購物/待辦事項清單、計畫餐點，並設定提醒。**免費供 iPhone、Android、Blackberry、Windows 8.1 系統使用**

Finovera*

記錄每月帳單和銀行帳戶，包括公司網站上的付款提醒和帳單檢索。**免費供 iPhone 和 Android 系統使用**

MediSafe*

安全地記錄多種藥物服用，設定提醒，並建立您的摯愛服藥追蹤記錄報告。**免費供 iPhone 和 Android 系統使用**

*這些是第三方資源，Boehringer Ingelheim 不擁有、不管理，不背書第三方資源。

†這些網站也有智能應用程式。

實用資源

給護理者的書籍

護理者生存手冊

作者：*Alexis Abramson* 博士

這本書提供可靠和實用的指導，幫助您獲得協助、促進獨立生活，並平衡您自我時間和資源。



這裡沒有聖徒：

看護者的日常

作者：*Susan Allen Toth*

這是一本親歷者描述如何面對護理患病摯愛的挑戰之真實自白

人妻護理者手冊：

照顧您的重病丈夫，關愛您自己

作者：*Diana B. Denholm*

這本書提供了6名人妻護理者的親身歷程，以及生存訣竅和個人軼事

老年人照護協助:

涵蓋健康、財務與法律考量的實用指南

作者：Sandy Myerson

這本書以系統的、邏輯的風格提供了護理日漸衰老的父母的簡潔實用指南。

照顧您準備好了嗎？

作者：Charles Puchta

這本書提供了清晰、公正的資訊和見解，以幫助護理者和被護理者做出明智的決定。

他們也是您的父母！

孩子們如何與日漸衰老的父母和諧共同生活

作者：Francine Russo

這是一本有關護理的心理和實踐導引。

您已經擔任 重要的角色。

在照顧您的摯愛時，請務必妥善照顧自己。

關於 IPF 的啟發和資訊，
請造訪網址：LungsandYou.com





The Caregiver's Journey in IPF

Helpful tips for the road ahead as you begin caring for your loved one with idiopathic pulmonary fibrosis (IPF)

Introduction

Caring for someone with IPF is an important and gratifying job, but it can also be very challenging. Being a caregiver means caring for the health and welfare of another person with compassion and kindness. It also means tending to your own emotional and physical needs. **This booklet will provide tips for both.**

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Key facts about IPF

Defining idiopathic pulmonary fibrosis, or IPF



Idiopathic
(ID-ee-oh-PATH-ik)
means that the cause of
the disease is unknown



Pulmonary
(PUHL-mon-air-ee)
refers to the lungs



Fibrosis
(fye-BRO-sis)
means scarring

In other words, something of unknown origin is causing the lungs to become scarred.

Four things you need to know about IPF:

1

Progressive:

IPF worsens over time.

2

Unpredictable:

IPF progresses at different rates for different people. Some will remain stable while others may worsen rapidly without warning.

3

Permanent:

IPF causes irreversible damage to the lungs.

4

Restrictive:

The scarring makes it hard for the lungs to expand and inhale enough oxygen.

Your role as caregiver is essential

Be an advocate

As a caregiver for someone with IPF, you support comprehensive care for them in several key areas.

- You know your loved one best, which means you are in the best position to speak up on their behalf, and to ask the difficult questions
- One of your jobs is to seek out the appropriate care—at the appropriate time

Encourage independence and preserve dignity

It's a delicate balancing act, but as much as you may want to help your loved one, you want them to be as independent as possible. It's good for both of you.

Be nurturing.


Encourage any effort at independence, no matter how small

Be patient.

Even if you can do something faster, let your loved one take care of it

Be respectful.

Don't treat your loved one like a child



Your loved one should be included in all decisions regarding their care. Treat them with respect, and help them maintain a sense of control and privacy whenever possible.



Listen closely and pay attention to your loved one's worries and concerns



Provide help on their terms; tasks like dressing and bathing are personal and private—don't help unless requested



Be understanding. Keep in mind that anyone with a progressive disease may be frustrated at times

Emotional support and day-to-day care

Staying connected

While you may now have a patient/caregiver relationship, the roles you had before are still important. If you are a wife caring for your husband or vice versa, it's important that you continue to relate as spouses.

Make sure neither of you
become isolated

Try to pay attention to little things
that bring each of you pleasure

Offer emotional support if your loved
one feels afraid or depressed about
their disease



Remember:

Keep a list of all the patient's doctors and a list of medications where you can find it easily, such as on the refrigerator or on your phone.

Monitor their condition

It can be very helpful for you or your loved one to keep a daily log of their condition. Note any worrisome changes and share with the rest of the healthcare team. To that end, it's essential that both you and your loved one know when to call the doctor, including for:

- Increasingly difficult breathing
- Increased coughing or chest pain
- Mucus that is bloody, has an odor, or is green or yellow
- Swollen ankles or feet
- Increased fatigue
- Fever
- Loss of appetite
- Muscle cramps or weakness
- Shortness of breath that interrupts sleep

Manage their schedule

Another important aspect of caregiving is to help guide your loved one's daily schedule:

- Make sure medications are taken as directed
- Refill prescriptions before the medications run out
- Help with scheduling medical appointments
- Arrange transportation to doctors and lab visits

Palliative care

Palliative care is a general term used to describe the treatment of symptoms and stress associated with a progressive disease like IPF. **The goal of palliative care, which is not to be confused with hospice, is to improve or maintain a patient's quality of life.** Some examples of palliative care include:



Medications to help address specific symptoms



Oxygen therapy to relieve shortness of breath and improve sleep



Interventions that can help reduce stress, depression, and pain

Palliative care is considered a key component in IPF supportive treatment and may be considered **“routine medical management”** by your doctor and insurance provider.



Oxygen use may increase with IPF progression

As breathing becomes more difficult and oxygen use increases, **your loved one may require a higher level of care.**

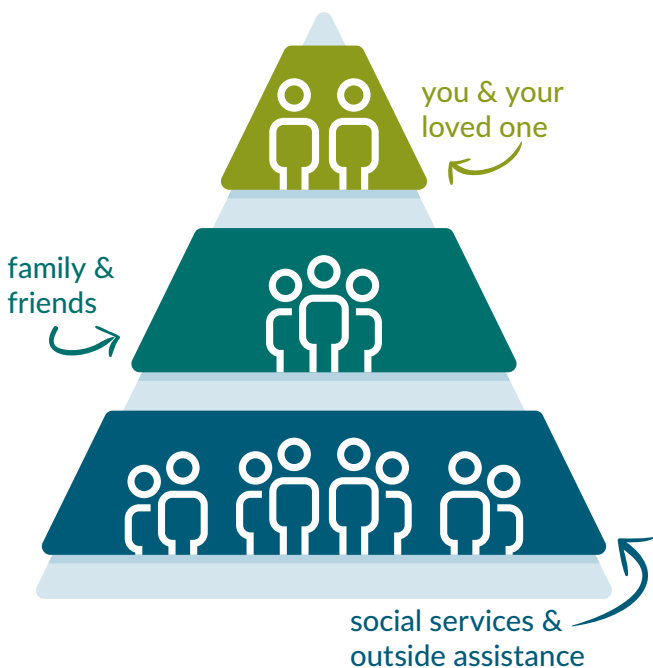
- When your loved one is “early” in their disease, no supplemental oxygen may be needed
- As they progress, they may need oxygen with activity, but not when at rest
- Eventually, constant oxygen use might be needed during activity, when your loved one is at rest, or asleep
- Advanced oxygen supplementation might be necessary if your loved one needs high-flow oxygen or the portable concentrator delivery system is insufficient

Oxygen: Points to consider

- Guidelines recommend starting oxygen therapy when blood levels fall to 88% or less. Medicare and other insurers won’t cover oxygen if blood levels are over 88%, so low oxygen levels must be verified and documented
- Oxygen is written as a prescription by a doctor
- A prescription for oxygen may also be determined by a walk test

Getting the support you need

In general, caregivers have less stress when they have help. Trying to be responsible for all of the caregiving by yourself is not best for you or the person you are caring for, so don't hesitate to ask for help.



Think of caregiving as a pyramid.

You and your loved one are at the top. The next level is family and friends who want to help you. The third level is social services and outside assistance.

Caregiving decisions can be stressful

One of your most important roles will be making decisions regarding your loved one's health. **Be sure to include your loved one whenever possible.** Getting input from doctors and family members is helpful, but ultimately, you should be making decisions that are aligned with your loved one's wishes.

Smaller steps make it easier. **Sometimes it helps to approach a big and potentially overwhelming decision by breaking it down:**

Step 1

Identify a specific goal

Step 2

Get information

Step 3

Find alternatives

Step 4

Make a plan

Step 5

Give your decision time to work

Step 6

Evaluate how well it's working

Asking family and friends for help

When you need a break, asking family or friends to pitch in can be beneficial:

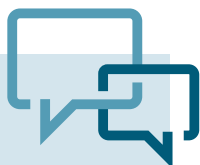
- Your loved one will be more comfortable being cared for by someone they know
- You will feel better leaving them with someone you know
- Friends and family members may be more familiar with routines and preferences
- You can avoid the cost and difficulty of arranging for outside care

Being around other friendly faces can help your loved one feel less isolated





How to ask for the help you need



Be prepared.

Have a list ready when people ask how they can help

Be specific.

“Could you take Dad to his respiratory therapy appointments on Mondays?”

Be positive.

“I really appreciate it when you get groceries for Mom.”

Offer choices.

“I need to get Uncle Bob’s prescriptions. Could you pick them up or stay with him while I go?”

Social services and outside assistance

Home health aides

A home health aide (HHA) is trained to help people in their own home and can provide daily care such as:



Washing
and dressing



Fixing
meals



Helping your loved
one to the bathroom



Light
housekeeping

Most HHAs are registered with home care agencies that recruit and train their staff. Always make sure that both the agency and the HHA are registered. If you do not hire an HHA through an agency, check that the HHA is fully insured and can provide you with references.

Consider how often you want an HHA and how long each visit should be. For example, your loved one may require at-home assistance every morning, several times a week, or sometimes overnight.

Paying for a home health aide

- Medicare will sometimes cover HHA costs for a few weeks after a hospital or rehab discharge
- Your state Department of Aging may pay for extended care
- Otherwise, private funds would need to be used



Remember:

There may be assistance to help pay for these services.

Other types of professional help



Respite care

Respite care is full-time care for a short period, providing you with a respite from day-in and day-out caregiving. Home is usually the most comfortable place for your loved one to stay when you are unavailable. Often, the simplest solution is to ask your HHA if they can provide respite care.

You may be able to access free services, such as transportation, home care and maintenance, and home support. Check with your local government offices, volunteer organizations, and senior services to see what may be available in your community.



Adult daycare

Adult daycare centers provide **supervised care outside the home**, so your loved one can interact with new people, make friends, participate in activities, and feel less isolated.



Residential care

Another option is to have the person you are caring for stay for a **short time in an assisted living facility** or skilled nursing facility. This way you can relax, knowing that appropriate care will be available as needed.

Caregiver support groups

A helpful way to learn more about IPF, ask for advice, and find resources

While being a caregiver can be a rewarding and gratifying experience, it can also be both physically and emotionally draining. In addition, it is a role that is often lonely and isolating. Caregiver support groups can:

- Help to reassure and validate your experiences
- Help you connect with others who are in a similar place
- Empower you to share your feelings—both positive and negative—about caring for someone with IPF

Meet in person, by phone, or online



Finding a support group

Do an online search for local groups

The Pulmonary Fibrosis Foundation (pulmonaryfibrosis.org) lists IPF support groups by state

Inspire.com has a “Caring for Pulmonary Fibrosis” community

Contact national organizations (see those listed on page 32), to connect with a local chapter

Ask your healthcare professional or local Department of Social Services to suggest groups

Spiritual and religious organizations have faith-based support programs

Caring for YOU

Taking some “me” time

When you are caring for someone, you may think that your needs are not the top priority. Or, you may feel that you’ve immersed yourself so fully into your caregiver role that there’s no longer any time for you. **Surprisingly, the reverse approach is more effective.**

Caring for your own needs and desires can give you the strength you need to carry on. Below are some ways you can take care of yourself.

Pace yourself.

- It may seem obvious, but it’s easy to become overly tired. If you become too tired, you’re more likely to make poor decisions or to take out your frustrations on others

Make time to enjoy activities or hobbies that you find relaxing.

- Quality time alone can help you feel refreshed
- Meditation and yoga can help you find emotional balance
- Daily exercise will help you stay in shape, both physically and emotionally



Rest and renewal reminders

Do not do everything yourself

Ask family members and friends to help with various tasks such as preparing meals

Get an HHA when you need support

Use a nursing home or assisted living facility for vacations

Encourage adult daycare attendance

For full-time care, nursing homes or assisted living facilities may be the best options

Everyone experiences grief

Grief is a process, and it's different for everyone. It may first hit you when you learn your loved one has IPF, and later as you realize you are likely spending some of your final days together. Birthdays and holidays may be especially hard—and it's normal for both you and the person you are caring for to feel sad.

Although you cannot avoid your gloomy feelings, here are some suggestions that may help you feel better:

Being alone helps

There may be times when you feel overwhelmed with grief. You may want to cry, sleep, go for a walk, or sit quietly. Do not feel guilty about needing to be alone.

See family and friends

Accept invitations and spend time with those you love and care about. Reach out to someone close if you're feeling down.

Get plenty of rest

Caring for a seriously ill person is tiring. Take time to rest and regain your physical and mental energy.

Stick to a routine

Even though your life has changed, try to stick to a routine of healthy eating, exercise, and regular sleeping.

Learn when to get help

If you are feeling extremely depressed or anxious, you may want to seek help from a professional therapist.

Preparing for the future

Living will

Many adults have a living will or an advance directive, which details the medical care they would want to receive if they become unable to communicate

State laws may define when a living will goes into effect and may restrict the medical interventions to which it applies

Be sure to speak with a lawyer about the living will laws in your state

POLST form

- POLST is an acronym for “Physician Orders for Life-Sustaining Treatment”
- It is a short document that provides medical orders to healthcare providers in an emergency
- POLST forms vary from state to state, but the key information is similar
- The POLST form must be signed by the primary physician or another doctor to be legally valid



Durable Healthcare Power of Attorney (POA)

- It's also important for your loved one to consider signing a Durable Healthcare Power of Attorney document or select a healthcare proxy. This is the person who makes medical decisions when your loved one is no longer able to do so
- Most people appoint a close friend, family member, minister, or lawyer
- The designated person should be able to support your loved one's decisions, understand their treatment choices, and know what they want



Remember:

Encourage your loved one to speak with an attorney and their physician about all these documents.

Talking about end-of-life planning

It's an important conversation

Creating end-of-life or advance care plans may be difficult because it means admitting that your loved one's health is declining.

However, having a clear idea of their wishes can also bring peace of mind to both of you. You won't be left guessing what they would prefer if an emergency occurs.

- Since these conversations can be difficult, some people find it easier to break the ice with “what if” questions (eg, “What if someone else needs to speak on your behalf?”)
- You will want to talk to your loved one and their doctor about how worsening symptoms may indicate IPF progression, and how that may affect treatment planning
- Make sure your loved one understands they can always revise their plan, but it's important to have an initial plan in place

Put it in writing

Advance directives should be in written form. Some of the topics that should be addressed include:

Naming a person who has the authority to make decisions if they are too sick

Deciding what to do in an emergency

Acceptable treatment options and medical interventions

Time limits for use of ventilators, resuscitation devices, or feeding tubes

Creating an advance care plan

The completed advance care plan should:

Name the healthcare proxy
(ie, the person who has been granted decision-making authority)

Provide acceptable treatments and medical interventions in both routine and emergency medical settings

Be available to any caregiver in your loved one's home, nursing home, or hospital

Ask an attorney to review

Advance care plans should be reviewed by an attorney to ensure your loved one's wishes will be followed and that the documents are legal and binding. A lawyer may also be able to assist with wills, life insurance policies, and other financial matters depending on your loved one's needs.

Hospice care

As IPF progresses, your loved one may want to enter hospice care, which offers end-of-life comfort care and support for patients and their families. Most of the time, hospice care is provided at home, but inpatient hospice may also be an option.

Medicare offers hospice care as a key benefit for most people with IPF. State Medicaid programs include hospice benefits, as do most private health insurance plans, although coverage varies.



Remember:

Check with your insurance provider for coverage information.

Helpful Resources

Online support

**American Association
of Retired Persons (AARP)***
aarp.org/caregiving



American Lung Association*
Lung.org

BreathlessIPF
BreathlessIPF.com

Caring Bridge*†
caringbridge.org

Family Caregiver Alliance
caregiver.org

Inspire.com (Caring for PF community)*
Inspire.com

Lotsa Helping Hands*†
lotsahelpinghands.com

Lungs and You™
lungsandyou.com

Pulmonary Fibrosis Foundation (PFF)*
Pulmonaryfibrosis.org; 1-888-733-6741

Pulmonary Fibrosis M.D.*
pulmonaryfibrosismd.com

VA Caregiver Support
www.caregiver.va.gov



Mobile apps

Carezone*

A care profile for the person receiving care. Includes a task list and journal that you can share with family/friend helpers. Medication tracking and file sharing services are also available. **Free for iPhone, iPad, and Android; carezone.com**



Cozi*

Manage the family schedule, organize shopping/to-do lists, plan meals, and set reminders. **Free for iPhone, Android, Blackberry, Windows 8.1**

Finovera*

Keep track of monthly bills and bank accounts. Includes payment reminders and bill retrieval from company Web sites. **Free for iPhone and Android**

MediSafe*

Securely keep track of multiple medications, set reminders, and create reports about how well your loved one sticks to their regimen. **Free for iPhone and Android**

*These are third-party resources that are not owned, managed, or endorsed by Boehringer Ingelheim.

†These websites have mobile apps as well.

Helpful Resources

Books for caregivers

The Caregiver's Survival Handbook

by Alexis Abramson, PhD

A supportive, reassuring, and practical guide to getting help, fostering independence, and balancing the demands on your own time and resources.

No Saints Around Here: A Caregiver's Days

by Susan Allen Toth

An intimate account of the realities of meeting the challenges of caring for a loved one.

The Caregiving Wife's Handbook: Caring for Your Seriously Ill Husband, Caring for Yourself

by Diana B. Denholm

Profiles of 6 women in caregiving situations who offer survival tips and personal anecdotes.



**Elder Care Assistance:
A Practical Guide Covering Health,
Financial and Legal Considerations**

by Sandy Myerson

A concise, straightforward guide to caregiving for aging parents, written in a systematic, logical format.

CAREGIVING Ready or Not

by Charles Puchta

Clear, unbiased information and insight to help caregivers and care receivers make informed decisions.

**They're Your Parents, Too!:
How Siblings Can Survive Their Parents'
Aging Without Driving Each Other Crazy**

by Francine Russo

A psychological and practical roadmap through caregiving.

You've taken on a big role.

Caregiving is an important responsibility.
Be sure to take good care of yourself
while taking care of your loved one.

For inspiration and information
about IPF, visit LungsandYou.com



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