

生命的終點

本情況說明書介紹生命接近終點時會發生的情況以及如何作相應的計畫。

本資料告訴您，若在家接受照料有誰可以幫助您，以及在您生命的最後幾個星期和最後幾天會發生什麼。另外還包括了為您的親屬和好友提供的資訊，讓他們知道在您過世之後應該做哪些事。您或許也想閱讀這部分內容。

您可能會發現閱讀其中一些內容時會讓您感到沮喪難過。讓您的一位近親、好友或專業醫護人員也閱讀這些內容。他們可以給您援助，你們可以一起討論相關內容。

我們希望本資料可解答您的問題。若您還有其他問題，請詢問您的醫生或護士。

我們還在本資料的末尾列出了來自麥克米倫的其他有用資訊。這些資訊大多數只有英文版本。若您想用母語跟我們的癌症支援專員談話，我們有專為非英語人士安排的口譯員。

週一至週五上午9時至晚上8時，您可以免費致電英國麥克米倫癌症援助熱線(Macmillan Support Line)：0808 808 00 00。若您有聽力方面的困難，可使用我們的文本電話 0808 808 0121 或文字中轉。也可以造訪網站 macmillan.org.uk

本資料內容

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您可能會有什麼感覺

當聽到自己的生命即將結束的消息時，您可能會非常難過。您可能會有許多不同的感覺。您可能會覺得所發生的事情太不公平。您可能會對以後的事感到恐懼。您也可能會以淚洗面，感到悲傷，不知該如何應對這些感覺。

把自己的感受告訴家人和朋友可能會有所幫助。您也可以向您的醫生、護士傾訴，或者向一位麥克米倫的癌症支援專員傾訴。

您可能會在某些日子裡感覺良好，在某些日子裡感覺比較乏力。對許多人而言，在感覺良好的時候提前做好計畫和充實度日非常重要。您也許希望為家人或朋友做些美好的事情。您也許還想做一些重要的事，例如訂立遺囑或計畫葬禮。

宗教和靈性 在生命接近終點時，人們往往會對宗教信仰或靈性的感覺更有感悟。篤信宗教的人往往會發現這非常有幫助。其他人可能會質疑自己的信仰，或者開始思考死後是否有來生。

有些人在祈禱或冥想中尋得安慰。許多人發現，知道別人在為他們祈禱很有幫助。

即使您不確定自己信奉什麼，也可以與教士、牧師、神父、法師或者其他宗教團體領袖交談。靈性團體和宗教團體的領袖都有助人的習慣，您可以尋得內心的寧靜。

提前計畫

訂立遺囑 若您尚未訂立遺囑，那麼您應該去做這件重要的事。若要確保您的財物和財產歸於您指定的人，立遺囑就是唯一的方法。

您的遺囑是一種法律文書，必須正確撰寫。通常最好是聘請律師來幫您寫遺囑。他們會確保您的意願清楚明確，並且如您希望的那樣得到執行。若您需要有人幫您找律師，可聯繫律師公會（見本資料末尾）。

籌畫您的葬禮 您也許想籌畫自己的葬禮。您可以考慮採取土葬還是火葬，要哪一種儀式，用什麼歌曲，穿哪些衣服。

與家人和朋友談談您的葬禮願望很有幫助。他們也可以得知您的想法，這有助於他們向您告別。當您決定您的想法之後，將您的願望寫下來，好讓家人和朋友執行。

誰能在家中照料您

照料的工作可能會很艱難，所以您和您的照料者都要獲得所需的支援，這一點很重要。有很多人可以幫助您。

您的家庭醫生

您在家期間，由您的家庭醫生(GP)負責您的醫療護理。遇到以下情況時，他們可以幫助您：

- 您擔心自己的症狀有變化
- 您在自己的狀況變得較差時想談談可能會發生什麼事
- 您需要瞭解在家裡如何獲得護理照料或其他幫助

地區護士

地區護士(DN)與家庭醫生密切配合工作。他們會上門探訪，安排您的護理需求。他們可以在以下方面幫助您：

- 安排您的護理——若您需要其他人的幫助，您的地區護士可以聯繫他們
- 留意您可能會出現的症狀，並給予治療
- 幫您打針和換藥
- 針對如何止住皮膚疼痛提供建議
- 針對如廁問題（例如失禁和便秘）提供建議
- 提供幫您止住皮膚疼痛的裝備（例如椅墊或特別的床褥），或提供便桶、尿壺或便盆。
- 向您的親屬或照料者示範如何移動您和照料您。

地區護士通常跟安寧療護專科護士配合工作（見第 00-00 頁）。他們可以支援您和您的照料者，好讓您可以留在家中。

Marie Curie Nursing Service 「瑪麗·居裡護理服務」

瑪麗·居裡護理服務的護士為生命接近終點的人提供關懷和照顧。他們上門探訪，可提供過夜照顧或白天部分時間照顧。這使您的照料者可以在夜裡好好睡眠，或者可以在白天稍作休息。這些護士也能幫助您應對自己的感受。

瑪麗·居裡護理服務的護士是免費服務的。但是在安排護士的頻度上，通常有所限制。您的地區護士或家庭醫生會為您安排一名來自瑪麗·居裡護理服務的護士。

社區安寧療護專業團隊

他們是專科護士和醫生。他們為面對癌症之類疾病的患者及其家屬提供支援。

若您需要專業支援或護理，例如您出現了需要協助處理的症狀，那麼您可能會被轉介給一個專業安寧療護團隊。他們可以上門探訪您。

居家臨終關懷護理團隊

若您希望在家中離世，有些臨終關懷醫療機構可以安排護士和照料者在您家裡幫忙照料您。這種照料通常是在您生命的最後幾個星期提供的。您的社區安寧護理專科護士會為您安排這種照料。

社會工作者/護理主管

社會工作者可以組織安排家務、購物和烹飪方面的協助，或者安排人來幫忙清洗、穿衣等。若您需要這類幫助，他們可以安排人來為您做這些事情。您或您的醫生或地區護士可以聯繫社會工作者，請他們來照顧您的需要。若您能承擔得起，您可能被要求支付這類幫助所需的費用。

職業治療師

職業治療師能為您提供裝備來幫助您活動以及讓您能夠自己做一些事情。他們會上門探訪，看看您需要什麼裝備。其中可能包括樓梯欄杆、扶手以及用於淋浴或坐浴的裝備。

職業治療師還可以提供有關某些小物品及其購買地點的建議。例如，雙柄口杯和特別餐具之類的物品。

若您需要幫助，您的護士或醫生可向您介紹其他人。他們還會告訴您在當地可以獲得哪些類型的幫助。

生命的最後幾個星期

在生命的最後幾個星期裡，您可能會意識到以下一些變化。

情緒變化

您可能會產生不同的情緒，包括擔憂、焦慮、恐慌、憤怒、悲傷和抑鬱。在面對死亡時感到擔憂或焦慮很正常。與家人或護士交談可能有助於讓您感覺好一些。有些人比較願意跟自己不認識的人交談，例如諮詢師。您的醫生或護士可以幫您介紹一位諮詢師。

身體變化和症狀

疲倦和乏力 您會感到乏力和無法自理，這很平常。您在白天的時候可能需要大量的休息。慢慢調整自己的節奏，請人幫您處理清洗和穿衣等令您疲勞的事情。不要不吃正餐。嘗試少食多餐。

睡眠障礙 有些人發現夜晚無法安睡。原因可能是多方面的。例如，可能是您太擔憂，或者您受到某些症狀的困擾。若您睡不好覺，請告訴您的醫生或護士，好讓他們幫助您。

以下有助於睡眠：

- 減少光亮和噪音，確保您既不太熱也不太冷
- 睡覺之前喝一杯熱飲，但是要避免咖啡因和酒精
- 睡覺之前的一小時內避免面對任何螢幕，例如電視螢幕或電腦螢幕
- 睡覺之前借助減壓CD或DVD，或者聽一些舒緩的音樂。

疼痛 若您感到疼痛，請告訴您的醫生或護士。他們會在這方面幫助您，必要時會給您止痛藥。

止痛藥有很多種。您的醫生或護士會決定哪一種最對您的疼痛最適合。不同類型的止痛藥包括：

- 簡單止痛藥，例如撲熱息痛 (paracetamol)
- 中等強度止痛藥，例如可待因 (codeine) 和曲馬多 (tramadol)
- 強力止痛藥，例如嗎啡 (morphine)、經考酮 (oxycodone)、芬太尼 (fentanyl) 和二乙醯嗎啡（又名海洛因）
- 消炎藥，例如布洛芬 (ibuprofen)

- 針對神經痛的止痛藥，例如加巴噴丁 (gabapentin) 和普瑞巴林 (pregabalin)。

關於何時服用止痛藥，請務必遵醫囑。大多數止痛藥在白天定期服用最為有效。

所提供的止痛藥通常為片劑、液體或皮膚貼片。若您無法吞咽或者正感到噁心作嘔，照料者可能會透過注射方式或借助一種叫做注射器助推器的小型便攜泵式裝置來讓您攝入止痛藥。您的護士或醫生可以針對這方面作進一步的解釋。

中等強度止痛藥和強力止痛藥有可能會引起嗜睡、噁心和便秘。嗜睡的情況通常會在幾天後逐漸消退。若您感到噁心，抗噁心藥可以起到幫助作用。噁心的情況通常會在幾天後逐漸好轉。便秘比較常見。服用中等強度或強力止痛藥的人多數需要定期服用輕瀉藥。您的醫生、護士或藥劑師可以告訴您更多的相關資訊。

也許您可以做一些簡單的事情來減輕您的疼痛。例如，您可以採取舒適的姿勢坐著或躺著。您還可以對疼痛部位施加熱度或進行降溫。

噁心和嘔吐 您的疾病、有時候加上您使用的藥物，可能會使您感到噁心或產生嘔吐。若出現這些情況，您的醫生或護士可向您提供抗噁心藥。您可以服用這類藥物的片劑，但是若您無法吞咽藥片，則可以嘗試其他方式。您的醫生或護士會告訴您更多的相關資訊。若您感到噁心，可嘗試姜茶、薑味啤酒或薑餅。小口啜飲汽水，少食多餐。

體重減輕和食欲不振 您的體重可能會減輕，這可能會讓您和您的親屬感到不安。

隨著時間的推移，您可能會不想進食。嘗試增加進食次數而減少每次的進食量，選擇高卡路里（高熱量）的食物並且吃一些零食。

在生命接近終點時，您可能會什麼都不想吃。不要強迫自己去吃。吃您喜歡的食物，但每次只吃少量。您可能會發現 **Build Up[®]** 和 **Complan[®]** 之類的營養飲品比較容易喝得下去。您可以向藥劑師或者從超市購買這些飲品。

便秘 許多人都有便秘的情況。這是因為他們活動得不多或者飲食、飲水不足。有些藥物也可能會引起便秘。若您覺得便秘，請告訴您的醫生或護士。他們可以提供輕瀉藥來幫助您。請攝入大量的飲品。

呼吸急促 若您呼吸急促，請告訴您的醫生或護士。

您的護士可以向您和您的照料者示範最好讓您坐在或站在什麼位置，以幫助您改善呼吸。坐下來做一些事情，例如清洗和穿衣。若您呼吸急促，請用一台風扇吹向自己的臉，或者坐在打開的窗戶旁。若您需要跟另一個房間的人講話，請使用嬰兒監視器/警鐘，這樣您就不需要起來了。

您的醫生可能會給您藥物，以幫助您改善呼吸。如有必要，您也可以在家裡吸氧。

口部問題 您可能會口乾，也可能會長潰瘍或發炎。有時候，這些問題可能會因您使用的藥物而變得更糟。若您有口部問題，請告訴您的護士或醫生，好讓他們來處理。

您可以透過保持口腔清潔來幫助改善。每天用含氟的牙膏刷牙兩次。若您的口腔疼痛，請使用柔軟的嬰兒牙刷。若您有漱口水的處方，請按照指示使用。少碰那些會讓您口乾或口腔不適的東西，如咖啡因、酒精或香煙。若您感到口乾，可小口啜飲汽水，吮吸冰塊或咀嚼無糖口香糖。

治療較難應對的症狀 您的症狀往往可以在家治療，但是有時候可能需要在臨終關懷機構或醫院裡治療。您的護士或家庭醫生會與您談到這方面。當您感覺稍微好些的時候，通常就可以再回家了。

生命的最後幾天

人在生命的最後幾天裡會有不同的體驗。知道究竟會發生什麼以及何時發生，可能會讓人非常難過。通常您會漸漸變得非常衰弱，幾乎沒有力氣。您可能會：

- 發現很難挪動，需要有人幫忙才能從床上坐到椅子上
- 一天的大部分或全部時間都需要待在床上
- 對您身邊的事物和您在乎的人（例如親人）失去興趣
- 睡得很多，醒著的時候也感覺嗜睡
- 感到迷惑，不確定自己是不是在做夢。

身體上的照顧

照顧您的人需要為您付出許多關懷。若您的家人在照顧您，當他們需要有人協助為您清洗的時候，您的護士可以安排。他們也可以向您的家人示範如何安全地移動您。

您可能會變得口乾，需要經常濕潤。您的護士可以拿來口腔護理棒（就像棉花棒），向您的照料者示範如何使用。他們也可為您塗上潤唇膏，防止您的嘴唇乾燥和開裂。

為了防止您的皮膚疼痛，您的照料者需要幫您潤膚，還需要頻頻幫您變換位置。護士可向您的照料者示範如何在您無法自己挪動的時候讓您感覺舒服些。

可能很多時候您都不需要做任何事。您可以只是靜靜地躺著，您的親屬或朋友可以坐著陪您。若您想談話或者想自己單獨待一會，請讓他們知道。您也許想聽一聽自己最喜歡的一些音樂。

症狀

您的護士或醫生有時可能會改變給您的藥物。他們可能會停止提供您不再需要的藥物。若您出現了新的症狀，您可能會開始服用新的藥物。

若您吞咽困難，可能會以注射或皮膚貼片的方式或借助一種小型便攜泵式裝置來讓您用藥（請參看關於疼痛的那部分內容）。您的專科護士或醫生可能會幫您安排在家注射某些藥物。您的地區護士會在您需要時幫您注射這些藥物。

有些人會出現以下症狀。因為您會變得嗜睡，您不太可能會察覺到這些症狀。

呼吸變化 有時，您的呼吸道裡可能會積聚液體。這可能會使您的呼吸出現雜音，但是這通常不會給您造成任何痛楚。您的醫生或護士可以給您藥物來幫您應對這個問題。

躁動不安 有些人會變得躁動不安。當他們憂慮時，往往就會發生這種情況。有些藥物可供您使用，以便幫助您放鬆和睡眠。若有一位親人或宗教團體領袖陪您坐著、交談或祈禱，那也可能有所幫助。

膀胱變化 您可能會無法控制自己的膀胱。您的護士可為您帶來特別的床單和墊子。他們可以將一根管子（導尿管）插到您的膀胱來匯出尿液。

若您的照料者對您的任何症狀感到擔憂，則應該聯繫您的家庭醫生或護士。

接近死亡

想到死亡可能會讓人非常恐懼。對將會發生的事感到擔心是正常的。

在您接近死亡的時候，您可能希望有些事情被執行，或希望禱告被念出來。您還可能希望有一位靈性或宗教團體的領袖陪在您身旁。把您的意願告訴您的親屬，好讓他們確保落實。

會發生什麼

對許多人來說，死亡是很平靜安詳的。您通常會進入深度睡眠狀態，然後發現難以醒來。

通常，您會睡得很沉，無法被喚醒。您也許仍能聽得見，也知道家人和朋友就在身旁。有些人有時候會清醒並且能說話，然後又進入到深度睡眠中。

若您在家中時發生了令您的家人擔心的情況，他們應該聯繫您的護士或家庭醫生。

當您接近死亡時，您的手腳會變得冰冷，您的皮膚可能會變得稍微發青。這是正常現象。您的呼吸也可能會變化。呼吸可能會變得緩慢，每次呼吸的間隔變得更長。最終，您的呼吸會完全停止。

在某些文化裡，人們相信，人死後思維或靈魂仍然會在肉體附近停留一段時間。也有人認為思維或靈魂迅速轉移到另一個地方去了。有些人認為生命就此終結，逝者的思維或靈魂都不會有任何的殘留。

過世之後

這部分內容是為您的親屬或照料者而寫的，但您或許也想閱讀。

每個人對死亡的反應都不同。起初您可能會感到震驚或麻木。您也可能會非常難過。許多人會感到如釋重負，因為自己的親屬或朋友此時終於享受安寧了。

大多數文化和宗教在人之將死時都有各自要執行的儀式。請您慢慢執行這些儀式。對您來說，讓一位靈性或宗教團體的領袖在旁幫您處理這些事情或許也很重要。

若您願意的話，您可以在逝者身邊停留一些時間。許多人喜歡坐在逝者身邊說話或握著手，看著逝者平靜安詳的樣子。您也許希望有一位親屬或朋友在那裡支援您。

您的家庭醫生會做些什麼

若您的親屬在家中離世，您需要告訴其家庭醫生或地區護士。家庭醫生或護士會上門確認其死亡。家庭醫生來的時候還會交給您一份死因醫學證明書和一份叫做「申報人通知書」(Notice to informant) 的表格。該資料告訴您如何登記死亡（見下方）。護士或診病時間外的醫生上門時，他們會進行死亡確認，但是您可能需要在第二天從您的家庭醫生那裡領取死亡證明。

您的殯儀師會做些什麼

完成死亡確認之後，您可以聯繫殯儀師（殯葬承辦人）。他們提供 24 小時服務，可以告訴您下一步該怎麼做。殯儀館的詳細資訊可在您的本地電話簿或網上找到。

殯儀師會在您要求的時間到來。若您想在葬禮之前一直讓他們在家中幫忙照看您親屬的遺體，請告訴他們。或者也可以讓他們將遺體送到殯儀館的停屍間。若您願意的話，您可以前往停屍間，待在親屬的遺體旁。

殯儀師會照料您親屬或朋友的遺體。具體做法可能因不同的宗教和文化而異。通常包括將遺體清潔乾淨和擦乾，以及合上眼瞼和嘴巴。殯儀師會問您想讓逝者穿什麼衣服。

有些人希望進行防腐。這是指將身體的血液抽乾，換成防腐液。這樣可以保存遺體。這道程式是在殯儀館進行的。

登記死亡

在舉行葬禮之前，您需要先到本地的登記處去辦理死亡登記。必須在五天之內進行登記（在蘇格蘭則是八天之內）。您可以在電話簿中找到本地登記處的詳細資訊。這些資訊也可能出現在死亡證明書的信封上。在登記死亡之前先打電話給登記處，因為您可能需要預約。

籌畫葬禮

葬禮是紀念一個人的生平和道別的方式。

您的親屬或朋友也許已經跟您說過他們的葬禮願望，或者已在遺囑上寫明。若是這樣，就會有助於您籌畫他們的葬禮。在某些文化和宗教裡，在人去世後儘快舉行葬禮非常重要。若有這個需要，請告訴殯儀師。

殯儀師會幫您安排。您也可以向宗教團體或靈性團體的領袖尋求幫助。假如您摯愛的人沒有留下任何遺願，殯儀師會指引您完成葬禮籌畫。

哀傷會給您帶來什麼影響

親近的人離世之後，您感到哀傷很正常。您可能會感到麻木、否認、憤怒、內疚，會思念逝者或感到抑鬱。這些感覺最初可能會很強烈，但是隨著時間推移，它們會慢慢變淡。

向親人或好友傾訴您的感覺可能會有所幫助。還有一些類似Cruse這樣的組織可以為那些哀傷中的人舉行小組活動。

若您的感覺令您掙扎難抑，請告訴您的家庭醫生。他們可以向您介紹能夠支援您的人。

有用機構的詳細聯繫資訊

晚期癌症及臨終關懷

Age UK 「老年英國」

Tavis House, 1-6 Tavistock Square, London WC1H 9NA

電話（英格蘭和威爾士）：0800 169 6565

電話（蘇格蘭）：0845 125 9732

電話（北愛爾蘭）：0808 808 7575

（每日上午 8 時至晚上 7 時）

www.ageuk.org.uk

透過網站和諮詢熱線為英國各地的老年人提供資訊和建議。另外也發佈無偏見的、資訊豐富的資料頁和建議指南。

Dying Matters 「臨終事項」

電話：08000 21 44 66

www.dyingmatters.org.uk

增加公眾對垂死、死亡和喪失親人的理解。

Marie Curie Cancer Care 「瑪麗·居裡癌症護理」

89 Albert Embankment, London SE1 7TP

電話：0800 716 146（週一至週五，上午9時至下午5時30分）

電子郵件：supporter.services@mariecurie.org.uk

www.mariecurie.org.uk

「瑪麗·居裡」的護士為人們提供免費的臨終護理，可上門或在各處瑪麗·居裡臨終關懷機構提供。這些臨終關懷機構一年365天每天24小時開放。

心理諮詢和情感支援

British Association for Counselling and Psychotherapy (BACP)

「英國心理諮詢及心理治療協會」

BACP House, 15 St John's Business Park, Lutterworth, Leicestershire LE17 4HB

電話：01455 883 300

電子郵件：bacp@bacp.co.uk

www.bacp.co.uk

提高人們對心理諮詢的意識，為人們指明獲取相關服務的管道。
您可以在這個網站上尋找符合資格的諮詢師：itsgoodtotalk.org.uk

為照料者提供的支援

Carers UK 「英國照料者」

電話（英格蘭、蘇格蘭、威爾士）：0808 808 7777

電話（北愛爾蘭）：028 9043 9843

（週三至週四，上午 10 時至中午 12 時、下午 2 時至下午 4 時）

電子郵件：advice@carersuk.org

www.carersuk.org

為英國各地的照料者提供資訊和支援。可以幫人們聯繫到他們所在地區的照料者支援團體。

為喪親者提供的支援

Cruse Bereavement Care 「克魯斯喪親關懷」

PO Box 800, Richmond, Surrey, TW9 1RG

電話：0844 477 9400（週一至週五，上午 9 時 30 分至下午 5 時）

電子郵件：helpline@cruse.org.uk

www.crusebereavementcare.org.uk

分支機構遍佈英國各地，為任何有需要的人提供喪親後的支援。您可以在這個網站上查找您當地的分支機構：crusebereavementcare.org.uk/LocalCruse.html

找律師

The Law Society for England and Wales 「英格蘭和威爾士律師公會」

113 Chancery Lane, London WC2A 1PL

電話：020 7242 1222

www.lawsociety.org.uk

推薦英格蘭和威爾士的律師，可提供律師的詳細資訊。

The Law Society of Scotland 「蘇格蘭律師公會」

26 Drumsheugh Gardens, Edinburgh EH3 7YR

電話：0131 226 7411

www.lawscot.org.uk

推薦蘇格蘭的律師，可提供律師的詳細資訊。

The Law Society of Northern Ireland 「北愛爾蘭律師公會」

96 Victoria Street, Belfast BT1 3GN

電話：028 9023 1614

www.lawsoc-ni.org

推薦北愛爾蘭的律師，可提供律師的詳細資訊。

相關的麥克米倫資訊

- 控制癌症疼痛
- 控制噁心嘔吐
- 應對疲倦

若需獲取這些相關資訊，請撥打免費電話 **0808 808 00 00** 或造訪 **macmillan.org.uk**

本情況說明書由麥克米倫癌症援助中心的癌症資訊開發小組負責編寫、修訂和編輯。本情況說明書經麥克米倫腫瘤醫學顧問兼麥克米倫醫學總編 **Tim Iveson** 博士審核。

感謝安寧療護臨床專科護士 **Theresa Mann**、安寧療護膳食專員 **Rosie Pole-Evans** 及所有受癌症影響、閱讀本檔案的人員。

編撰本資料時使用了來自多個可靠的資訊來源，包括：

- **Department of Health** 「英國衛生部」。臨終關懷策略——促進高品質的成年人臨終關懷護理。2008 年 7 月。
- **National Institute for Health and Care Excellence (NICE)** 「英國國家健康與臨床卓越研究所」。《改善針對成年人的支援和安寧療護：手冊》。2004 年 3 月。
- **National Institute for Health and Care Excellence (NICE)** 「英國國家健康與臨床卓越研究所」。安寧療護中的鴉片類藥物：在成年人安寧療護中以安全有效的方式開具強力鴉片類藥物處方。2012 年 5 月。
- **National Institute for Health and Care Excellence (NICE)** 「英國國家健康與臨床卓越研究所」。品質標準 13。成年人臨終關懷品質標準。2011 年 8 月。

我們盡最大努力確保本文所提供資訊的準確性，但是，由於醫療研究現狀不斷變化，所以請勿過度依賴此資訊。具體情況請諮詢您的醫師。麥克米倫不對由於本文資訊或網站所連結的網站上的資訊等第三方資訊的不準確性造成的任何損失或損害承擔任何責任。

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MAC14363



End of life

This fact sheet is about what happens at the end of life and how to plan for it.

It tells you about who can help if you are being cared for at home and what to expect in the last few weeks and days of life. It also includes information for your relatives and close friends about what to do after your death. You may want to read this section too.

You may find some of the information upsetting to read. Ask a close relative, friend or a healthcare professional to read it as well. They can support you and you can discuss the information together.

We hope this fact sheet answers your questions. If you have any more questions, ask your doctor or nurse.

We have listed other helpful information from Macmillan at the end of this fact sheet. Most of this is only in English. If you would like to talk to our cancer support specialists in your own language, we have interpreters for non-English speakers.

You can call the Macmillan Support Line free on **0808 808 00 00**, Monday–Friday, 9am–8pm. If you have problems hearing you can use textphone 0808 808 0121, or Text Relay. Or you can visit **macmillan.org.uk**

On this page

- How you may feel
- Planning ahead
- Who can look after you at home
- The last few weeks of life
- The last few days of life
- Nearing death
- After death

How you may feel

Hearing the news that you may be reaching the end of your life can be very difficult. You may have many different feelings. You may feel it is very unfair that this is happening. You may fear what the future will bring. You may also find yourself tearful and sad and not sure of how to cope with these feelings.

It can help to tell your family and friends how you are feeling. You could also talk to your doctor or nurse. Or you can speak to one of Macmillan's cancer support specialists.

You will probably have good days when you feel well and bad days when you have less energy. For many people it's important to plan ahead and make the most of the days when you feel well. You may want to do some nice things with your family or friends. You may also want to do important things, such as making a will or planning your funeral.

Religion and spirituality Towards the end of life, people often become more aware of religious beliefs or spiritual feelings. People with a strong religious faith often find this very helpful. Others may question their faith or start to think about whether there is a life after death.

Some people find comfort in prayer or meditation. Many people find it helpful knowing that other people are praying for them.

You can talk to a chaplain, minister, priest, rabbi or other religious leader even if you're not sure about what you believe. Spiritual and religious leaders are used to helping, and you may find peace of mind.

Planning ahead

Making a will If you haven't made a will it's important to make one. A will is the only way to make sure that your belongings and property go to the people you choose.

Your will is a legal document and you must write it properly. It's usually best to use a solicitor when writing your will. They will make sure your wishes are clear and that they are carried out as you wish. If you need help finding a solicitor you can contact the Law Society (see the end of the fact sheet).

Planning your funeral You may want to plan your own funeral. You can think about whether you want a burial or cremation, what type of service you want, what songs you'd like, and what clothes you want to wear.

It's helpful to talk about your funeral wishes with your family and friends. They may also have ideas that will help them to say goodbye. Once you've decided what you want, write down your wishes so that family and friends can carry them out.

Who can look after you at home

Caring can be hard work, so it's important that you and your carers have the support you need. There are many people who can help.

Your GP

While you're at home, your GP (family doctor) is in charge of your medical care. They can help if you:

- are worried about any changes in your symptoms
- want to talk about what may happen as you become less well
- need advice about how to access nursing care or other help in the home.

District nurses

District nurses (DNs) work closely with GPs. They will visit you at home and manage your nursing needs. They can help you by:

- managing your care – if you need help from other people your DN can contact them
- keeping an eye on and treating any symptoms you may have
- giving injections and changing dressings
- giving advice on how to stop your skin getting sore
- giving advice about toilet problems, such as incontinence and constipation
- supplying equipment, such as a chair cushion or special mattress to help stop your skin getting sore, or a commode, urinal or bedpan
- showing your relatives or carers how to move you and take care of you.

District nurses often work with specialist palliative care nurses (see pages below). They can support you and your carers so that you can stay at home.

Marie Curie Nursing Service

Marie Curie nurses care for people who are nearing the end of their life. They visit people in their home and can provide care overnight, or for part of the day. This allows your carers to have a good night's sleep or a break during the day. The nurses also help you cope with your feelings.

Marie Curie nurses are free. But there is usually a limit to how often you can have one. Your district nurse or GP will arrange a Marie Curie nurse for you.

Community specialist palliative care teams

These are specialist nurses and doctors. They support people and their families who are coping with illnesses like cancer.

You may be referred to a palliative care team if you need specialist support or care, for example if you have symptoms that you need help with. They can visit you at home.

Hospice at Home care teams

If you wish to die at home, some hospices have nurses and carers who can help care for you in your home. This care is usually provided in the last few weeks of your life. Your community specialist palliative care nurse will arrange it for you.

Social workers/care managers

Social workers can organise help with housework, shopping and cooking, or someone to help with jobs like washing and dressing. If you need this sort of help, they can arrange people to do these jobs for you. You or your doctor or district nurse can contact a social worker to ask them to look at your needs. If you can afford it, you may be asked to pay towards the cost of this help.

Occupational therapists

Occupational therapists can provide you with equipment to help you move around and do things for yourself. They will visit your home to see what equipment you need. This may include stair rails, grab rails and equipment for your shower or bath.

Occupational therapists can also give advice on small gadgets and where you can buy them. For example, things like two-handled mugs and special cutlery.

Your nurse or doctor can refer you to others if you need help. They will also tell you about the types of help available in your area.

The last few weeks of life

During the last few weeks of life, you may be aware of some the following changes.

Emotional changes

You may have different emotions that include worry, anxiety, panic, anger, sadness and depression. It is normal to be worried or anxious when you are facing death. Talking to your family or your nurse may help you feel better. Some people prefer to talk to a person they don't know, such as a counsellor. Your doctor or nurse can refer you to one.

Physical changes and symptoms

Tiredness and lack of energy It's usual to lack energy and not be able to do things for yourself. You may need to rest a lot during the day. Pace yourself and get help with tasks that tire you out, such as washing and dressing. Don't skip meals. Try to eat small amounts of food regularly.

Sleep disturbance Some people find they can't sleep well at night. There may be many reasons for this. For example, you may be worried or you may have symptoms that

are bothering you. Tell your doctor or nurse if you're not sleeping well so that they can help.

To help you sleep:

- reduce light and noise, and make sure you're not too hot or cold
- have a hot drink before going to bed, but avoid caffeine and alcohol
- avoid using any screen, such as a TV screen or computer screen, for one hour before going to bed
- use a relaxation CD or DVD, or listen to some soothing music before you go to bed.

Pain Tell your doctor or nurse if you have pain. They will help you with this and give you painkillers if you need them.

There are many types of painkiller. Your doctor or nurse will decide which one is best for your pain. Different types of painkiller include:

- simple painkillers, such as paracetamol
- moderately strong painkillers, such as codeine and tramadol
- strong painkillers, such as morphine, oxycodone, fentanyl and diamorphine
- anti-inflammatory drugs, such as ibuprofen
- painkillers for nerve pain, such as gabapentin and pregabalin.

Always follow your doctor's instructions on when to take painkillers. Most work best when they are taken at regular times during the day.

Painkillers are usually given as tablets, liquid medicines, or patches stuck onto the skin. If you aren't able to swallow or are being sick, you may be given them by injection or by a small portable pump called a syringe driver. Your nurse or doctor can explain more about this.

Moderately strong and strong painkillers can cause drowsiness, sickness and constipation. Drowsiness usually wears off after a few days. If you feel sick, anti-sickness medicines can help. Sickness usually gets better in a few days. Constipation is common. Most people taking moderately strong or strong painkillers need to take a laxative regularly. Your doctor, nurse or pharmacist can tell you more about this.

There may be simple things you can do to reduce your pain. For example, you can sit or lie in a comfortable position. You can also use warmth or cold on the area of pain.

Feeling sick and vomiting Your illness, and sometimes your medicines, may make you feel or be sick. If this happens, your doctor or nurse can give you anti-sickness drugs. You can take these as tablets, but if you can't swallow tablets you can try other ways. Your doctor or nurse will tell you more about this. If you feel sick try ginger tea, ginger beer or ginger biscuits. Sip fizzy drinks and eat little but often.

Weight loss and loss of appetite You may lose weight, and this can be upsetting for you and your relatives.

As time goes on, you may not feel like eating. Try eating smaller, high-calorie meals more often and nibble on snacks.

As you near the end of your life, you may not feel like eating anything. Don't force yourself to eat. Have small amounts of things you enjoy. You may find nourishing drinks such as Build Up[®] and Complian[®] easier to take. You can buy these from chemists and some supermarkets.

Constipation Many people get constipated. This is because they aren't moving around or eating and drinking as much. Some medicines also cause constipation. Tell your doctor or nurse if you feel constipated. They can give you laxatives to help. Drink plenty of fluid.

Breathlessness Tell your doctor or nurse if you are short of breath.

Your nurse can show you and your carers the best place for you to sit or stand to help your breathing. Sit down to do jobs like washing and dressing. If you are breathless, use a cool fan to blow air onto your face or sit by an open window. If you need to talk to someone in another room, use a baby monitor/alarm so that you don't need to get up.

Your doctor may give you medicines to help with your breathing. You can also have oxygen at home if you need it.

Mouth problems Your mouth may become dry or you may get ulcers or an infection. These problems can sometimes be made worse by the medications you're taking. Tell your nurse or doctor if you have mouth problems so that they can treat them.

You can help by keeping your mouth clean. Brush your teeth twice a day using a fluoride toothpaste. Use a soft baby toothbrush if your mouth is sore. If you have been prescribed a mouthwash, use it as directed. Cut down on things that can dry or irritate your mouth, such as caffeine, alcohol or smoking. If your mouth is dry, sip tonic water, suck ice cubes or chew sugar-free gum.

Managing difficult symptoms Your symptoms can often be treated at home, but sometimes they may need to be treated in a hospice or hospital. Your nurse or GP will talk to you about this. Once you are feeling a little better, you can usually go home again.

The last few days of life

People will have different experiences in the last few days of life. It can be difficult to know exactly what will happen and when. Usually you will slowly become very weak and have little energy. You may:

- find it difficult to move around and need help getting from your bed to a chair

- need to spend most or all of the day in bed
- lose interest in things around you and people you care about, such as your close family
- sleep a lot and feel drowsy when you are awake
- feel confused and unsure whether you are dreaming.

Physical care

The people looking after you will need to give you a lot of care. If your family are looking after you and they need help to wash you, your nurse can arrange this. They can also show your family how to move you safely.

Your mouth may become dry and will need to be moistened regularly. Your nurse can get mouthcare sticks (like big cotton buds) and show your carers how to use them. They can also put lip balm on your lips to stop them getting dry and cracked.

To stop your skin getting sore, your carers will need to moisturise it and help you change your position regularly. The nurses can show your carers how to make you comfortable when you can't move yourself.

There may be a lot of time when you don't need to have anything done. You can just lie quietly and your relatives or friends can sit with you. Let them know whether you'd like to talk or have some time on your own. You may want to listen to some favourite music.

Symptoms

Sometimes your nurse or doctor may change your medicines. They may stop any medicines you no longer need. If you develop new symptoms, you may be started on new ones.

If you have problems swallowing, your medicines can be given either by injection, by patches stuck on to the skin, or by using a small portable pump (see the section about pain). Your specialist nurse or doctor may arrange for you to have injections of some medicines at home. Your district nurse will give you these if you need them.

Some people develop the symptoms below. You're unlikely to be aware of these symptoms, as you will be sleepy.

Breathing changes Fluid can sometimes collect in your breathing passages. This may make your breathing noisy but it won't usually cause you any distress. Your doctor or nurse can give you medicines to help this.

Restlessness Some people become restless. This often happens if they are worried. Medicines can be given to help you relax and sleep. Having a close family member or a religious leader sit, talk or pray with you can also help

Bladder changes You may not be able to control your bladder. Your nurse can get you special bed covers and pads. They may put a tube (catheter) into your bladder to drain away the urine.

If your carers are worried about any of your symptoms they should contact your GP or nurse.

Nearing death

Thinking about dying can be very frightening. It's normal to worry about what will happen.

You may want practices carried out, or prayers read, as you near death. You may also want a spiritual or religious leader with you. Tell your relatives what you would like so that they can make sure this happens.

What happens

For many people dying is very peaceful. You will usually fall into a deep sleep and find that it's difficult to wake up.

Usually you become so deeply asleep you can not be woken. You may still be able to hear and know that family and friends are close by. Some people have times when they are awake and can talk, and then go back into a deep sleep.

If you are at home and anything happens that worries your carers, they should contact your nurse or GP.

As you near death, your hands and feet become cold and your skin may turn slightly blue. This is normal. Your breathing may also change. It may become slower with longer gaps between each breath. Finally your breathing will completely stop.

In some cultures, there is a belief that the person's mind or soul stays around the body for some time after death. Other people feel that the mind or soul moves on quickly to another place. Some people believe that life just ends and nothing is left of the person's mind or soul.

After death

This section is written for your relatives or carers, but you may want to read it too.

Everyone reacts to death differently. At first you may feel shocked or numb. You may also be very upset. Many people feel relieved that their relative or friend can now be at peace.

Most cultures and religions have practices that they carry out at the time of death. Take your time to carry these out. It may also be important for you to have a spiritual or religious leader with you to help with these.

If you want, you can spend time with the person who has died. Many people like to sit and talk or hold hands, and see the person at peace. You may want to have a relative or friend there to support you.

What your GP will do

If your relative died at home you will need to let their GP or district nurse know. The GP or nurse will come to the house to confirm their death. If your GP comes, they will also give you a medical certificate for the cause of death and a form called 'Notice to informant'. This tells you how to register the death (see below). If a nurse or an out-of-hours doctor comes, they will confirm the death but you may need to get the death certificate from your GP the next day.

What your funeral director will do

Once the death has been confirmed, you can contact the funeral director (undertaker). They provide a 24-hour service and can tell you what to do next. Details of funeral directors are in your local phone book or on the internet.

The funeral director will come as soon as you want them to. Let them know if you would like them to help you look after your relative's body at home until the funeral. Or they can take the body to the funeral director's chapel of rest. You can visit the chapel to be with your relative's body if you would like to.

The funeral director will take care of your relative's or friend's body. How this is done may vary for different religions and cultures. It usually involves washing and drying the body, and closing the eyelids and mouth. The funeral director will ask you what clothes you would like them to wear.

Some people want to be embalmed. This is when blood is drained out of the body and replaced with embalming fluid. This preserves the body. It is done at the funeral directors.

Registering the death

Before the funeral happens you need to register the death at your local registrar's office. This has to be done within five days (eight days in Scotland). Details of your local registrar's office are in your phone book. They may also be on the envelope containing the death certificate. Telephone the registrar's office before going to register the death, as you may need to make an appointment.

Planning the funeral

Funerals are a way of celebrating someone's life and saying goodbye.

Your relative or friend may have told you their funeral wishes or written them in their will. If they have, this will help you plan their funeral. In some cultures and religions it's important to have the funeral soon after the death. Tell the funeral director if this needs to happen.

The funeral director will help you with the arrangements. You can also get help from a religious or spiritual leader. If your loved one didn't leave any information about their wishes, the funeral director will guide you through planning a funeral.

How grief might affect you

Grief is normal after the death of someone close to you. You may feel numbness, denial, anger, guilt, a longing for the dead person or depression. Although these feelings can be very strong at first, with time they slowly lessen.

Talking through your feelings with close family or friends can help. There are also organisations, such as Cruse, that run groups for people who are grieving.

Tell your GP if you are struggling with how you're feeling. They can refer you to someone who can support you.

Contact details of useful organisations

Advanced cancer and end-of-life care

Age UK

Tavis House, 1–6 Tavistock Square, London WC1H 9NA

Tel (England and Wales) 0800 169 6565

Tel (Scotland) 0845 125 9732

Tel (Northern Ireland) 0808 808 7575

(Daily, 8am–7pm)

www.ageuk.org.uk

Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

Dying Matters

Tel 08000 21 44 66

www.dyingmatters.org.uk

Promotes public awareness of dying, death and bereavement.

Marie Curie Cancer Care

89 Albert Embankment, London SE1 7TP

Tel 0800 716 146 (Mon–Fri, 9am–5.30pm)

Email supporter.services@mariecurie.org.uk

www.mariecurie.org.uk

Marie Curie nurses provide free end-of life care to people in their own homes, or in Marie Curie hospices, 24 hours a day, 365 days a year.

Counselling and emotional support

British Association for Counselling and Psychotherapy (BACP)

BACP House, 15 St John's Business Park, Lutterworth, Leicestershire LE17 4HB

Tel 01455 883 300

Email bacp@bacp.co.uk

www.bacp.co.uk

Promotes awareness of counselling and signposts people to appropriate services.

You can search for a qualified counsellor at itsgoodtotalk.org.uk

Support for carers

Carers UK

Tel (England, Scotland, Wales) 0808 808 7777

Tel (Northern Ireland) 028 9043 9843

(Wed–Thu, 10am–12pm and 2–4pm)

Email advice@carersuk.org

www.carersuk.org

Offers information and support to carers across the UK. Can put people in contact with support groups for carers in their area.

Bereavement support

Cruse Bereavement Care

PO Box 800, Richmond, Surrey, TW9 1RG

Tel 0844 477 9400 (Mon–Fri, 9.30am–5pm)

Email: helpline@cruse.org.uk

www.crusebereavementcare.org.uk

Has a UK-wide network of branches that provide bereavement support to anyone who needs it. You can find your local branch on the website, at

crusebereavementcare.org.uk/LocalCruse.html

Finding a solicitor

The Law Society for England and Wales

113 Chancery Lane, London WC2A 1PL

Tel 020 7242 1222

www.lawsociety.org.uk

Represents solicitors in England and Wales and can provide details of solicitors.

The Law Society of Scotland

26 Drumsheugh Gardens, Edinburgh EH3 7YR

Tel 0131 226 7411

www.lawscot.org.uk

Represents solicitors in Scotland and can provide details of solicitors.

The Law Society of Northern Ireland

96 Victoria Street, Belfast BT1 3GN

Tel 028 9023 1614

www.lawsoc-ni.org

Represents solicitors in Northern Ireland and can provide details of solicitors.

Related Macmillan information

- Controlling cancer pain
- Controlling nausea and vomiting
- Coping with fatigue

For copies of this related information call free on **0808 808 00 00**, or see it online at macmillan.org.uk

This fact sheet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by our Chief Medical Editor Dr Tim Iveson, Consultant Medical Oncologist and Macmillan Chief Medical Editor.

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This fact sheet has been compiled using information from a number of reliable sources, including:

- Department of Health. End of life care strategy – promoting high quality care for adults at the end of life. July 2008.
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- National Institute for Health and Care Excellence (NICE). Opioids in palliative care: safe and effective prescribing of strong opioids for pain in palliative care of adults. May 2012.
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