

幫助您的孩子瀕臨死亡 Helping Your Child When Death Is Near

“我瞭解我的孩子可能正步向死亡。我如何才能知道死亡已靠近了，並且使我能夠不驚慌而以支持和愛面對？”

本資訊將協助您面對孩子步向死亡的過程。我們提供的這份資訊是預備讓您知道那些變化表示死亡正逐漸接近。但願您永遠不需要它，只是萬一用得上時，隨時有份資料可以參考，希望它有助於掌握狀況。在您覺得夠堅強的時候看它，而不必現在就看。有些父母把這份資料存檔，需要時才參考。

如果孩子接受安寧療護，醫療團隊瞭解，這是您和家人們最困難的時間，他們會全力支持，並解答您的問題。

如果孩子尚未接受安寧療護，現在也許是聯絡他們的時候。安寧療護能提供家人超出想像的支援，但是有些人遲遲不願去找他們，以為去了就是放棄孩子。我們知道，參加安寧療護的孩子，情況也可能會有所改善。所以不要覺得聯絡安寧療護就是放棄您的孩子，其實，這是為孩子和家人得到更多的協助，讓每個人，尤其是孩子，感覺好得多。如果您不願意自己打這個電話，可以請醫生或社工人員幫忙。

安寧療護團隊是誠實、坦白但婉轉而有所幫助的

您的主治醫師和安寧療護的護士會回答任何有關的問題，告訴您通常會出現的狀況以及能做些什麼讓孩子更舒適些。

這些變化是孩子的身體在準備進入生命的最後階段，並不是每個孩子都會出現所有的變化，也不是依所述的順序發生，但在數天或數小時的一段時間裡，您能或多或少的注意到這些變化。您最瞭解自己的孩子，會注意細微的變化，這些變化反映出您的孩子的生理狀況。

體溫的改變

當體溫調節系統停止運作，首先是手腳會冰冷，顏色可能變白或青，臉色會有些黯灰，唇或鼻呈現藍色。儘管多數孩子在此刻不一定會覺得冷，您還是可以問問他是否要加床毯子；有些例子是孩子會覺得發熱而臉紅，您可以用冷毛巾擦拭，或用以前用過的類似方法來舒緩。

脈搏的改變

當心臟慢下來時，心跳會開始不規則，血液循環跟著變慢，手腳的脈搏會非常微弱。由於心跳不規則，會時快時慢。隨著循環系統逐漸失去作用，會出現體溫和膚色的變化。

胃腸的改變

在身體自然地減少能量的消耗時，孩子對食物和水的需求就會降低；控制口腔、咽喉和胃腸的肌肉功能也會消退。只要孩子想喝也還能嚥得下時，可以喝些像果汁、碎冰或汽水等流質的東西。如果虛弱到無法喝的時候，您可以用湯匙、注射筒、或滴管來餵，記得稍稍抬高他的頭以免噎到。一旦不能順利吞嚥，就不能再餵任何流體食物。儘管父母對不再積極加強營養感覺非常不自然，但在這種末期階段，身體通常無法忍受也並不再需要養分。安寧療護團隊會幫您找其他方式使孩子舒適，而您也感覺在有效地照顧孩子。因為他不太消耗體力、睡得多或者更虛弱了，身體對食物和水份的需求也會減少，這種狀況下，由於循環和消化系統運作緩慢，過多的水份反而會引起更多痛苦、肺積水以及全身不適。如果正在使用鼻胃管或靜脈注射，安寧團隊會和您商量是否要依孩子能接受的情況逐漸減少餵食的份量。

呼吸的改變

孩子可能會呼吸困難，這時候有幾件事情您可以做：規律地替他翻身，頭要托高；或者背部靠坐坐高；也可以抱到您的腿上，疏解呼吸不順，同時也安撫他。用氧氣也會有幫助和有必要，護士會評估需氧氣的現象而通知醫生。

呼吸也可能變快，又變淺且不規則，間有 10 至 30 秒不呼吸的狀況，稱作“呼吸暫停”。可能嘴巴或喉嚨裡會有過多分泌物、黏液，孩子虛弱到吞不下或排不出去。那會引發咕嚕聲，聽起來好像不太安穩，其實通常孩子不會覺得不舒服。要協助排除這些分泌物，您可以讓孩子側睡或者把頭墊高，護士也要評估是否需要藥物來減少這些可能隨著死亡接近而增加的分泌物。維持一個安靜、安心的氣氛也有助於緩和及順暢的呼吸，也可以試著引導孩子想些輕鬆的景象或回憶。

清醒/睡眠的改變

有些孩子到最後一刻都是警覺而清醒的，有些則是會迷惑、亢奮、嗜睡、很難叫醒或者時醒時睡。說話可能變成混亂或難懂，即使孩子無法用語言和您溝通，請假設他能聽到您、感覺到您的撫摸和知道您在旁邊。一般相信“聽覺”是最後才消失，所以和孩子說話、保持溫柔的身體接觸或播放些舒緩的輕音樂也很好。有時候一些非語言的暗示可以確定他的感受，例如眉毛動一下、臉上表情變了、眼睛眨動、手抓握或肢體移動以及呼吸頻率的改變等。熟悉的聲音、口音、撫摸和擁抱能持續帶給孩子舒適及安全感，您也會有同感。

疼痛和舒適的改變

有些孩子到了生命盡頭也沒有疼痛不舒服，有些則已經需要定時使用止痛劑。需要持續用止痛藥的孩子，準確地遵守用藥時間表是非常重要的。儘管孩子無法與您溝通，從孩子的休息狀態，您也絕對能夠知道他是否在痛。一些非語言的疼痛現象如：表情扭曲、呻吟、容易受刺激、煩躁不安、睡眠受干擾及呼吸改變等。如果孩子無法吞嚥，要和醫生、護士密切合作，必要時得換藥方或給藥方式（例如：藥效強一點的、換成液體的、用注射的、用栓劑等）。每個孩子情況都不同，所以對舒適的需求也要依他們漸漸無法活動、軟弱的情況而改變，這些也要適當處理以確保他們的舒適。

重要的是您能瞭解安寧療護的護士是 24 小時都能接聽您的詢問電話，談任何有關上述的變化，必要時也能到您家來。在孩子進入最後階段時，有些家庭會希望有護士陪伴，有些則希望只有家屬在場，如果是後者，護士還是可以代您打些電話（給醫生、殯儀館、其他醫護人員，必要的話，還有驗屍員），還有通知醫院、小兒科或其他您們常去的醫療單位等。也許在已下班時間，還有社工和神職人員可以支持您們度過這個階段。

家屬常表示，相較於在醫院過世，讓孩子在家可以有更足夠的時間來道別。他們可以叫來其他親戚、禱告、幫孩子沐浴和穿戴、做些手印或腳印、留一綵頭髮或不論什麼活動、儀式能覺得有意義和安慰就好。如果殯儀館的人來了，您可能會希望自己抱孩子上車，有些父母覺得“自願交出”孩子，和讓孩子“被帶走”是不一樣的。也有些父母覺得，假如殯儀館人員在上車前不要把孩子的頭、臉蓋起來，比較好過一點。一定要把您的意願說出來。切記您有很多的選擇，儘量依您和家人覺得舒服和對的方法去做。安寧團隊會協助您做抉擇、計劃以及最後的安排。不論日夜他們都會待命幫助您。

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Helping Your Child When Death Is Near



"I understand that my child may be actively dying. How will I know when death is near so that I can be supportive and loving and not panic."

Here is some information that will help you cope as your child passes from this life. We share this information to prepare you to anticipate the changes which can indicate approaching death. We hope you never need it. But just in case you do need it, you might want to keep a copy of this article handy so you can refer to it if the time comes. This information is intended to help you feel more in control of the situation. Review it when you feel strong enough. You need not do it right now. Some parents put this in their "information file" and refer to it later.

If your child is receiving hospice care, the hospice team realizes that this period of time is certainly the most difficult for you and your family. They can be of great support and answer any questions you have.

If your child is not on hospice, this may be the time to call them. Hospice provides incredible support to families but many families are reluctant to call hospice because they feel they are giving up. We have known children who have gone on hospice and gotten better. You do not have to feel like you are giving up on your child by calling hospice! Rather, you are getting support for your child and your family that will make everyone, especially your child, feel much better. Ask your doctor or social worker to call for you and make a referral if you do not wish to make the call yourself.

The hospice team will be as honest, straightforward yet gentle and helpful as possible.

Your physician and the hospice nurse are available to answer any questions you may have about this information. We will tell you what to expect in general ways, as well as what you can do to make your child more comfortable at this time.

These changes are how your child's body prepares itself for the final stages of life. Not all of these changes appear with each child, nor do they occur in any prescribed order, but you may notice some or all of these over a period of days or hours. You know your child best and may notice subtle changes that will tell you what is happening to your child's physical condition.

Temperature Changes

As the body's heat regulating system fails, the hands and feet become cool first. They may be pale or bluish in color. Your child's face may become grayish and the lips or nose blue. Since most children at this phase do not necessarily feel cold with this sign, you may want to ask if a blanket would make your child feel warmer. In some instances, your child may feel feverish and appear flushed. You can use cool wash cloths to sponge him or her off and other familiar comfort steps you may have used in the past.

Pulse Changes

As the heart slows down, the heartbeat becomes irregular, and blood circulation slows. The pulses in the wrists and feet become very faint. Because the heartbeat is irregular, it may be very rapid at times and slower at others. As the circulatory system slowly fails in its effectiveness, changes in temperature and color may occur.

Gastrointestinal Changes

Your child's need for food and drink will decrease as the body naturally begins to conserve energy.

The muscles that control the mouth, throat, stomach and bowels will be less effective also. Fluids such as tea, juices, ice chips, frozen juice pops or sherbet to suck on can be offered as long as your child wants to drink and can swallow. If too weak to drink, you can give fluids using a teaspoon, oral syringe or medicine dropper. You may need to raise their head a bit to prevent choking. Do not give any fluids by mouth if your child can no longer safely swallow. Although it may feel very unnatural to not be aggressively pushing nutrition, *the body often does not tolerate or need the fuel at this late stage*. The hospice team will help you find other ways to be comforting and feel active in your child's care. The body's requirements for fluids and food decreases as they use less energy and are sleeping mostly or becoming more frail. Too much fluid at this point of their condition can actually cause more distress, lung congestion and general discomfort since circulation and digestion are greatly slowed. If your child has a tube feeding or IV fluids the team may discuss with you the possibility of slowly decreasing the amount based on how they can tolerate it.

Breathing Changes

Your child may experience difficulty with breathing. If he or she does, there are a number of things you can do. Regularly turning your child side to side, with the head elevated, or propping in a well-supported sitting position or holding him or her in your lap will relieve shortness of breath, and provide comfort as well. Using oxygen may be helpful and necessary. The nurse can evaluate the indications for oxygen and contact your child's physician.

Breathing may become rapid, and then become very shallow and irregular with 10 to 30 second periods of no breathing. This is called apnea. There may be excessive secretions/ watery mucus in your child's mouth or throat that he/she is too weak to swallow or clear. This may cause a gurgling sound; which can sound unsettling, but usually does not cause the child any discomfort. To aid in drainage of these secretions, you can turn your child on his or her side or to keep the head elevated. Your nurse will evaluate the need for medication to help reduce these secretions which may increase as death becomes near. Maintaining a calm, reassuring atmosphere also helps relieve labored breathing. You may also try guiding your child through relaxing images/memories.

Alertness/Sleep Changes

Some children are alert and mentally clear until the last moment of life. Others are confused, restless, sleep a lot, may be difficult to rouse, or may go in and out of wakefulness. Speech can become confused or difficult to understand. Even if your child cannot communicate with you in words, assume he or she can hear you, feel your touch, and / or sense your presence. Hearing is believed to be the last of the senses to be lost, so talking to your child, maintaining gentle physical contact or playing soothing music is encouraged. Sometimes nonverbal cues can confirm this, i.e., eyebrow movement/expressions, facial expression change, fluttering in eyes, hand grasp or extremity movement, and changes in respiratory rate/patterns. The familiar sounds, voices, touch and embrace continue to bring comfort and security to your child- as well as to you.

Pain and Comfort Changes

Some children reach the ending of their lives without experiencing any pain at all. Others may already be taking doses of pain medication around the clock at this point. Your child will need to continue taking their pain medication so it is important to keep him or her on their schedule. Even if your child cannot communicate with you, rest assured that you will be able to tell if he or she is experiencing pain. Some non-verbal signs of pain are grimacing, moaning, increasing irritability, restlessness, interrupted sleep, and changes in breathing. Work closely with your child's physician or the hospice nurse, if he or she can no longer swallow, to change the type of medication or how it is given (i.e., something stronger, switching to a liquid form, an infusion, suppositories) if this becomes necessary. Each child's condition is unique so comfort needs may be due their increased immobility and weakness, inability to move themselves. These too should be treated to assure they are comfortable.

It is important for you to understand that a Hospice nurse is available, 24 hours a day to speak with you on the phone about any or all of these changes, or to come to your home if necessary. Some

families have wanted a nurse there before and during the time the child is at this final stage, while others have wanted to be alone when their child died, seeing this as a private time for family only. If this is the case, the nurse can still make the appropriate phone calls for you (to the doctor, mortuary, others involved in your child's care, and coroner if required), as well as notify the clinic, pediatrician, others on the care team you went to regularly if appropriate. There may also be a social worker and/or a chaplain available after regular business hours to support you in your journey.

Families have often commented that by having their child die at home, as opposed to dying in a hospital, they could take as much time as they needed to say goodbye. They could call in other family members, say prayers, bathe and dress their child, make handprints or footprints, save a lock of hair, or whatever activities or rituals they found meaningful and comforting. If you have mortuary attendants come to your home, you may want to carry your child out to the car, as there is a difference for some parents between "surrendering over" your child to them and their "taking" your child from you/your home. Some parents feel it is easier if the attendants do not cover up your child's head and face until they have them in their vehicle. **Please let your preferences be known.** There are lots of choices so remember that you need only do what is comfortable and right for you and your family. The hospice team can help support you in making decisions, plans and final arrangements. They are there for you day and night.

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