

Stanford Pediatrics Residency

# **The Death Exam Handbook**

---

Christina Turn, MD & Kelly Sanders, MD, MSc



## Table of Contents

Foreword

**Section one:** Signs of impending death

**Section two:** Where you will encounter death and what your role may be

**Section three:** What to do when you are called about a patient's possible cardiopulmonary death

**Section four:** Completing Epic paperwork

**Section five:** A word on brain death

**Section six:** Self care after a patient's death



## Objectives

- Appreciate the importance of declaring death as a resident.
- Recognize rotations/scenarios in which residents will be most likely responsible to call a death.
- Locate and use the intranet policy procedures, checklists, and EPIC order sets.
- Demonstrate the process required to declare cardiorespiratory versus brain death, including the logistics, the paperwork, and communication skills necessary.



## FOREWORD

It is inevitable that you will take care of dying patients during your residency training; some of them will die while you are present. First, let us offer you our sincerest condolences. Losing a patient is one of the most difficult part of a pediatrician's career, and we often are not trained on the practical aspects of pronouncing a patient dead during medical school. The process of examining a patient who has died and managing the aftermath (paperwork, consoling the family, contacting various departments and outside groups) can be overwhelming, especially the first time you do this.

We definitely felt anxious, unprepared, mournful, and scared the first time we encountered situations in which we needed to pronounce a patient as deceased. We hope that this guidebook will provide you tools to help you to navigate the complex initial phases of a patient's death and to support the family, your coworkers, your team, and yourself during this undoubtedly difficult time. While the instructions in this guide are Stanford-specific, we tried to incorporate general tips that will serve you well both in your career at Stanford and wherever you practice in the future.

## SECTION ONE: SIGNS OF IMPENDING DEATH

When a patient is actively dying, his or her body will start to slow down the processes required for continued survival. There are many common signs and symptoms seen as a patient progresses closer towards death (See Figure 1), many of which can be quite frightening for family members and staff who have never seen someone die. When patients are starting to die, the treatment focus should be switched to **comfort care measures** (a focus on alleviating symptoms rather than curing the underlying cause). The article on “Easing a Patient’s Suffering” on the LPCH Heme/Onc rotation website provides an excellent overview of some of these comfort care measures.


When you are covering for a team and a patient is expected to die soon (possibly while you are covering), you should ask your colleagues on the day team to provide you more information about the child and their current circumstances. Ask them when they anticipate a patient may die, and to provide you with information critical to interacting with the family.

### BOX 36-1 Signs of Impending Death

- Profound progressive weakness
- Sleeping much of the time
- Little interest in food and drink
- Difficulty swallowing
- Disorientation to time, with increasingly short attention span
- Urinary incontinence or retention
- Oliguria or anuria
- Dropping blood pressure not related to hypovolemia, with rising, weak pulse
- Changes in respiratory rate and pattern, which may include a Cheyne-Stokes pattern characterized by oscillation of ventilation between apnea and tachypnea with a crescendo-decrescendo pattern in the depth of respirations
- Noisy breathing, airway secretions
- Mottling and cooling of skin
- Mental status changes, such as delirium, restlessness, agitation, and coma

Adapted from Bicanovsky L. Comfort Care: Symptom Control in the Dying. In Walsh, D et al Palliative Medicine 1<sup>st</sup> Edition, Saunders, An imprint of Elsevier Science, 2009.

Many families, especially those who have never witnessed a person dying, might appreciate an explanation of the processes that commonly occur in the imminence of death. This type of explanation may help them to prepare for the events to come when a patient is nearing death. Take the opportunity to ask whether the family has any



questions that you might answer; remember that predicting *exact* timing is NOT something we should or can do.

Some of you may have witnessed the death of a family member or friend and been at the bedside for a prolonged time. We want to emphasize that dying does not always consist of an acute, emergent death or “dying in one’s sleep” and can be distressing to watch. If you have not witnessed the process before, we encourage you to speak with someone who has so that you are not caught in the position of deciding whether something is normal when you simply do not know.

Patients with brain death may demonstrate different signs and symptoms compared to those undergoing cardiopulmonary arrest. The brain death exam is more complex than the cardiopulmonary death exam and will be discussed separately. You will not be expected to conduct a brain death exam on your own during your residency.

## SECTION TWO: WHERE YOU WILL ENCOUNTER PEDIATRIC DEATHS & WHAT YOUR ROLE MAY BE

At LPCH, you will mostly encounter critically ill and children who are actively dying on the following services:

1. *Hematology/Oncology*: There are often ill patients on this service who may be admitted with the anticipation they will die in the hospital. Sometimes during disease-oriented treatment, it becomes clear that cure is not possible, and palliation is pursued. These patients may die expectedly or unexpectedly while you are caring for them. You often get to know these patients and their families well while you are caring for them, and the process of watching a child die and declaring them dead can be extremely challenging.
2. *Pediatric ICU*: As you may expect, you are most likely to encounter dying patients in the ICU. Deaths are more commonly emergent and sometimes unexpected in this setting and may be less anticipated by families. Because there is always a fellow in-house, it is rare that you will be alone in calling a death in this setting, but you still will likely be expected to complete post-mortem administrative tasks. At Valley, you will be expected to declare a patient dead but will always have another resident to help do so.
3. *Emergency Department*: Deaths in the ED are relatively uncommon because we are often able to stabilize patients well enough to get them to the PICU. The deaths you may encounter are most likely to be secondary to trauma with resultant cardiopulmonary or brain death. Patients may also arrive in the ED after they have already died. In these cases, your first encounter with the patient and his or her family is when you declare them dead.
4. *Neonatal ICU*: Very ill infants are admitted to the NICU, and you may encounter dying patients here. Some of these deaths are expected, based on prenatal testing, but many are not. Regardless of the circumstances, deaths of infants are often very difficult for both the family members and for the healthcare providers. The procedures for declaring brain death in neonates are different than for older children, and you will not be expected to make this declaration without the assistance of a fellow and an attending. A fellow is always available on the unit, so you likely will not be declaring a patient dead on your own. However, like in the PICU, you will be expected to complete administrative tasks and to assist the family after the death.
5. *Palliative patients on the medical units*: This occurs less commonly than on adult acute care floors. There are circumstances, however, in which patients are transferred from the ICU to pursue comfort measures. This occurs most commonly on the Blue, Purple, and Yellow teams.

## SECTION THREE: WHAT TO DO WHEN YOU ARE CALLED ABOUT A PATIENT'S POSSIBLE CARDIOPULMONARY DEATH

### 1. Take a minute to prepare and to take a deep breath.

If this is the first time that you have declared a patient dead, many emotions may overwhelm you. It is important to take a moment to prepare yourself and to practice what you will say. Declaring a patient dead under anticipated circumstances is **not** an emergency. Take your time to prepare; your approach will differ depending upon whether or not the death was expected.

### 2. Decide if you need to call anyone to help you.

There are always resources available to help you in the hospital. Overnight you can call the stem cell hospitalist, the overnight hospitalist, the senior night float resident, the PICU fellow, the hematology-oncology resident, or the palliative care team. If the death occurs during the day, let your team know. It is helpful to have another person confirm death, particularly the first time you declare a patient dead.

### 3. Gather your supplies.

This is a suggested list of materials/people to bring with you:

- Stethoscope
- Stopwatch (either on phone or separate)
- Penlight
- If needed, an interpreter
- The patient's nurse

### 3. Enter the room, introduce yourself to the family, and describe what you will be doing.

This step is incredibly important to ensure that the family understands what you will be doing and to prevent any interruptions while you are listening. Make sure to use the child's name. You may provide the family the opportunity to step out of the room at this time, if they would prefer to do so.




*Example:*

“My name is **[your name]**, and I am the pediatric resident doctor on-call. I am so sorry for everything that you are going through. I am here to examine **[child’s name]**. This will take some time – I will be listening to **[his/her]** heart for several minutes and examining **[him/her]**. I will be listening very carefully, so I will not be able to talk to you during that time. I may\* have my phone out so that I can set my timer to make sure that I listen for the appropriate amount of time.”

#### 4. The Cardiopulmonary Death Exam

- Watch the child. Do you see chest wall movement? What does their skin look like?
- Place your stethoscope on the child’s chest over the PMI and listen for at least **two minutes** (taking more time to ensure an accurate exam is ALWAYS appropriate) for any heartbeats and breath sounds. You may also palpate for pulses. You may think you feel pulses that are actually your own, so take your time.
- Checking for pupillary reactions is NOT required, but if you would like to further confirm your results, use a penlight (not a flashlight).
- **Breaking News to the Family**
  - It is best to speak simply and to use plain language. Using the word “died” is better than using euphemisms like “he/she is gone”, “has fallen asleep”, “is with God”, or “is now resting peacefully”. This kind of language, while seemingly comforting, may confuse the family. However, if the family has always referred to death in a certain way, mirroring their language is better to help them to understand and to be comforted.
  - Use the child’s name! Do not refer to “the body”.
  - Examples of what to say:
    - “I’m so sorry, Mr. and Mrs. **[Name]**, but **[child’s name]** has died. I’m very sorry for your loss.”
    - “I am so sorry to have to tell you this, but based on my exam, **[child’s name]** is no longer alive. **[He/She/They]** has died.”
  - Explain to the family that you will need to leave to complete required post-death tasks and to start making arrangements but that you are available for further discussion and support. Ask the family if there is anything you can do at this time to help them. Reassure them that you will return when you are



able. Please ask the bedside nurse to keep you informed about how the child's family is doing while you are completing paperwork or doing other patient care; they may or may not need frequent visits to ensure they know the medical team is present and cares.

- The family will likely want to spend time with their loved one after death. While they may wish privacy, it is helpful for you to reassure them that you are nearby, or you can check in at the bedside to provide support at intervals while you are completing the required paperwork. (*Jones et al.*, *Hanson et al.* and *Back et al.*)
- Ask the family whether they would like someone to call the chaplain or community religious figure.
- Contacting the social worker is usually useful for the family, since he or she may have a close, long-term relationship with the parents. Additionally, the social worker can assist with funeral arrangements and other immediate concerns. On nights and weekends, however, an on-call social worker may need to come in, and he or she may not know the family as well.
- **You must complete these tasks within the first hour of the patient's death:**
  - Contact the medical examiner's office at (408) 793-1900 for Santa Clara County. Be prepared to provide the child's name, date of birth, the circumstances of the death, and what will likely be listed as the cause of death on the death certificate.
    - This is necessary for the coroner to determine if the death will need to be investigated and you will be asked questions about the mechanism of death. If the coroner decides that an autopsy is required and the child is from outside of Santa Clara County, he or she will pass the case along to that county and will instruct you in the next steps. Most often the coroner will tell you no further action is needed unless the family would like an autopsy.
    - Contact Donor Network West at (800) 553-6667 to notify them of the patient's death and the circumstances/underlying illness. Make sure to obtain the DNW Reference Number from the representative on the phone, along with whether the decedent is an organ or tissue donor candidate.



- Be prepared with time and cause of death (ex: cardiopulmonary arrest at 8 pm secondary to terminal metastatic neuroblastoma) and extenuating circumstances (sepsis, any sign of infection). (For instance, terminal cancer patients are unlikely to be appropriate even for corneal collection.) The DNW personnel will usually make an assessment of whether a patient is a candidate for donation. You will likely be asked if there is a possibility your patient was septic prior to death, so it would be helpful to have that information prior to calling.s
- You usually will not be the first person to discuss organ donation with the family. According to a recent change in the LPCH policy, you and the medical team are permitted to broach this subject with a family, but you should emphasize that the Donor Network West representatives will be in soon and are the experts to answer their questions. Alternatively, you may let the family know that another team will be coming to discuss the next steps for their child and allow Donor Network West to approach the family.
- **Asking about autopsy:**

This can feel like an incredibly difficult question to ask a family so soon after the death of their loved one. If this death was expected, hopefully the primary team will have brought this subject up prior to the child's death. We recommend that you discuss this aspect with the primary team when you are covering a patient who is expected to die soon. As part of the death documentation, unless the coroner has required it the family must be asked whether they wish to have an autopsy performed.

Example scripts:

- “We are required by law to ask if you would like to have the pathology department conduct an autopsy after your child's death. Many families decline this option, but we would not want to deny you the opportunity to gain more information about your child's cause of death should you want it. This is not for medical research. We support whichever decision you make.”

## SECTION FOUR: COMPLETING EPIC PAPERWORK

After pronouncing the death of a patient, the patient must be “discharged” from the hospital. In order to do that, you will need to complete several forms within the ADT navigator. This section will outline the basic steps required to discharge a deceased patient.

### How to complete EPIC paperwork and the “death note”:

- Go to the ADT navigator and select the tab “Discharge as Deceased”.

The screenshot shows the ADT Navigator interface. The top navigation bar has tabs for Admission, Transfer, Discharge, and Discharge as Deceased (highlighted with a yellow star). The left sidebar lists various navigation options, with ADT Navigators highlighted at the bottom (also with a yellow star). The main content area displays a 'Deceased Instruction' box with orange text: 'All information in the navigator is REQUIRED documentation after a patient is deceased. Please address ever single line item to document appropriate info for HIMS to apply for Death Certificate from the County. Required to create 2 notes in this navigator: 1. Death Certification Checklist Note (bottom of navigator) - required ASAP for HIMS to apply for Death Certification for the family 2. Discharge Summary (Death Note)'. Below this, there are sections for 'Date/Time of Death' and 'Providers at Time of Death'.

- Fill in the date and time of death, and make sure that the providers listed (attending and treatment team) are correct. The time of death does not need to be completely precise - just round to the nearest five minutes.
- Scroll down to “Notification of Death” and open a “New Reading”. Fill in the dates and approximate times of notification to the family and attending. You will also need to provide contact information for both of these parties. You only need to fill in the name of one family member.

ADT Navigators

Admission Transfer Discharge **Discharge as Deceased**

DOCUMENTATION

Deceased Instruct...  
Date/Time of Death  
Providers at Time...  
**Notification of Death**  
Donor Network W...  
Coroner & Autops...  
Restraints Info  
Death Info  
Discharge Summary  
Provider Notification  
PCP Follow Up  
PCP Contact Info

NOTES

Death Certificate...

**Notification of Death - Post-Mortem**

Time taken: 0834 12/29/2018

Show: ☒ Last Filed ☐ Details ☐ All Choices

Responsible

Attending Info

Attending Physician Notified ☐ Yes ☐ No

Attending Physician Pager Number

Date Attending Notified

Time Attending Notified

Location

Location

LPCH 725 Welch Rd, Palo Alto, CA 94304 Santa Clara Co...

Notification of Death

Family Notified of Death ☐ Yes ☐ No

- Open a “New Reading” under “Donor Network West”. It can be helpful to pull this up while on the phone with the Donor Network. Make sure to obtain the DNW Reference Number from the representative on the phone, along with whether the decedent is an organ or tissue donor candidate.

ADT Navigators

Admission Transfer Discharge **Discharge as Deceased**

DOCUMENTATION

Deceased Instruct...  
Date/Time of Death  
Providers at Time...  
Notification of Death  
**Donor Network W...**  
Coroner & Autops...  
Restraints Info  
Death Info  
Discharge Summary  
Provider Notification  
PCP Follow Up  
PCP Contact Info

NOTES

Death Certificate...

**Donor Network West - Donor Network West (DNW)**

Time taken: 0848 12/29/2018

Show: ☒ Last Filed ☐ Details ☐ All Choices

Responsible

Donor Network West (DNW)

DNW Notification Date

All deaths of live-borns (Appar > 0) must be reported to the Donor Network West within one hour of death, regardless of diagnosis or Medical Examiner cases. 1-800-553-6667 (1-800-55-DONOR).

\*Reminder: If either Coroner and/or Donor Network West (DNW) are contacted, the HIPAA (Disclosure Documentation Form) is required.  
[https://intranet.lpch.org/pdf/formsManualsReferences/patientCareForms/providers/dischargeForms/Core\\_Data\\_Disclosure\\_Documentation.pdf](https://intranet.lpch.org/pdf/formsManualsReferences/patientCareForms/providers/dischargeForms/Core_Data_Disclosure_Documentation.pdf)

DNW Notification Time

DNW Reference Number

DNW Notified By

Pager Number

Organ Donor Candidate ☐ Yes ☐ No

- Open a “New Reading” under “Coroner & Autopsy Info”. Most patients you see will have undergone a reportable death, but feel free to contact the coroner if you

have any doubt. Click on whether the coroner has decided to accept the case or to release it. Make sure to ask for the representative's name and badge number, along with the Case Number or Release Number.

ADT Navigators

Admission Transfer Discharge **Discharge as Deceased**

DOCUMENTATION

Deceased Instruct...

Date/Time of Death

Providers at Time...

Notification of Death

Donor Network W...

**Coroner & Autops...**

Restraints Info

Death Info

Discharge Summary

Provider Notification

PCP Follow Up

PCP Contact Info

NOTES

Death Certificate...

**Coroner & Autopsy Info - Coroner & Autopsy Info**

Time taken: 0850 12/29/2018

Show: ☒ Last Filled ☐ Details ☐ All Choices

Responsible

Coroner & Autopsy Info

Coroner Notified ☐ Yes ☐ Not reportable

It is the **LEGAL OBLIGATION** of the physician in attendance at death to notify the Medical Examiner **IMMEDIATELY** of a reportable death. Under the California Penal Code, willful failure to report a case to the Medical Examiner carries a penalty of **IMPRISONMENT 0 > To 5 Years** and a **FINE OF \$10,000**.

\* Reminder: If either Coroner and/or Donor Network West (DNW) are contacted, the HIPAA (Disclosure Documentation Form) is required.

[https://intranet.lpch.org/pdf/formsManualsReferences/patientCareForms/providers/dischargeForms/Core\\_Data\\_Disclosure\\_Documentation.pdf](https://intranet.lpch.org/pdf/formsManualsReferences/patientCareForms/providers/dischargeForms/Core_Data_Disclosure_Documentation.pdf)

**WHEN ANY DOUBT EXISTS, CALL SANTA CLARA COUNTY CORONER AT 408-793-1900**

1. Suicide
2. Homicide
3. Accidents and all falls prior to or during hospitalization (i.e. fall, trauma)
4. Injury
5. Medical attendance less than 24 hours (death within 24 hours of hospital admissions)
6. Poisoning (food, chemical, therapeutic agents, drug\* including prescription, over the counter meds, and herbals)
7. All deaths in operating rooms
8. All deaths occurring within one week of a surgical procedure
9. Any deaths potentially related to any procedure
10. All deaths in which patient is comatose throughout the period of physician's attendance (whether in home or hospital)
11. Aspirations (any and all)
12. Embolisms (any and all)
13. Physician unable to state the cause of death (the physician must be genuinely unable and not merely unwilling)
14. Grounds to suspect that the death occurred in any degree from a criminal act
15. No physician in attendance
16. In the continued absence of the physician (not having seen the patient in the 20 days before death)
17. All deaths where a patient has not fully recovered from an anesthetic, whether in surgery recovery room, or elsewhere
18. All other deaths (noted by a physician, medical professional, or medical staff)

- Fill in the information regarding when you discussed autopsy with the family and their decision. If they choose to proceed with autopsy, there is a link for the autopsy consent form, which you can print and give them to sign.

ADT Navigators

Admission Transfer Discharge **Discharge as Deceased**

DOCUMENTATION

Deceased Instruct...

Date/Time of Death

Providers at Time...

Notification of Death

Donor Network W...

**Coroner & Autops...**

Restraints Info

Death Info

Discharge Summary

Provider Notification

PCP Follow Up

PCP Contact Info

NOTES

Death Certificate...

Coroner's Response ☐ Accept case ☐ Release case ☐ Not a coroner's case

Case #

Release #

Name Of Medical Examiner/Coroner Notified Of Death

Date Of Medical Examiner/Coroner Notification

Time Of Medical Examiner/Coroner Notification

Autopsy Consent ☐ Yes/Consent signed ☐ Declined ☐ Undecided

The physician is expected to approach the family for permission to perform an autopsy with every perinatal, pediatric, or obstetric death. The indication for autopsy is the death of the patient.

If there is question concerning autopsy, call the Autopsy Service at (650) 723-6265 or page the Autopsy Pathologist on-call.

Physician must obtain signature of legal next-of-kin or durable power of attorney for healthcare on the Autopsy Consent form. An unsigned form is invalid.

Autopsy Consent Form:

[https://intranet.lpch.org/pdf/formsManualsReferences/patientCareForms/providers/dischargeForms/Autopsy\\_Consent.pdf](https://intranet.lpch.org/pdf/formsManualsReferences/patientCareForms/providers/dischargeForms/Autopsy_Consent.pdf)

- For Donor Network West and the coroner's office, make sure to fill out the HIPAA Disclosure Documentation Form and have it scanned into HIMS.

**Lucile Salter Packard Children's Hospital**  
STANFORD UNIVERSITY MEDICAL CENTER  
725 Welch Road, Palo Alto, CA 94304

Medical Record Number  
Patient Name  
Addressograph or Label

**CORE DATA - DISCLOSURE DOCUMENTATION** Page 1 of 2

HIPAA grants patients and their personal representatives the right to an accounting of external disclosures of Protected Health Information (PHI). Therefore, all external disclosures of protected health information (PHI) including those required or permitted by law, but excluding use and disclosure of PHI for treatment, payment, and health care operations (TPO) must be documented.

Use this form to document all non-TPO external disclosures and all disclosures without the patient's (or representative's) authorization.

Instructions:

1. Complete the table below for each disclosure.
2. Forward/Send the original of the completed form to the HIMS Department, MC 5900, for inclusion in the legal medical record.

Date of Disclosure:	
PHI Disclosed To: (External Agency)	Name of Agency/Person:
	Address (if known)
Reason for Disclosure: (i.e. abuse reporting, public health reporting, public health screening, etc.)	Meets Coroner's criteria
Type of PHI Disclosed: (contains any or a combination of PHI – see next page for list of PHI)	Medical history

Signature and Title of Person Who Disclosed the Information \_\_\_\_\_ Date \_\_\_\_\_

152124 Revised 6/07 (04/13)

- Click on “New Reading” under “Restraints Info”. Choose the appropriate responses for the patient situation.
- Click on “New Reading” under “Death Info”. Answer whether there were any biopsies or falls during the hospitalization. Then complete the death information, including the immediate cause of death (i.e. the process that acutely resulted in the patient's demise), along with how long the patient had that condition. Fill in this section to the best of your ability.
  - For instance, if a patient died of cardiopulmonary arrest secondary to a respiratory viral infection exacerbating underlying neuromuscular condition, the immediate cause of death would be “cardiopulmonary arrest”, which lasted for a few minutes before the death. The diseases/conditions leading to cause of death would then be the viral respiratory infection (started 3 days prior to death) and the neuromuscular disease (diagnosed at two months of age).

**Death Info - Biopsy, Accident, Death Info**

Time taken: 0856 12/29/2018

Show: ☒ Last Filed ☐ Details ☐ All Choices

Responsible

---

**Biopsy**

Biopsy Performed In This Hospitalization ☐ Yes ☐ No

---

**Accident/Fall**

Accident/Fall Occurred To Patient Before Or During Hospitalization ☐ Yes ☐ No

---

**Death Information**

A. Immediate Cause of Death   
Final disease or condition resulting in death

Time Interval Between Onset and Death   
(e.g. minutes, hours, days, months, years)

B. Disease or Condition Leading to Cause of Death (Underlying Cause)

- There are several tabs to document the notification of the death to referring providers and to the patient's PCP. Fill these out to the best of your ability as you contact these individuals.



- TWO notes must be completed with each patient death: The discharge summary and the death certificate checklist.
  - The discharge summary is like any other discharge summary but uses the template IP DISCHARGE SUMMARY (DEATH NOTE). Several items from the ADT Navigator will auto-populate in the note. However, you will need to include a brief description of the events surrounding the time of death.
  - The death certificate checklist will also auto-populate with items from the ADT Navigator. You should sign your name at the bottom of the note and then sign the note.

ADT Navigators

Admission Transfer Discharge **Discharge as Deceased**

DOCUMENTATION

- Deceased Instruct...
- Date/Time of Death
- Providers at Time...
- Notification of Death
- Donor Network W...
- Coroner & Autops...
- Restraints Info
- Death Info**
- Discharge Summary
- Provider Notification
- PCP Follow Up
- PCP Contact Info

NOTES

- Death Certificate...

**Discharge Summary**

Create Note See All Notes Refresh

No notes of this type filed.

**Notification to Referring Providers**

New Reading Flowsheets

No data found.

**PCP**

New Reading Flowsheets

No data found.

**PCP Contact Info**

Primary Care Physician: PENDING INTERVIEW Phone Number: None Department: None

**Death Certificate Checklist**

Create Note See All Notes Refresh

## SECTION FIVE: A WORD ON BRAIN DEATH

You may care for patients in the PICU or ED who have experienced brain death. You should take the opportunity to participate in the brain death exam with your attending and fellow or with the neurology team, but you will not pronounce brain death as a resident at Stanford/LPCH. Of note, the brain death exam in children consists of two exams, separated by at least 12 hours in children and by at least 24 hours in infants. For premature infants, you should discuss how the criteria differ. The main components of the brain death are noted in the AAP brain death checklist below by Nakagawa et al. You can also find the guidelines at <http://pediatrics.aappublications.org/content/128/3/e720.figures-only>

Brain Death Examination for Infants and Children					
Two physicians must perform independent examinations separated by specified intervals.					
Age of Patient		Timing of first exam		Inter-exam. interval	
Term newborn 37 weeks gestational age and up to 30 days old		<input type="checkbox"/> First exam may be performed 24 hours after birth OR following cardiopulmonary resuscitation or other severe brain injury		<input type="checkbox"/> At least 24 hours <input type="checkbox"/> Interval shortened because ancillary study (section 4) is consistent with brain death	
31 days to 18 years old		<input type="checkbox"/> First exam may be performed 24 hours following cardiopulmonary resuscitation or other severe brain injury		<input type="checkbox"/> At least 12 hours OR <input type="checkbox"/> Interval shortened because ancillary study (section 4) is consistent with brain death	
<b>Section 1. PREREQUISITES for brain death examination and apnea test</b>					
<b>A. IRREVERSIBLE AND IDENTIFIABLE Cause of Coma (Please check)</b>					
<input type="checkbox"/> Traumatic brain injury <input type="checkbox"/> Anoxic brain injury <input type="checkbox"/> Known metabolic disorder <input type="checkbox"/> Other (Specify) _____					
<b>B. Correction of contributing factors that can interfere with the neurologic examination</b>		<b>Examination One</b>		<b>Examination Two</b>	
a. Core Body Temp is over 95° F (35° C)		<input type="checkbox"/> Yes <input type="checkbox"/> No		<input type="checkbox"/> Yes <input type="checkbox"/> No	
b. Systolic blood pressure or MAP in acceptable range (Systolic BP not less than 2 standard deviations below age appropriate norm) based on age		<input type="checkbox"/> Yes <input type="checkbox"/> No		<input type="checkbox"/> Yes <input type="checkbox"/> No	
c. Sedative/analgesic drug effect excluded as a contributing factor		<input type="checkbox"/> Yes <input type="checkbox"/> No		<input type="checkbox"/> Yes <input type="checkbox"/> No	
d. Metabolic intoxication excluded as a contributing factor		<input type="checkbox"/> Yes <input type="checkbox"/> No		<input type="checkbox"/> Yes <input type="checkbox"/> No	
e. Neuromuscular blockade excluded as a contributing factor		<input type="checkbox"/> Yes <input type="checkbox"/> No		<input type="checkbox"/> Yes <input type="checkbox"/> No	
<input type="checkbox"/> If ALL prerequisites are marked YES, then proceed to section 2, OR <input type="checkbox"/> _____ confounding variable was present. Ancillary study was therefore performed to document brain death. (Section 4).					
<b>Section 2. Physical Examination (Please check)</b>		<b>Examination One</b>		<b>Examination Two</b>	
<b>NOTE: SPINAL CORD REFLEXES ARE ACCEPTABLE</b>		<b>Date/ time:</b>		<b>Date/ Time:</b>	
a. Flaccid tone, patient unresponsive to deep painful stimuli		<input type="checkbox"/> Yes <input type="checkbox"/> No		<input type="checkbox"/> Yes <input type="checkbox"/> No	
b. Pupils are midposition or fully dilated and light reflexes are absent		<input type="checkbox"/> Yes <input type="checkbox"/> No		<input type="checkbox"/> Yes <input type="checkbox"/> No	
c. Corneal, cough, gag reflexes are absent		<input type="checkbox"/> Yes <input type="checkbox"/> No		<input type="checkbox"/> Yes <input type="checkbox"/> No	
Sucking and rooting reflexes are absent (in neonates and infants)		<input type="checkbox"/> Yes <input type="checkbox"/> No		<input type="checkbox"/> Yes <input type="checkbox"/> No	
d. Oculovestibular reflexes are absent		<input type="checkbox"/> Yes <input type="checkbox"/> No		<input type="checkbox"/> Yes <input type="checkbox"/> No	
e. Spontaneous respiratory effort while on mechanical ventilation is absent		<input type="checkbox"/> Yes <input type="checkbox"/> No		<input type="checkbox"/> Yes <input type="checkbox"/> No	
<input type="checkbox"/> The _____ (specify) element of the exam could not be performed because _____. Ancillary study (EEG or radionuclide CBF) was therefore performed to document brain death. (Section 4).					
<b>Section 3. APNEA Test</b>		<b>Examination One</b>		<b>Examination Two</b>	
No spontaneous respiratory efforts were observed despite final PaCO <sub>2</sub> ≥ 60 mm Hg and a ≥ 20 mm Hg increase above baseline. (Examination One)		Pretest PaCO <sub>2</sub> : _____		Pretest PaCO <sub>2</sub> : _____	
No spontaneous respiratory efforts were observed despite final PaCO <sub>2</sub> ≥ 60 mm Hg and a ≥ 20 mm Hg increase above baseline. (Examination Two)		Apnea duration: _____ min		Apnea duration: _____ min	
		Posttest PaCO <sub>2</sub> : _____		Posttest PaCO <sub>2</sub> : _____	
<input type="checkbox"/> Apnea test is contraindicated or could not be performed to completion because _____. Ancillary study (EEG or radionuclide CBF) was therefore performed to document brain death. (Section 4).					
<b>Section 4. ANCILLARY testing is required when</b> (1) any components of the examination or apnea testing cannot be completed; (2) if there is uncertainty about the results of the neurologic examination; or (3) if a medication effect may be present.				<b>Date/Time:</b>	
Ancillary testing can be performed to reduce the inter-examination period however a second neurologic examination is required. Components of the neurologic examination that can be performed safely should be completed in close proximity to the ancillary test					
<input type="checkbox"/> Electroencephalogram (EEG) report documents electrocerebral silence OR				<input type="checkbox"/> Yes <input type="checkbox"/> No	
<input type="checkbox"/> Cerebral Blood Flow (CBF) study report documents no cerebral perfusion				<input type="checkbox"/> Yes <input type="checkbox"/> No	

---

## **SECTION SIX: CARING FOR YOURSELF AFTER A PATIENT'S DEATH**

Everyone responds differently to a patient's death, and there can be a continuum of responses to this situation. Each patient death is unique and will likely affect you differently. You may feel devastated, angry, confused, guilty, relieved, or nothing at all - all of these emotions are normal! Some deaths will affect you more than others, depending upon your level of involvement in the case or on your personal situation.

In the immediate aftermath of a patient death, it may be helpful to take some time to yourself for a little while. Ask your team if they can support your other patients while you take the time to grieve or to think. At times, you may not feel anything, but do not be surprised if the full impact of the patient death hits you later on.


Some studies have demonstrated that it can be helpful for a team to conduct a debrief session, in which all those involved with the patient's care can discuss the situation and their feelings about it in a safe space, including whether anything could have been done differently and the effect of the death on members of the team (Eng J *et al* 2015).

A pediatric death affects everyone who cared for the child. At times, the Enterprise Resiliency Team led by Julie Collier will be called to support the entire team, including residents, fellows, attendings, nurses, social workers, child life specialists, and other team members. You are welcome to participate in these debriefings as much as you feel comfortable. The palliative care team (available on pager 24/7) is also available to facilitate debriefings, either on a one-on-one basis or as a group.

### **What resources are available for residents coping with a patient death?**

The palliative care team can be an invaluable resource to you, and not just for your patients and their families! The palliative care team at LPCH is always willing to be consulted to help residents who are coping with tragic events in their patients. The chaplaincy is also available to assist residents. Additionally, the chiefs and residency program leadership may also serve as good resources while grieving.

Through Stanford, you are eligible for 12 free sessions with one of 60 non-Stanford Clinic psychiatrists and psychologists. These are confidential sessions. The main contact is Janet Spraggins, MD, and her phone number is (650) 346-3241.



Stanford also has the Well Connect service to facilitate timely access to counseling, mental health services, and coping skills. Phone number: (650) 724-1395. This service is available 24/7, including for emergencies.


Another resource is the Stanford Physician Peer Support Program, which is a confidential, legally-protected service comprised of trained physicians (including residents and fellows) to provide active listening, coping support, and other resources to physicians in need. Contact [medpeersupport@stanford.edu](mailto:medpeersupport@stanford.edu) for more information. Additional information is available at <http://wellmd.stanford.edu/get-help/peer-support.html>

**Should I communicate with families after a patient death? What forms of communication would be acceptable?**

Literature shows that families often feel abandoned in the months to years after the death of a loved one, and some families will seek out connections with those who knew their child well in his or her last days (*Jones et al.*, *Hanson et al.*, and *Back et al.*)

Some families will extend invitations to the residents and to their care team to attend their child's funeral. You are not under any obligation to attend but are certainly welcome to do so if invited. Depending on the family's culture, some parts of the ceremony, such as the interment of the body, are much more private and may be restricted to family members only. If you have any concerns, feel free to ask the family or other attendees about what is appropriate. If you choose to attend the funeral or other services, it is recommended to attend with another medical professional who cared for the child.

Some residents find solace in maintaining some level of communication with the family of a patient who has died, while others would rather avoid further contact with the family. If you developed a close relationship with the family while caring for their child, you may continue to maintain a professional relationship with them. Sending a sympathy card or email is certainly acceptable and is deeply appreciated by families. Some families may find it too difficult to continue to communicate with those who remind them of their time in the hospital, while others are eager to remain connected with someone who knew their child in their final hours or days. When considering pursuing further communication with a family, you should always be cognizant of whose needs are being met: yours or the family's, or both.



Every family of a child who has died at LPCH is invited to the hospital-wide Annual Day of Remembrance and Rededication in the fall of each year, and all residents are invited to attend this ceremony as well. Families are only invited to this event if their child died more than six months ago, but they are welcome to attend for as many years as they wish. The oncology division holds its own event like this in the spring of each year. These ceremonies will provide good opportunities for you to reconnect with patient families, if you so desire. The families who attend this event greatly appreciate connecting with the individuals who treated their children.

## REFERENCES

- Back, Anthony L et al. "Abandonment at the End of Life from Patient and Clinician Perspectives: Loss of Continuity and Lack of Closure." *Archives of internal medicine* 169.5 (2009): 474–479. *PMC*. Web. 21 Sept. 2018.
- Beattie L, Ryan M, Rowe J, Mazin R. A pediatric death from non-accidental trauma. *MedEdPORTAL*. 2015;11:10064. [https://doi.org/10.15766/mep\\_2374-8265.10064](https://doi.org/10.15766/mep_2374-8265.10064)
- Eng J, Schulman E, Jhanwar SM, and Shah MK. "Patient death debriefing sessions to support residents' emotional reactions to patient deaths." *Journal of Graduate Medical Education*. 2015 Sep; 7(3):430-6.
- Hobgood C, Woodyard J, Sawning S, Savage K. Delivering the news with compassion: the GRIEV\_ING death notification protocol. *MedEdPORTAL*. 2010;6:8210. [https://doi.org/10.15766/mep\\_2374-8265.8210](https://doi.org/10.15766/mep_2374-8265.8210)
- Jones, Barbara L., Nancy Contro, and Kendra D. Koch. "The duty of the physician to care for the family in pediatric palliative care: context, communication, and caring." *Pediatrics* 133.Supplement 1 (2014): S8-S15.
- Hanson LC, Danis M, Garrett J. What is wrong with end-of-life care? Opinions of bereaved family members. *J Am Geriatr Soc*. 1997 Nov;45(11):1339–1344.
- Murphy T, Saul D, Hollenkamp E, et al. A child's last hours—multidisciplinary training in end-of-life care in children's hospitals: adolescent with cystic fibrosis. *MedEdPORTAL*. 2016;12:10372. [https://doi.org/10.15766/mep\\_2374-8265.10372](https://doi.org/10.15766/mep_2374-8265.10372)
- Marks A, Hollenkamp E, Bradman S, et al. A child's last hours—multidisciplinary training in end-of-life care in children's hospitals: school-aged child with terminal cancer. *MedEdPORTAL*. 2016;12:10371. [https://doi.org/10.15766/mep\\_2374-8265.10371](https://doi.org/10.15766/mep_2374-8265.10371)
- Nakagawa, Thomas A., et al. "Clinical report—Guidelines for the determination of brain death in infants and children: an update of the 1987 task force recommendations." (2011): peds-2011.
- Schultes K, Saks N. Death on the wards: preparing medical students for clinical and clerical duties. *MedEdPORTAL*. 2012;8:9254. [https://doi.org/10.15766/mep\\_2374-8265.9254](https://doi.org/10.15766/mep_2374-8265.9254)
- Senthil K, Serwint JR, and Dawood FS. Patient end-of-life experiences for pediatric trainees: spanning the educational continuum. 2016;55(9):811-818.

[http://journals.sagepub.com/doi/abs/10.1177/0009922816631513?url\\_ver=Z39.88-2003&rfr\\_id=ori%3Arid%3Acrossref.org&rfr\\_dat=cr\\_pub%3Dpubmed&](http://journals.sagepub.com/doi/abs/10.1177/0009922816631513?url_ver=Z39.88-2003&rfr_id=ori%3Arid%3Acrossref.org&rfr_dat=cr_pub%3Dpubmed&)

Siegelman J, DeSandre P, Quest T. Child death disclosure - standardized patient case. MedEdPORTAL. 2015;11:10051. [https://doi.org/10.15766/mep\\_2374-8265.10051](https://doi.org/10.15766/mep_2374-8265.10051)

Teno JM, Clarridge BR, Casey V, et al. Family perspectives on end-of-life care at the last place of care. Jama. 2004 Jan 7;291(1):88–93.