Building Bridges along the Death Care Continuum

Advocating for home funerals in hospices, hospitals, and care facilities
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“A dedicated group of friends cared for A during her brief illness and were present at her death. She was clear that she wanted to remain in her home for three days after her death. Her family members were supportive of her desire to have a home vigil and deeply grateful to her friends for their guidance in washing, dressing and blessing her body, preparing the house for the vigil, moving her from the bed to the casket and using Techni-ice to keep the body cold. A vigil was kept round the clock by close friends and family members. During certain hours of the day the home was open for friends and associates to view her body, sign a guest book and offer condolences. On the morning of the third day, mementos were added to the casket and the cover put into place. As her body was being carried to a waiting van, several community members who had gathered outside the house were singing hymns. A’s father and two of her friends accompanied the body to the crematory. I can’t imagine doing this any other way.” — KD, Wisconsin
Introduction

Overview and Intent

Hospital policies and procedures have long assumed the release of dead bodies involve professional funeral directors and transport firms only. Likewise, nursing facilities routinely ask for a funeral home to be selected upon admission, and hospice case workers are trained to ask which funeral home to call when death occurs. Through these policies and procedures, facilities inadvertently cut out the right to custody and control that belongs to the next-of-kin.

In a handful of states, the law gives custody and control to the family but requires that they hire a professional—at their own expense—to handle the details. In all states, the failure of our caring institutions to recognize and empower the legal authority for the next-of-kin to act on his or her rights is an unfortunate disservice to those families.

The purpose of this book is to provide alternative language that better serves families while partnering with policymakers in hospices, hospitals and nursing care facilities to create effective, accurate, and family-friendly policies.

As the medical world has evolved, there has been an understandable institutional need for formal policy and procedures. Policies were necessarily conceived by administrators in an attempt to bring order to best practices through the subjective lens of commonly accepted cultural practices.

But with more families taking responsibility for the after-death care of their loved ones, we are discovering that those policies are often in direct opposition to the state laws, whether stated or implied, that give families the right to care for their own dead.

Rather than hire a professional, home funeral families opt to exercise the right to keep the body at home for vigil, to file paperwork, transport the body, or complete other tasks. When those rights are infringed upon by institutional policy, it undermines the intent of the law and the fundamental freedoms we are accorded under constitutional family law, creating a separation of authorities that leaves families disempowered.

It is our hope that as home funeral advocates approach hospices to explain the need for family-centered, legally
compliant policies, that divide will cease to exist. Ensuring that the policies in our institutions are family-friendly and legally compliant are of the utmost importance to the successful transition from any facility to the home after death.

We hope these resource materials and suggestions will be useful in effecting policy changes that benefit home funeral families and staff alike.
One of the hardest things to ascertain when dealing with agencies and facilities is where to begin and who to speak with. As with all of this work, how to be an effective change agent has a lot to do with understanding the system and the players you are trying to negotiate with. Rural hospitals may have a different reporting or authority structure than a major metropolitan hospital, and a teaching hospital might have another. Privately owned nursing facilities are going to operate differently than three-tier care facilities that cater to different populations, disease progressions, and a myriad of other demographic factors such as religious affiliation. And there will be a world of difference between a VNA (Visiting Nurse Associations) and a for-profit hospice, whether they serve in the home or in an institutional hospice house.

Here we have tried to provide you with a basic understanding of the roles people play in all of these facilities, and to give you a general idea of how they relate to one another. Knowing who the appropriate person to contact first can, in some cases, be instrumental in being successful in advocating for families’ rights. Doing your homework by learning who the players are in your target facility will go a long way to ensuring your success.

Physicians

Depending on the size of the hospital, there may be a number of physicians treating a particular patient. Often, there is a primary treating physician who is overseen by a Medical Director of a Department or Care Facility. In teaching hospitals, there are also Residents (physicians in training) or Hospitalists (Internal Medicine physicians who treat patients admitted at the hospital) who care for patients.

If you are advocating for or on behalf of a person/loved one at the time of their death, it is best to find out the name of the patient’s primary treating physician is. This is the physician who knows their medical history best. Sometimes, it is the patient’s primary care physician or Internal Medicine physician. If the patient has had a more complicated, chronic medical condition, it may be a specialist physician.

When a person dies suddenly or unexpectedly in an emergency room, there are usually resident physicians who are assigned to specific patients, but it is best to speak directly with the Chief Resident who is the physician in charge.
of an emergency room. If the emergency room physician in charge is unavailable, it is best to speak directly with the nurse in charge of the patient and/or emergency room.

When advocating for hospital or hospice-wide system or policy changes, it is best to communicate with the Chief of Medicine or Medical Director of the care facility.

As advocates, who we contact first will depend on whether we are advocating at a person’s time of death (more immediate) or if we are attempting to make in-roads at a new care facility and, in the process, building relationships.

**Nurses**
Nursing staff can be the source of our main contacts at a care facility during and after death care. Hospice and palliative care nurses work closely with physicians and other health providers (social workers and chaplains) as part of the interdisciplinary team. They provide 24-hour nursing services, pain and other symptom management, and emotional/family support. They also provide counseling services and compassionate care to patients and families.

Nurses can work within a patient’s home or as part of an in-patient unit at a hospice or hospital setting. Nurses also work with and visit patients in long-term care settings, such as assisted living facilities or nursing homes.

Within a hospital/hospice setting, a nurse manager or a nurse supervisor is in charge of a unit or department. Often, they communicate and relay important information between families and physicians. In the moment, when a person has died, it is best to speak directly with the head of nursing in a department or unit in order to discuss releasing the body, forms that will need to be completed by the physician and communicating a families’ wishes.

**Social workers**
Health care professionals who provide emotional and psychological support, case management, and advocacy to patients and their families are social workers. In a palliative care or hospice setting, the social worker may provide help in many different ways. Social workers assist patients and families with healthcare decisions and navigating the healthcare system; assess the emotional, cultural, psychological, economic needs and social supports of a patient and family; ensures that the patient’s end-of-life wishes are documented; assists with advance directives, Do Not Resuscitate (DNR) orders or Physician Orders for Life-Sustaining Treatment (POLST) forms; helps families by contacting local agencies and/or community resources (i.e., hospice agencies); assists with health care insurance
such as Medicaid and Medicare paperwork; assists with funeral planning; and identifies and refers patients and families for grief counseling or spiritual care services.

Typically, one social worker is assigned to a patient to provide continuity of care. It is best to reach out to the specific social worker assigned to the patient or the social worker who is assigned to a specific unit of a hospital or department. The social worker will build a relationship with the hospice patient and their support system and assist in areas of need that they identify together. Most hospice agencies have a social worker on call for urgent patient and family needs after hours as well.

**Chaplains**

Spiritual caregivers in a hospital/hospice setting are called chaplains. Chaplains in a hospital/hospice setting are from varying faiths and provide services to a diverse group of patients. Chaplains provide spiritual counseling before surgeries or traumatic events. They provide bereavement services and support to patients and their families, as well as spiritual counseling during end-of-life planning.

Patients and families call upon chaplains to communicate their end-of-life wishes or to receive comfort, support or prayers. Families may often feel comfortable expressing these wishes to a spiritual care provider rather than a physician. Chaplains work with the patient care team and can be a strong and steady advocate for patients and their families in carrying out end of life wishes. They work in concert with physicians, nurses and social workers and can often communicate a patient’s and their family’s wishes to the care team. They can also provide memorial services within the hospice/hospital setting.

**Patient Advocates**

Patient advocates are hospital/hospice staff members who handle patient complaints. Larger facilities often have a Patient Advocacy Department. Advocates also provide information about Advance Directives to patients and their families. If you have questions and you are having difficulty finding answers for a person or would like to get your funeral plans and end of life wishes written down, patient advocates may be a good resource as they can assist in helping with Advance Care Directives. They also are able to reach a specific treating physician or communicating a person’s and/or family’s wishes to the right healthcare provider and team.

**Hospital/Hospice Administrators**

Administrators are CEOs, Vice Presidents, Executives, Department Heads who “run” the hospital. It is important to get acquainted with the hospital/hospice structure and culture in your area.
The larger the institution, the more complex the structure will be. Administrators are those who oversee the budget and finance of the institution and who make and create policies and procedures.

In order to discuss policies and procedures, a standing committee may meet regularly to discuss and review best practices within a care facility. It may be called “Policy and Procedure Committee” or “Continuous Quality Improvement Committee”. The committee names vary depending on the facility, but most settings will have some type of administrative committee where policies are discussed. These committees are often interdisciplinary with the Heads of Departments, Managers/Vice Presidents representing Physicians, Clinical staff, Finance and Legal. Depending on how complex the hospital organizational chart is, you may find it difficult to identify the “go to” administrator. It is best to begin with a primary provider for a patient (i.e. physician, nurse, social worker) and work your way up the organizational chart. Every healthcare staff member has a supervisor/manager to whom they report and can be a great resource in finding out more information on how policies are made, changed and carried out.

**Hospitalists**

Of important note to home funeral advocates, advocacy and interventions will differ based upon whether you are managing a person’s death in the moment or whether you are broadly advocating for policy and systems changes within a new care facility. In the moment, the rule of thumb is to contact a person’s primary, treating physician (whether in a hospital, hospice or other care facility). Physicians who are responsible for hospitalized patients within a hospital are called Hospitalists. During off hours, reaching out to a Hospitalist can be a next resource. In many situations, if the physician is unavailable, the “go to” healthcare staff will be the Director of Nursing or Nurse Supervisor of a Unit/Department.
Advocating for Home Funerals in Hospices

Of all the agencies involved, hospice seems to be the most natural fit. Families who have cared for their loved one at home already understand the needs of the body and the lack of urgency at the time of death, and tend to share an ethic that fosters family-centered home care in lieu of institutional care.

There is a natural segue from hospice care to after-death home care. In fact, many times the nurse called to pronounce the death will stay at the invitation of the family to help bathe, wash hair, put on fresh clothing, and tend to the laying out of the body. Families take their cue from hospice about taking time to be present. Often, hospice staff will partner with home funeral families to acquire the necessary signatures from the hospice or attending physician.

More importantly, hospice and home funeral advocates share a philosophy of care that includes a long list of qualities that support families as full participants in care decisions, including advanced directives and funeral planning. Both wish their loved one to be treated with honesty, respect, compassion and dignity. Families look to home care as a familiar and safe place where they can feel validated in their grief and in their spirituality. They trust that the sanctity of the body will be respected before and after death by all who participate. And both share a belief in empowering families to care for their own.

The biggest impediment to families attempting to exercise their responsibility to care for the person they now have custody and control of is often well-meaning hospice nurses and personnel who misunderstand the legal limits of their authority. Although state law tends to state specifically that they no longer have the responsibility for the body after pronouncement is complete, often written or unwritten policies dictate that the hospice representative stay on hand until a funeral director arrives.

On occasion, agencies have violated HIPAA regulations by tracking and speaking about patients that were no longer on their service. This can create conflict for both the family and the hospice worker. Making these matters clear, and understanding on both sides that further involvement is voluntary and at the invitation of the family benefits both parties.
Sample Letter to Hospices
Offering in-service presentations and workshops

Mary Brown
YOUR ORGANIZATION

John Smith
Your Local Hospice
On your local street
Everytown, Everystate

Dear John,

I am writing to you today to share information with you and your agency regarding home funerals in hopes that we might pool our resources to help families who are searching for heartfelt and meaningful, eco-conscious and economical ways to honor their departed loved ones.

<INSERT YOUR ORGANIZATION’S NAME>’s mission is to educate agencies and the public about all the available options that address the funeral needs of families. We provide kitchen-table planning for families, phone consultations, public presentations, and home funeral workshops. Our website connects people and services to anyone in our area with home funeral questions.

Over the years, we have presented many in-services and trainings to hospice nursing staff and volunteers that focus on the changing landscape of after-death care, including topics such as how to be an informed funeral consumer and the legal responsibilities for hospice nurses and personnel who might be involved with a family choosing to keep or bring a loved one home after death.

We are eager to share information that will expand your employees’ and volunteers’ knowledge about their role when serving home funeral families. Please consider scheduling a presentation designed specifically for your next in-service or training.

I look forward to hearing from you soon. Thank you,

Mary Brown
Many hospice families could benefit from receiving more information about their funeral choices. Often staff members, including social workers, nurses, chaplains and administrators, would like to offer more information but don’t have the time or the knowledge. This is where a home funeral volunteer can help by providing a wide base of information that includes information on affordable, meaningful, and practical options.

The family is usually asked upon admission or at subsequent visits what funeral firm they would like to have called. This halts any questions the family might have about other options and limits their ability to make informed choices.

When advocating for home funeral families to hospice personnel, suggest that they ask instead if the family would like to talk to someone about their funeral choices. Explain that funeral educators can give families the information they need to be able to design and carry out meaningful, family-centered funerals that reflect their values while staying within their means.

Explain that by offering this service, their facility will expand its offerings at no cost, either actual or for any of their staff. Often patients and families find this conversation difficult and time-consuming. By having a knowledgeable professional to facilitate this discussion, staff is freed up to concentrate on patient care, and families receive appropriate, compassionate attention that results in a comprehensive family-directed after-death plan.

In the same conversation, plan to cover the following questions:

Q. Who will ask the question offering funeral planning rather than calling professionals?
A. Social workers, nurses, chaplains or administrators broach the topic while doing the admission. They explain that the volunteer can offer information regarding ways to make funerals and final dispositions more eco-friendly and affordable.

Q. Who will they ask?
A. Sometimes this is a question to be asked discreetly of the next-of-kin rather than the patient at admission, but if a patient is interested in participating in this decision, it should be addressed early in the process.

Q. What is the process for when families ask for assistance?
A. The volunteer is notified by the case manager or whoever is handing the
case. The volunteer is given contact information with which to call the family and set up a visit in a place that is convenient for the family. The meeting must occur as quickly as possible and include people chosen by the patient or next-of-kin. A follow-up meeting may be necessary if there is a lot of information to digest, complex decisions to be made, or more people to involve. Sometimes the patient wants to conduct his or her own planning alone with a volunteer’s assistance; sometimes it is a facilitated family discussion around the kitchen table; sometimes the discussion occurs between the volunteer and the next-of-kin over coffee at a café or senior center or wherever it is private.

Q. What happens at a funeral options conference?
A. The basic goals for the meeting are to:
   • discover initial thoughts
   • offer suggestions on all available choices
   • assess family dynamics, values, considerations, concerns, financial constraints, spiritual needs, ability to take on responsibilities
   • determine what further information is needed
   • briefly go over a price list comparison and how to read it
   • listen and clarify
   • answer questions
   • give referrals
   • provide and explain applicable handouts
   • assist in filling out an action plan
   • determine if and when staff can help and communicate that to both family members and staff
   • offer to provide a follow-up visit

Q. What other duties does a volunteer have?
A. Keeping the lead nurse/social worker and staff informed of decisions and concerns as appropriate. Other issues may arise that require coordinating with other professionals.

Q. What needs to happen after the death?
A. The volunteer may:
   • maintain contact with the family, be available to answer questions
   • attend funeral services as a representative of the agency
   • maintain confidentiality, meet HIPAA requirements
   • document the visit

Q. How will the visit be documented?
A. Documentation is completed the same way as the agency records other volunteer hours.

Q. Will any standard forms need to be modified?
A. Check the agency’s admission packet for any materials that may need to be reviewed and changed to include a wider base of non-biased options.
Q. Do any policies need to be reviewed?
A. Often institutional policies around after-death protocol are developed without regard for compliance with funeral law, or laws have changed without policy updates. Home funeral educators are a valuable resource in evaluating existing policies that may inadvertently restrict the rights of families and assist in crafting new policies that support after-death care choices.

Q. What staff education is needed?
A. Home funeral educators are equipped with presentation tools to provide in-services designed to inform staff of their legal responsibilities and how they can assist families most productively when carrying out their tasks.

Q. What additional education might be needed?
A. Often physicians, agency or facility administrators, policy makers, clergy, and others are unaware of the variety of choices patients have. In-service presentations and written materials are helpful for keeping everyone on the team informed and in a position to support patient and family choices.
Giving In-service Trainings and Presentations to Hospices

Many hospices have policies in place that impede home funeral families and place their own employees at risk for liability. In an effort to partner with hospices, the NHFA has developed a PowerPoint presentation expressly for training hospice staff and volunteers. It is designed to meet time requirements for in-services for busy professionals, and highlights the nature of home funerals and how they relate to hospice care. It relays state-specific information regarding legal requirements and liability concerns. Here are some basic tips for personalizing yours:

Basic Presentation
A running script has been provided in the Notes section to give the speaker a general idea of the flow and intention of the slides. Feel free to improvise using your own voice.

Customizing the Presentation
The presentation lends itself to customizing simply by re-ordering the existing slides or adding ones that speak to your specific audience. To replicate the fonts and sizing, most styles are set in the Master slide, though others have been customized. For more information on how to design or edit the existing slides, go to the Help menu or follow the instructions and recommendations below.

Change Text
You can edit text just as you would in any word processing program by highlighting, cutting, copying and pasting, or by highlighting and simply typing. Several slides will require that the presenter do some local and state homework to ascertain the accurate information as indicated. And it never hurts to tell a good story.

Replace Photos
Don’t like the photo on a given slide? Switch it out with one from the Photo Gallery or upload your own. Simply highlight the offending photo, delete it, highlight the one you want and paste it in place. Grab a corner to resize it, highlight it and move it to the desired location. Don’t forget to change the credits.

Add Video Clip
To add a video clip to your presentation, select the slide you want to use (create a new one by clicking on New Slide). Click Insert at the top of your menu bar, then go to Movie or Media on the same bar. Click Movie from File (presumably you have it downloaded onto your computer and filed somewhere easy to find), then navigate to the file you want; click on it, then hit OK. You will get an alert box asking if you want
the film to begin automatically or manually.

Change the Slide Order
Slides are easy to move around, so if you have a better flow in mind, feel free to change it. Click on the slide you want to move on the left hand column under Slides. It will get an orange frame so you’ll know what you are working on. Click and drag it up or down to its desired location.

Edit the Commentary
Easy. Just like any other text. If there is text in the main slide that you want to remove, simply highlight, cut and paste it into the Notes section. This is space reserved for you and only you, so load it with good facts and figures so you will have access to it if you need it.

Create Custom Presentations
If you don’t want to create completely different documents just to eliminate or add a slide, another option is to create a custom slide show for a specific event. Open the master slide show and click on Slide Show on the main top menu bar. Then click on Custom Shows, Edit Custom Shows. Here you will be able to name a new presentation by clicking NEW, then typing the name of your new presentation. Select the slides you want to use, reorder them if necessary with the up and down arrows, and you will have a show specific to the audience you are addressing. To play, just go to Custom Shows and click to begin.

Animate
To bring in lines and images when you want them during your show, go to Animations on the top menu bar. Click on the textbox you want to animate. You can either highlight the box itself or highlight each line in the order you choose. Once highlighted, click on Entrance Effects. Use ONE STYLE for your presentation, not a circus of different zips in and out. To change the order of appearance, click on Reorder on the top right and use the arrows. If you want to have things disappear, use Exit Effects. Be careful with these commands, as they are often distracting.

Dress Up Images, Text Boxes
To add text boxes, go to the Insert section of the Home page. There you will find a text box with a big A on it. Click, then touch down on the slide and begin typing. Adjust the font, style, color and size as necessary. To add frames around text boxes and images, click on the image or box. This will highlight Format on the menu bar. Click on Format, then find Line. Choose colors, then More colors to customize, Weight to determine width of lines, Effects to change shape, and any number of other ways to customize. Try not to create a circus of colors—choose one and use it uniformly.
General Image Placement
The same design theory applies to placement. Each slide needs to have common elements in order for the eye to read it comfortably. Keep images in the same general vicinity from slide to slide so the reader knows what to expect. Text size should also be uniform so as to appeal to the reader for content, not shock value.
Hospice In-Service Presentation
See the List of Links at the back of this book for the location of this presentation

Bridging the Death Experience
Helping families transition from hospice home care to after-death home care

Today’s Topics
- providing a continuum of care for hospice patients who become home funeral families
- state and federal laws and how they matter to hospice workers and families

A hospice Home Funeral Story
- your story points
- your story photo

Our Shared Philosophy
Hospice and home funeral advocates believe that patients and families
- are full participants in care decisions
- are treated with honesty, respect, compassion and dignity
- look to us to feel validated in their grief and in their spirituality
- trust us with ensuring that the sanctity of the body will be respected
- need to know what to expect leading up to and after death
### The Home Funeral Movement

Goals include:
- empowering families to care for their own after death
- educating the public to their innate family rights
- promoting environmentally sound and caring practices

### Home Funerals are Legal and Safe

- families may keep patients home after death in all states
- embalming is not required by any state for home funerals
- according to the CDC, NCID, PAHO and WHO, bodies do not pose an increased risk of infection after death
- cooling techniques sufficient
- body cleanliness is key
- universal precautions only if necessary

### The Needs of the Dying

- to be cared for by those who can maintain hope, however fleeting this may be
- to participate in decisions concerning one’s care, including advanced directives
- for children, family and friends to participate in whatever way they are comfortable
- to know that the sanctity of the body will be respected after death

### The Needs of the Family

- to be treated with honesty, respect, compassion and dignity
- to feel validated in their grief and in their spirituality
- to know what to expect physically leading up to and after death
- to understand the legal issues regarding care and custody of the body
<table>
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<tr>
<th>What Home Funeral Families May Do</th>
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<tbody>
<tr>
<td>• contact appropriate authorities</td>
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<tr>
<td>• conduct care of deceased</td>
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<tr>
<td>• shelter deceased in home</td>
</tr>
<tr>
<td>• ensure death certificates are filed, permits are obtained and filed*</td>
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<tr>
<td>• arrange for cemetery or crematory*</td>
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<td>• transport the body*</td>
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<tr>
<th>The Role of Home Funeral Guides</th>
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<tr>
<td><strong>Home funeral guides teach, advise and consult with families</strong></td>
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<tr>
<td>• preplan</td>
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<tr>
<td>• file documentation</td>
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<tr>
<td>• prepare and bathe the body</td>
</tr>
<tr>
<td>• procure burial and cremation vessels</td>
</tr>
<tr>
<td>• acquire permits for transporting</td>
</tr>
<tr>
<td>• locate crematory, cemetery contact information</td>
</tr>
<tr>
<td>• write obituary or memorial announcements</td>
</tr>
<tr>
<td>• prepare the home for service or visiting</td>
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<tr>
<td>• create a unique, intimate ceremony</td>
</tr>
<tr>
<td>• include clergy, musicians, funeral directors</td>
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<tr>
<td>• obtain funeral goods and services</td>
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<th>What Hospice Personnel Need to Know</th>
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<td>• Find and cite here the exact laws in your state that:</td>
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<tr>
<td>• define next-of-kin’s right to custody and control of the body</td>
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<td>• state when the hospice nurse has fulfilled his or her duties</td>
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<td>• direct nurse to complete the medical portion and give it to the next-of-kin to obtain physician’s signature and cause of death</td>
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HIPAA Consent to Share Information

- Admission forms ask permission to share with:
  - physicians and other health care providers
  - Medicare and other insurance providers
- Consent to share list specifics:
  - individuals, next-of-kin, designated agents
  - legal guardians
- HIPAA 45 CFR 164.510(b), ensures that an individual’s health care information remains private even after death

164.512 (2) Funeral directors. A covered entity may disclose protected health information to funeral directors [next-of-kin or designated agent] … as necessary to carry out their duties with respect to the decedent …

Expanding Your Hospice Services

- Offer to arrange a funeral planning visit
- What a funeral planning visit entails
  - facilitating a funeral discussion with patient, if possible
  - educating families about home and blended funeral care
- At admission, the planner
  - offers comparative area funeral home information along with home funeral information
  - assists in developing an action plan

What Home Funeral Families Say

Add quote(s) from your hospice/home funeral family
For More Information

- National home funeral alliance
  [National home funeral alliance]
- The Funeral Rule, under the authority of the Federal Trade Commission, seeks to keep the funeral industry honest
  [The Funeral Rule]
- The Funeral Consumer Alliance acts as a legal watchdog, advocacy federation, and provides consumers with accurate information
  [The Funeral Consumer Alliance]
- Final Rights: Reclaiming the American Way of Death by Josh Slocum and Lisa Carlson
  [Final Rights: Reclaiming the American Way of Death]

Your Name or Organization Name

State your focus here: Educational Presentations
Trainings and Seminars
Home Funeral Advocacy
Natural Burial Advocacy

Your name
Address
Email
Phone
Logo
Hospice to Home Funeral Blueprint

Because home hospice already has the loved one present with the family experienced in caring for him or her, the transition from hospice service to home after-death care can be seamless with very little effort. Here are some key items that should be addressed when hospice families choose to continue to care for the body until disposition.

1. Patients complete written advance directives regarding after-death care. Include signed, and witnessed designated agent form if someone other than the next-of-kin is chosen to be responsible.

2. If the legal next-of-kin is the responsible party, make sure that person knows his or her responsibilities. Check with the law in your state to confirm the order of legal responsibility if necessary.

3. Ensure agreement with the home funeral plan with all family members prior to the death if possible.

4. Inform the hospice personnel of your plans to keep the body at home as early as possible.

5. If there is concern on the part of hospice personnel about legal responsibilities for either family members or staff, refer them to the laws in your state that:
   a. Confirm your right to conduct a home funeral
   b. Confirm your right to care for your own at home with the support of a funeral director
   c. Describe the limits to legal authority for hospice personnel after completion of the time of death on the medical portion of the death certificate
   d. Show the legal language that indemnifies the staff members from responsibility after release of the body to the legally designated person with custody and control, whether that is the next-of-kin, a hired funeral professional, or a designated agent.

6. Invite hospice staff to help with any aspect of care as volunteers if desired, such as bathing, dressing and laying out the body or assisting in completing the medical portion of the death certificate by obtaining the physician’s signature after completing cause of death.
Advocating for Home Funerals to Hospitals

One of the greatest challenges to home funeral families whose loved one has died in hospital is overcoming body release policies that are either counter to the law or nonexistent. In the case of muddy or absent policy, the confusion over authority can create negative experiences or court battles that serve no one.

Reaching out to hospitals is essential to ensuring that families will have access to their loved one’s body should he or she die in the hospital. The difficulty lies in the disparity between law, which in most states supports families who wish to transport the body themselves, and policy that was most likely written with no awareness of the right of next-of-kin to custody and control.

Most existing policies circumvent the legal responsibility of people charged with custody and control, bypassing their authority and creating a de facto agreement to hire a professional at their own expense without informed consent. What it does at a deeper level is strip the family of their choice, reinforcing the cultural stereotype that every mourner is incapable of managing his or her own affairs.

Though they do not have to be complicating factors, organ donation and autopsy can seem overwhelming to families and staff alike. But regardless of extenuating circumstances, the same holds true: once the Medical Examiner/Coroner or donor team have completed their work, the body is released to the family where they resume custody and control. If anything needs more clarity in hospital policy language, it is in these cases.

Another issue that can contribute to confusion when trying to determine hospital policy is finding the proper authority. Some hospital policy is written by nursing staff, some by social workers, and some hospitals have whole legal teams. Start at the front desk and work your way to the person who can answer your questions about policymaking. Some questions to ask include:

- Can you help me to locate the hospital’s Body Release Policy?
- Can you help me locate the person in charge of policies and procedures that deals with releasing bodies?
- Who in your hospital is responsible for enforcing written policies and procedures when someone dies?
With well-crafted body release policies and procedures, hospital staff can empower families who may not have known that they had a choice. Given that unanticipated deaths occurring in hospitals are common, having the information to pass on is empowering for staff as well.

The following samples are meant to help narrow in to the most important language when assisting with writing or re-crafting body release policy. Note that your state law will determine whether that language can direct release to next-of-kin, funeral directors, and/or designated agents, so come to the table with a thorough understanding of your state law.

A note about terms: In the sample policies that follow, you may note that there is terminology used that likely differs by region and state. For instance, in many rural areas, death certificates may be filed with local authorities such as town or county clerks. In more urban areas, filing might occur in a city registrar’s office.

In all cases, the point is to get the death certificate information transferred to the State for record keeping purposes by way of the Electronic Death Registration System (EDRS) being adopted by states, all differently. Those state offices might be called Vital Statistics or Vital Records or some other title. By the way, in some states it is still possible to file a hand-written death certificate directly at the appropriate State office.

As you read these examples of existing hospital policies, try not to be intimidated by the terms used or the many rules listed. We have included more of the sample policy language than just what applies to releasing bodies to home funeral families so that you can familiarize yourself with the whole policy picture and become accustomed to searching for the pertinent passages. We have cheated a bit by helping you find them easily.

What you are looking for is:

- language that ensures that families have the right to remove a body with the proper paperwork;
- language that transfers death certificates and permits, either temporary or permanent, directly into the hands of the next-of-kin or a designated agent; and
- language that ensures that the family may sign and complete forms that indemnify the hospital for releasing the body directly to them.
Sample Letter to Hospital Administrators
Requesting a meeting to discuss body release policy

John Smith, Hospital Operations
Your Medical Center
Everystreet
Everytown, Everystate

Dear Mr. Smith,

As the person in charge of policy at Your Medical Center, I would like to request a meeting with you to discuss body release policy to next-of-kin as provided for by State Law § Law Number. My concerns are related both to the ease with which families will be accommodated by staff should they request this, and to the awareness of hospital staff to their role in being compliant with the law through hospital policy and procedures.

I would also be happy to discuss offering staff training through in-services or workshops that will:

- ensure that the staff is aware of the possibility that a family may choose to take custody and control of a loved one’s remains after death
- ensure that staff understand the procedures in place for the body to be released in the same manner it would be released to a funeral director
- educate the staff to their legal responsibilities in relation to releasing a body to the family

Although this may not be an everyday occurrence in your facility, it might be prudent to be prepared for the occasion when it presents itself. I am eager to collaborate on policy revision if necessary. I come to this conversation well prepared through home funeral training and with the support of the National Home Funeral Alliance, and am willing to offer my time at no cost to your hospital.

I look forward to hearing from you to set up a time to speak soon.

Sincerely,

Your Name
Your Organization
Others accompanying you to the meeting
Sample of Home Funeral-Friendly Body Release
Hospital Policy Language

MRP: Nursing Director Intensive Care Unit/Oncology OR WHOEVER IN YOUR HOSPITAL SETS POLICY

Policy:
It is the policy of XXXXXXXX Hospital that the staff will take specific measures to ensure the necessary identification, documentation, preparation and holding of a deceased patient and the security of all valuables and personal effects until appropriate release of the body.

Procedure:
1. Nursing notifies the attending physician, nursing supervisor and registration office of the patient’s death. A physician or nurse (see RN Pronouncement of Death Policy) will pronounce the patient. The physician notifies the family of the death.

2. If there is to be an autopsy, or if the patient meets the Medical Examiner/Coroner notification criteria (see attached), the Medical Examiner/Coroner dispatch is notified at PHONE NUMBER and a Request for Autopsy Form is filled out. The Medical Examiner/Coroner must be notified prior to decisions about organ donation.

3. Nursing notifies the Name of Your Organ Bank of the death at XXX-XXXX within 1 hour.

4. If death occurs while a patient is restrained or in seclusion, or for deaths occurring within 24 hours after the patient has been removed from restraints and/or seclusion, or where it is reasonable to assume that a patient’s death is a result of such seclusion or restraint, law requires that the Disabilities Rights Center, Inc. be notified at LOCAL PHONE within 7 days of the death.

5. Nursing or a physician will initiate the Death Certificate. DO NOT MAKE COPIES unless the family or Designated Power of Attorney (DPOA) will be taking custody of the body. In that case only it is appropriate to place a copy in the patient chart; the original must go with the family or DPOA.
   a. The name of the deceased and the date of death are written along the upper left side of the death certificate.
b. The physician is responsible for assuring the completion of the Death Certificate in black ink.
   —If the nurse pronounces the death, he/she is responsible for completing IDENTIFY LINE ITEM NUMBERS of the Death Certificate.

6. Nursing will initiate the Postmortem Disposition Form and notify the funeral home if the family has communicated that they are electing to use one.

7. If the next-of-kin or legally responsible person wishes to take custody of the body for home services, they may do so if an autopsy is not required or requested and the patient is not a Medical Examiner case. The family may or may not request the assistance of a funeral home or a home funeral specialist to assist, though both may be offered. The Death Certificate must accompany the body and the responsible party must sign the Postmortem Disposition Form and the Postmortem Disposition of Personal Belongings Form. The family will be instructed to bring the Death Certificate to the town hall for their residence and upon presenting the Death Certificate will obtain a burial permit from the town clerk's office. Legal order of next-of-kin as defined in YOUR STATE is:
   a. The spouse
   b. An adult son or daughter
   c. A parent
   d. An adult brother or sister
   e. An adult grandchild
   f. An adult nephew or niece who is the child of a brother or sister
   g. A maternal grandparent
   h. A paternal grandparent
   i. An adult uncle or aunt
   j. An adult first cousin
   k. Any other adult relative in descending order of blood relationship

   Regarding Custody and Control Generally IDENTIFY YOUR SPECIFIC STATE LAW AND REPLACE THE FOLLOWING WITH THAT LANGUAGE, "If the subject has designated a person to have custody and control in a written and signed document {i.e., DPOA}, custody and control belong to that person."

8. If possible, all valuables will be removed from the body while the body is still on the unit. Valuables and personal belongings will be inventoried and listed on the Postmortem Disposition of Personal Belongings Form. The family member or responsible
person receiving these items must sign the form along with the nurse. A copy is kept in the patient chart.

Preparation of the body:
1. Close the patient’s eyelids if open and insert dentures if appropriate.

2. The patient MUST be clearly identified with an ID band on right hand.

3. If eyes are to be donated:
   a. Elevate head of bed 45 degrees
   b. Tape eyelids closed with paper tape
   c. Place ice bag over the eyelids with cloth or gauze between skin and ice bag

   2. a. Routine autopsy (for example, those requested by the family):
      XXXXXXXXXX Hospital has a contract with the pathologist at XXXXXXXXXX Medical Center and the body will go there via the funeral home of the family’s choice, or the closest available service will be used.

      b. Autopsy ordered by the Medical Examiner:
      DO NOT remove dressings, therapeutic tubes or access devices, sutures, endotra- cheal tubes, esophageal obturator and subclavical lines. The body will be transported to the appropriate facility via the family's funeral home of choice or the closest available service.

3. Be sure both the patient and the outside of the shroud are clearly identified. If the body will be placed in the custody of the family or DPOA, they must provide an appropriate container for transport.

4. If the family wishes to spend time with the deceased in the hospital, prepare the body for viewing and accompany family into the room. If the family wishes to spend time with the deceased after disposition to the morgue, the body will be transported back to a private room.

5. When a funeral director or family member acting as such picks up the deceased, he/she will sign and date the Postmortem Disposition and the Postmortem Disposition of Personal Belongings Forms.
Example of Home Funeral-Friendly
Hospital Body Release Language

Release of the Body from Nursing Unit Directly to Family or Their Designated Agent

Eligibility for release:
1) Check to make sure that the family has already been asked about an autopsy and has indicated that they do not want one. Be careful not to ask again as the family may perceive it to be disrespectful or harassment.
2) Make sure that the CDT has released the body, and that the deceased is not considered to be a Medical Examiner/Coroner case.

Documentation required from the family or designated agent:
1) A death certificate must be initiated and signed by the attending physician or a registered nurse, including the cause, time and date of death, and given to the family member or their designated agent to file with the Division of Vital Records.
   Whenever a contagious disease is involved, it must be stated on the death record prior to release.
2) Alternately, the death certificate may be filed by the physician or agent electronically, in which case the physician or APRN may provide the family or agent with documentation, including the death certificate and burial/transit permit.
3) A copy of the death certificate, as completed and filed with the Division of Vital Records, must be included in the patient file.
4) A family member or designated agent must show a form of photo identification. This information must be documented prior to release of the body.
5) A designated agent must provide a copy of the written signed document authorizing him/her to exercise custody and control on behalf of the family or the deceased.
6) The family or agent must provide a copy of the burial/transit permit for the patient record.

Handling of Fetal Remains

Procedure #1
In cases of neonatal death following a live birth, a birth certificate and then a death certificate will be filled out. If there is an autopsy, an autopsy permit will be filled out. In this case, the death certificate may be given to the funeral director, the responsible family...
member, or designated agent, and it is their responsibility to send the certificate to the State.

Procedure #2
If the family wishes to bury the remains on their own property, the zoning laws of the town of disposition apply. Suggest to the family that they may contact the Town Clerk in the town where death occurred, a Town Cemetery trustee, or the town sexton for information. The hospital will not release the remains to the family, for burial on the family’s property or otherwise, until a permit for burial/transit has been obtained and a copy added to the patient file.

Postmortem Nursing Care
Procedure #3
Nursing will initiate the Postmortem Disposition Form and inform the family (through their responsible family member as determined by the family, or next-of-kin as set forth in RSA xxx) of their options to contact a funeral home, designate an agent of their choosing, or take responsibility for arrangements themselves. Nursing will then notify the funeral home, home funeral consultant, or other designated agent as communicated by the responsible family member.

Preparation of the body #4
When the body is released, the funeral director, responsible family member or designated agent will sign and date the Postmortem Disposition and the Postmortem Disposition of Personal Belongings forms.

Source: Researched and written by Lee Webster
Example of Home Funeral-Friendly Body Release Policy
Fletcher Allen Health Care, Burlington, Vermont (FAHC)

Release of body from FAHC:
A) Release of the body from the nursing unit (for bodies that ARE NOT having an autopsy, being used for tissue donation or are ME cases)

2) Release of Body from Nursing Unit directly to Family:
   a. Check to make sure that the family has already been asked about an autopsy and has indicated that they do not want one. Be careful not to ask again as the family may perceive it to be may be disrespectful or even considered harassment to do so. Also make sure that the CDT has released the body, and that deceased is not considered to be a Medical Examiner case.
   b. Family should contact funeral home of their choice. The funeral home can ensure that the family will have the correct forms for transport of the body.
   c. If the family does not wish to involve a funeral home they must have the Vermont Certificate of Death filed at the Burlington City Hall as well as a Vermont Department of Health Permit for Temporary Removal of Dead Human Remains from Burlington City Hall (which they would receive after filing the Vermont Certificate of Death). The family should be made aware that Burlington City Hall only has these documents available during normal business hours. If the original copy of the Certificate of Death is released to the family, a copy must be made and placed in the patient’s medical record.
Sample Body Release Form

Postmortem Disposition signature section:

<table>
<thead>
<tr>
<th>Release to Funeral Home, Next-of-Kin, or Designated Agent</th>
</tr>
</thead>
<tbody>
<tr>
<td>This is to certify that the undersigned is authorized to remove the body of</td>
</tr>
<tr>
<td>Name ___________________________</td>
</tr>
<tr>
<td>Business name or Relationship __________________________</td>
</tr>
<tr>
<td>Notified by ____________________ Date/Time __________________</td>
</tr>
<tr>
<td>The undersigned has received the body from Your Hospital in accordance with Your State law.</td>
</tr>
<tr>
<td>Signature ____________________ License # if applicable ______________</td>
</tr>
<tr>
<td>Signature of staff member releasing the body _________________________</td>
</tr>
</tbody>
</table>
Samples of Existing Body Release Language

For comparison sake, take a look at some typical language used in body release policies:

<table>
<thead>
<tr>
<th>Existing Body Release Language</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>“The release of the body from the hospital to individuals other than Funeral Home personnel or Coroner is acceptable if released to a person who claims it for purposes of burial. Some evidence that burial arrangements have been made should be provided by the person claiming the body.”</td>
<td>This policy language presumes a legal authority over the intent of the next-of-kin that does not exist. Next-of-kin has the authority to determine what will happen to that body unless a Medical Examiner/Coroner has taken temporary custody, after which it will be returned to the family. There is no legal reason to require proof of burial or other disposition to hospital staff.</td>
</tr>
<tr>
<td>“The Nurse Manager, Nursing House Supervisor or designee will notify the mortuary designated by the family/guardian to arrange for disposition of the body.”</td>
<td>The question in this scenario is, “What funeral home do you want us to call?” instead of “What plans can we assist you in making?” which leaves the family with choices.</td>
</tr>
<tr>
<td>“It is the policy of … to maintain the individual’s dignity after death, to provide appropriate documentation of death and to prepare the body for expedient release to the funeral home.”</td>
<td>Again, the language imposes a directive on families that is not within the law in any state, regardless of whether a funeral director must be involved in some aspect or not and when that will occur.</td>
</tr>
<tr>
<td>“Residents who die at the facility will be removed immediately by funeral personnel.”</td>
<td>In most nursing home and care facilities, this kind of language is typical. Advanced notice of the families’ plans to respond appropriately to remove the body is often enough to relax this policy. Completion of the death certificate and the subsequent acquisition of a transport permit are usually managed by staff and</td>
</tr>
<tr>
<td>“The staff at the care facility will contact you to notify you of the death and your first call should be to a funeral home to coordinate the removal of the body and the completion of the death certificate.”</td>
<td></td>
</tr>
<tr>
<td>The staff at the care facility will likely be able to begin the process of issuing a death certificate, though <strong>you will need a licensed funeral director</strong> to complete the death certificate and remove the body from the care facility.</td>
<td>This depends entirely on the requirements of a handful of states, not a rule.</td>
</tr>
</tbody>
</table>
Giving In-service Trainings and Presentations to Hospitals

Despite attempts to encourage advance directive completion by hospitals, not all patients have medical plans in place, much less funeral plans on record. For those without means to pay for after-death care, sudden death in a hospital can become a family crisis very quickly. Offering practical, economical, and accurate advice to hospitals to have the policies in place to back the plan is a gift to the family and staff alike.

You can help hospitals put appropriate policies and procedures in place by offering in-services and presentations to staff and volunteers. Keep in mind that work time in hospitals is primarily designated time for patient service, not education, so what you offer must be brief, clear, and succinct. It must also speak directly to what the staff person needs to know to provide the best service to patients and their families.

Included in the offer to speak to hospital professionals is the understanding that you will be explaining what the benefits of being able to address the needs and questions of home funeral families. They will also need to be reassured that there is no more required of them to release a body to the next-of-kin or a designated agent than to a funeral director. Most importantly, staff need to know that they are not responsible for educating families who are unfamiliar with home funerals, and that you will be providing them with resources that will direct the families elsewhere for expert direction and support.

The following slides are designed to help you speak efficiently and accurately to hospital staff at in-service trainings. Because your training will depend largely on what specific information and language you uncover when researching your state law and the hospital policy, you may need to supplement some of the key slide suggestions significantly.

Below are some basic slides showing suggested areas to cover:
## Presentation to Hospital Staff

*See the List of Links at the back of this book for the location of this presentation*

### Releasing bodies to home funeral families

- Conduct care and shelter deceased at home
- File death certificates and obtain transport permits
- Transport the body home, to a church, or to disposition
- Hire a home funeral guide or funeral director to assist

### What home funeral families may legally do

- Conduct care and shelter deceased at home
- File death certificates and obtain transport permits
- Transport the body home, to a church, or to disposition
- Hire a home funeral guide or funeral director to assist

### Legal and safety facts

- Families may bring loved ones home after death in all states
- Includes after accidents, autopsies, organ donation
- Embalming is not required by any state for home funerals
- According to the CDC, NCID, PAHO and WHO, bodies do not pose an increased risk of infection after death
- Cooling techniques are sufficient
- Body cleanliness is key
- Universal precautions only if necessary

### Tell your hospital to home funeral story

- Why someone might want to bring a loved one home from the hospital
- What obstacles might be encountered

### HIPPA consent to share

- Admission forms ask permission to share with:
  - Physicians and other health care providers
  - Medicare and other insurance providers
- Consent to share list specifics:
  - Individuals, next-of-kin, designated agents
  - Legal guardians
### HIPAA 45 CFR 164.510(b), ensures that an individual’s health care information remains private even after death

- 164.512 (2) Funeral directors. A covered entity may disclose protected health information to funeral directors [next-of-kin or designated agent] as necessary to carry out their duties with respect to the decedent ...

### Other factors and concerns
- Your ideas and messages

### What hospital staff need to know

Find and cite here the exact laws in your state that:

- Define next-of-kin’s right to custody and control of the body
- State when the hospital staff person responsible for signing the death certificate has fulfilled his or her duties (Example: “…after certifying the fact of death and completing the death record …”)
- Indemnify the hospital personnel from legal responsibility (Example: *Any person or institution releasing a body shall be held harmless against and shall not be liable …* )
Hospital to Home Funeral Blueprint

When a death occurs in a hospital, the possibility for removal of a body by family may depend on a variety of factors, such as the cause of death, organ donation, autopsy, and many other considerations. This list of steps to take when asking for an exception to an existing policy can't cover every eventuality, but here are some key items that may be addressed should a family request to remove a body themselves or ask for additional time with the body. Keep in mind before asking for a policy exception that it is well within the hospital’s rights as an independent business to enforce their policies in support of their staff and other patients. The key is to find neutral ground where your family can voice their concerns and describe their intentions respectfully, with an eye to a positive outcome for all.

Here are some suggestions for families looking to bring a loved one home when there is restrictive policy in place:

1. Ensure agreement with the home funeral plan with all family members prior to approaching hospital personnel.
2. If possible, obtain the hospital’s Body Release Policy in writing. If it is compliant with the law to release to the family, the hospital staff should be versed in assisting families with appropriate paperwork completion and the removal.
3. If the Body Release Policy does not clearly state the right of family to remove, ask to speak with a social worker, nursing supervisor, or other staff with policy authority.
4. For this conversation, have with you (and hope not to need):
   a. Completed written advance directive regarding after-death care, including a signed and witnessed designated agent form if someone other than the next-of-kin is chosen to be responsible, if one exists.
   b. Identification documents (license, passport, etc.) and proof that you are the legal next-of-kin according to the law in your state.
   c. Confirmation of your right to have the body released to you according to specific statutes that give next-of-kin the right to custody and control of the body in your state.
   d. Legal statutes that describe the limits to legal authority for hospital personnel after completion of the time of death on the medical portion of the death certificate.
   e. Legal language that indemnifies the staff members from responsibility after release of the body to the legally designated person with custody and control, whether that is the next-of-kin, a hired funeral professional, or a designated agent.
   f. Consider enlisting the aid of clergy, a social worker, or a home funeral advocate to help negotiate the release.
5. Inform the hospital personnel of your plans to bring the body home as early as possible.

6. Invite hospital staff to help with bathing the body, washing hair, or assisting in completing the medical portion of the death certificate by obtaining the physician’s signature after completing cause of death.

7. Because hospitals may not have the capacity to hold a body for long periods of time, there may be pressure to remove the body before there is adequate time to get the paperwork processed along typical routes. You will need a transport permit to remove.
   a. Determine if your state issues provisionary transport permits without full death certificate registration and from whom.
   b. Ask medical personnel for help in expediting the completion of the medical portion of the death certificate.
   c. If immediate removal is required and you are unable to obtain the paperwork, ask for assistance in locating a transport company that will charge only for paperwork processing and transportation to the home.
   d. Call funeral directors to request similar services.

8. If an autopsy has been performed, there may be reluctance to release the body back to the family. The Medical Examiner/Coroner will be the person in charge of making decisions, so appeal directly to him or her if possible.

9. If organ donation has occurred, the harvesting care team will be in charge. You will need to assure them that you are capable of and willing to cope with the results of the procedure. Depending on the organs donated, you may require assistance in body care and moving the body.

10. If the person died of a contagious disease (not necessarily an infectious one), removal to the home will depend on what precautions will need to be followed, what medical agencies are involved, and other considerations, such as local and state health department protocols. Ask for assistance in understanding the particular needs and ways of dealing with them in a home setting.
Advocating for Home Funerals to Care Facilities

Nursing homes, senior housing, assisted living, two or three-tier care facilities—regardless of type, care facilities have similar needs as hospitals and on-site hospices. They simply need the beds, as there are often more people in need than can be housed at any given time. They are also not equipped with refrigeration units, morgues, or staff to accommodate lengthy vigils after the death of patients on site. Often residents have roommates who may or may not be interested in sharing a family’s desire to bathe or dress or spend additional time at bedside after a death has occurred.

Some facilities have policies in place that require removal within two hours or less; some will routinely wait until after residents’ bedtime to remove a patient who has died earlier in the day in an effort to avoid upsetting them. Often next-of-kin is alerted and there is no expectation that he or she or other family members will come to the facility at all, but will rather reroute to a funeral home instead. Belongings may need to be picked up from where they have been placed in storage by staff at a later date, or removed from the premises by the family within a tight time frame.

All this hurry is not usually conducive to a calm transition to family care. Families contemplating removal to a private home should be encouraged to check on facility policy and protocol well in advance to learn the specific time requirements for body removal and have a plan and a contingency plan in place. Respect for other residents must be considered.

Ceremony in care facilities
One of the gifts of having the family directing the after-death care themselves is that they can take the time they need for grieving and do things the way that makes most sense for their families.

In care facilities, residents are often confused and frightened when they are not told about their friends or fellow facility mates’ deaths. If care facilities require rapid removal, those left behind, including staff and friends, often benefit from some sort of observance or ceremony, however small or subtle, that recognizes that a loss has occurred within the community.

When advocating for home funerals in institutional settings, it makes sense to
understand what system, if any, the facility uses to inform and include residents that a death has occurred. It is also important that the ceremony demonstrate respect and care for the deceased by the facility staff and residents to the family.

Loved ones may be honored any time after the body has been removed by small, simple ceremonies. Some ways to make the loss known in a residential community might include:

- Placing a special blanket on the bed of a person who has died and leaving it there for a couple of days. This lets the other residents know why the person is no longer there so they will not wonder if the person is sick and had to go to the hospital, or if he or she left for some other reason. Once a month, there is a gathering and the blanket is used as an altar cloth for a short remembrance ceremony for residents. Family may be invited to attend.

- Placing a specific flower, such as a red rose, with the name of the deceased on a card, on a small table in an area where residents are likely to pass by daily. Often a table in a library, at the dining hall, or near the mailboxes is appropriate and highly visible.

- Processions play a major role in acknowledging the death and letting others know without words. Staff may choose to accompany the body as it is being removed, walking behind it as it is rolled out, wither in silence or with music or singing of a particular song that has meaning for the deceased or his or her family, or has been chosen by the residents and staff for this occasion.

**Veteran’s Homes and Hospitals**
The US Veteran’s Administration does not have authority over what happens in state facilities when it is provided for by state law. Since home funerals are legal in all states in the US, it is the policies in local facilities that need to be addressed. The federal VA requires that directors of state-run veteran’s facilities create and publish policies that include federal rules and guidelines, but also allow the prerogative to initiate additional policies, including those impacting body release to the family. The easiest way to learn what the body release policy is in your facility is to call directly.
Care Facility to Home Funeral Blueprint

In most cases, the person dying in a care facility will have been in residence for enough time to make it possible for family members to ascertain the facility’s policies and protocols for after-death care. The best outcome for removal will be obtained through negotiations when the person is admitted to the facility. Remember when assisting the family in negotiating that the facility has probably developed their procedures, including timing of removal, for the comfort and convenience of other residents, including possible roommates. Facilities are often independent businesses with the right to say what happens under their roof, so before the family requests an exception to the rules or a bending of the procedures, suggest that they consider the best way to make their case and in what ways they might be able to work together to achieve their goals.

Here are some suggestions for the family in negotiating ahead of time:

1. Ensure agreement with the home funeral plan with all family members prior to approaching personnel.
2. If possible, obtain the facility’s procedures in writing. If it is supportive, staff should be versed in assisting families with appropriate paperwork completion and the removal.
3. If the procedures do not clearly state the right of family to remove, ask to speak with a social worker, nursing supervisor, or other staff with policy authority.
4. For this conversation, have with you (and hope not to need):
   a. Completed written advance directive regarding after-death care, including a signed and witnessed designated agent form if someone other than the next-of-kin is chosen to be responsible, if one exists.
   b. Identification documents (license, passport, etc.) and proof that you are the legal next-of-kin according to the law in your state.
   c. Confirmation of your right to have the body released to you according to specific statutes that give next-of-kin the right to custody and control of the body in your state.
   d. Legal statutes that describe the limits to legal authority for the facility’s personnel after completion of the time of death on the medical portion of the death certificate.
   e. Legal language that indemnifies the staff members from responsibility after release of the body to the legally designated person with custody and control, whether that is the next-of-kin, a hired funeral professional, or a designated agent.
   f. Consider enlisting the aid of clergy, a social worker, or a home funeral advocate to help negotiate the release.
5. Invite staff to help with bathing the body, washing hair, or assisting in completing the medical portion of the death certificate by obtaining the
physician’s signature after completing cause of death.

6. Facilities may not have the capacity to hold a body for long periods of time, either in the resident’s room or in another area. To help you comply with the facility’s wishes for rapid removal:
   a. Determine if your state issues provisional transport permits without full death certificate registration and from whom.
   b. Ask medical personnel for help in expediting the completion of the medical portion of the death certificate.
   c. If immediate removal is required and you are unable to obtain the paperwork, ask for assistance in locating a transport company that will charge only for paperwork processing and transportation to the home.
   d. Have an arrangement with a funeral director already negotiated.
Release of a Body to Next-of-Kin

Release of a Body in Autopsy or Post-Mortem Investigation
When a body is being held at a hospital or refrigeration facility, they will need to be assured that the body can be released without review by a medical examiner or coroner. If an attending doctor does not stipulate a need to call an ME or coroner, the facility may release the body with the appropriate paperwork completed. At its simplest, it is either a coroner’s case or it isn’t, unless the family itself requests an autopsy, at the end of which the body will be returned into the custody of the next-of-kin, the same as with a coroner’s case.

Completing Paperwork for Release of the Body
Historically, the debate over who owns the dead has been resolved by the legal position that dead bodies are not personal property. However, someone must authorize post-mortem care and disposition in an accurate, responsible, and timely manner. Common law specifies next-of-kin as having legal custody and control of the body. Some states allow for designated agents. In order to effect a legal and orderly transfer of authority, most hospitals will require completion of a Request for Release of Body to Funeral Home and/or a Removal Authorization Request. Next-of-kin signs these forms when acting as his or her own funeral director in family-supportive states.

Ensuring that Legal Responsibility is Assigned Correctly
In the event that a family member requests to remove a body from a facility, positive identification and understanding of the person’s legal right to claim is of paramount importance. State law indicates in what order next-of-kin is defined. This cannot be stressed strongly enough. It is a point of law first and foremost, and it is only enacted when the eligible next-of-kin is unwilling or unable to be responsible, in the order indicated. While the person and institution doing the releasing is relinquished of any liability if done in accord with the legal process, all bets are off if the wrong person was mistakenly given authority.

Filing Required Paperwork
In most states, the next-of-kin has the legal authority to complete the demographic portion of the death certificate and file the completed form with
Obtaining Transit/Transport Permits

Once the death certificate has been signed off on, the only additional requirement for release of the body to the family is the acquisition of a Transport/Transit/Burial permit by the family that is generated with the successful filing of the death certificate. This permit must be documented by the facility prior to release. The permit essentially runs with the body, regardless of where it goes. All states accept transport permits issued by other states.

Crossing State Lines

State lines are of no concern. Unless you are removing an unembalmed body from one of two states where embalming is required to leave the state (Alabama and Arkansas as of 2016), there is no legal concern whatsoever. And in any case, in those states or others, there are no funeral police checking your trunk for a dead body. Just have all the proper paperwork on hand and correctly filed.

Legal Right to Authorize Disposition

Again, the person with the right to authorize disposition is the one expressly designated by law. Institutions need to understand is that how this is accomplished and by whom is not their business. Once they have released the body with all appropriate paperwork completed and filed, the family is responsible for making any and all further decisions.

Reporting Location of Final Disposition

In the case of a home funeral, it is the next-of-kin’s (or town sexton’s) responsibility to report where the final disposition occurred. When filling out the death certificate, the family will already have indicated the location. In the case of cremation, the crematory is noted as the place of disposition. There is no need to declare where the cremains are located.
Statutes or state laws all staff should know about if they don’t already:

- Anything regarding pronouncement by registered nurses
- Anything regarding release of the body to family or designated agent
- Anything regarding immunity from prosecution, such as: A party who, in good faith, acts upon the instructions of the party having custody and control is not liable for having carried out those instructions.
- Anything regarding HIPAA privacy in reference to medical information

Understanding Medical Privacy Issues in Regard to the Deceased

There is often confusion around what information can be shared after a patient has died in an institutional setting. HIPAA law indicates that individually-identifiable health information about a deceased individual is subject to the same privacy procedures as are required for the individually-identifiable health information of living individuals, with the exception of the applicability of the Privacy Act.

The Privacy Act includes the ability to share medical information with the following under these specific circumstances:

- To a law enforcement official if there is any suspicion that such a death may have resulted from criminal conduct.
- To a coroner or medical examiner for the purpose of identifying a deceased person, determining cause of death, or for other duties authorized by law.
- To a family member’s physician when it is determined that it is relevant to the treatment of a decedent’s family member, or consistent with applicable law.
- To funeral directors, either before or after the death occurs.

According to the Veteran’s Administration in Handbook 1605.1, “…the personal representative of a deceased individual has the same rights as the deceased individual that the personal representative is representing. If, under applicable law, an executor, administrator, or other person has authority to act on behalf of a deceased individual or on behalf of the deceased individual’s estate, VHA must disclose to the personal representative the individually-identifiable health information, but only to the extent that the individually-identifiable health information is relevant to such personal representation.” They further stipulate that next-of-kin is not considered a legal personal representative of a living individual. Next-of-kin only has authority over the deceased.
So what does this mean to the next-of-kin wishing to act as his or her own funeral director in non-restrictive states?

At issue is the lack of after-death legal education extended to hospice, hospital, and care facility personnel. These federal laws actually clarify and support the rights of next-of-kin to make decisions regarding their own dead in language that staff is familiar with.

When a family member has been recognized as the eligible representative of the deceased for receipt of medical information, it follows that he or she is also the authority in charge of legal custody and control.

**Infant and Fetal Remains Removal**

In the case of live infant death, extreme care is usually taken in determining cause, regardless of where the death occurred. Requirements for stillborn babies, miscarriage, or fetal remains differ by state and by facility. The definition for expired fetal remains depends on state law; an example of a typical description for a fetus might be less than 20 weeks gestation and less than 350 grams with no signs of life.

The mother’s signature will be required to authorize the release of the body; proven father may sign if mother is unable. A death certificate will be issued in the case of live birth infants.

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**The US Standard Certificate of Death**

Each state provides a death certificate form specifically for its own use. There is also a standard death certificate that meets the requirements of the US government called the US Standard Death Certificate. Each state form includes similar information, including:

- Medical certification, including the cause of death, by a medical authority
- Demographic information about the decedent
- Disposition information

The Funeral Directors’ Handbook on Death Registration and Fetal Death Reporting states:

“Most State certificates conform closely in content and arrangement to the standard. Minor modifications are sometimes necessary to comply with State laws or regulations or to meet specific information needs. Having similar forms promotes uniformity of data and comparable national statistics. It also allows the comparison of individual State data with national data and data from other States. Uniformity of death certificates among the States also increases their acceptability as legal records.”

Often, the reason for accurate death certificates is lost in the anxiety of figuring out how to file, who will help without charging, managing time requirements, inconvenient office hours, hunting
down doctors for signatures, and myriad other obstacles that may or may not come up. Keep your eye on the prize: focus on completing it correctly for the right reasons, as described in the Funeral Directors’ Handbook: “This information is used in the application for insurance benefits, settlement of pension claims, and transfer of title of real and personal property. The certificate is considered to be prima facie evidence of the fact of death. It can therefore be introduced in court as evidence when a question about the death arises.”

For additional information regarding death certificates, consult the Centers for Disease Control’s handbooks available online:

- Physicians’ Handbook on Medical Certification of Death
- Medical Examiners’ and Coroners’ Handbook on Death Registration and Fetal Death Reporting
- Funeral Directors’ Handbook on Death Registration and Fetal Death Reporting

**Electronic Death Registration Systems**

EDRS is a digital program used to file death certificates with the state Department of Vital Statistics or Vital Records. The system is accessible only by funeral directors, town or city clerks, medical examiners, coroners, deputy registrars, and/or physicians 24/7. Some states continue to accept paper death certificates, but all states require that the data then be entered into the central system to increase accuracy in collecting and extrapolating critical statistical information.
The Centers for Disease Control and Prevention's (CDC) National Center for Health Statistics (NCHS) has been collaborating with colleagues in the State vital statistics offices to revise the certificates of live birth and death and the report of fetal death. This process is generally carried out every 10 to 15 years. The most recent revision is 2003. This was created to assist in completing demographic and legal items. It may or may not be valid in your state, but you may use it as a template to collect the information that will be required on a Certificate of Death.
Talking Points

Here are a few talking points that may help families when speaking to authorities who are unfamiliar with procedures around home funerals:

“I’d like to bring Mom home myself instead of calling a funeral director when the time comes. Can you help me with that?”

“Dad always wanted to do things himself, so we’ve decided to keep him home after he dies. I’d really like to work with you on what the best ways are to make that happen.”

“I know you probably don’t get a lot of requests like this, so we’ll rely on you to let us know what you need from us. We’re open to your suggestions on how we can accomplish this.”

“We respect that you have a policy to call a funeral director right away when someone dies. What we need you to understand is that according to the law we don’t have to call one and we’re prepared to take care of things ourselves. Is there a way we can both do what we need to do?”

“Maybe if you could help us move the paperwork along more quickly, we could bring her home sooner.”

“What we’d like to discuss is how we can bring Mom home after she dies and how we can make that work, given the precedent in place at your institution for having people removed quickly.”

“We plan to have a vigil at home and would love it if your staff could come by. As soon as we get home, we’ll be setting that up.”

“What paperwork do you need from us that will help move things along more smoothly?”

“Would it help for you to speak with someone who does this frequently? To my minister? To a funeral director who knows about this? To a home funeral advocate”

“I appreciate that Mom’s roommate might not want us there for a long time after she dies. Is there a room we could use to spend time with her while we’re waiting for the permit to bring her home?”

“Bringing Dad home means a lot to all of us.”
Sample Handouts and Flyers

Following are four handouts you can copy and distribute as you speak to others about home funerals
- 12 Ways Funeral Directors Can Support Home Funeral Families
- 8 Ways Hospices Can Support Home Funeral Families
- 8 Ways Hospital Staff Can Support Home Funeral Families
- 10 Ways Care Facility Staff Can Support Home Funeral Families

These handouts are also available on the National Home Funeral Alliance website, www.homefuneralalliance.org/bildingbridges, as full color pdf files
12 Ways Funeral Directors Can Support Home Funeral Families

The most important thing funeral directors can provide home funeral families is the compassionate understanding that this is something families feel called to do for their loved one and themselves, their friends, and community. Home funeral families by and large are looking for simplicity, self-reliance, personal responsibility, and a shared, intimate experience that only they can conceive of and conduct. This doesn’t mean that home funeral families never need or want funeral directors to be involved. In some instances, it may be impractical to try to tend to all the details without assistance. Weather, family locations and travel plans, weekend paperwork filling, autopsy, organ donation, or any number of other factors can contribute to the decision to hire professional help. Families are looking for choice in what goods and services fit their particular circumstances and needs.

Here’s how funeral directors can help:
1. Provide information
2. Aid in completing the death certificate
3. Aid in procuring the transport/burial permit
4. Provide removal to the home
5. Assist with body preparation if desired
6. Organize vault delivery
7. Locate a cemetery or crematory
8. File death notices
9. Rent the prep room for body care with supervision
10. Deliver a casket, alternate container, shroud or other item to the home
11. Transport to gatherings or church, final disposition
12. Provide a checklist and assistance for military services


National Home Funeral Alliance, www.homefuneralalliance.org
8 Ways Hospices Can Support Home Funeral Families

For many families, taking care for a loved one after death can be a natural extension of the care provided during the last months or weeks on hospice service. However, long friends and family have lived with knowing that the death would eventually occur, there is a full between what we know intellectually and what we can absorb emotionally. Transitioning from death vigil to funeral vigil gives families time to acknowledge that their work is done, that they did it well, and that they didn’t let their loved one down. Despite the intensity and uncertainty of that time period, continuing to care—bathing, shampooing hair, dressing, and all the many small acts of compassion carried out for the final time by familiar, loving hands—is an unexpected gift to the living as well as the dead. Families wishing to slow the pace after the death are looking for partnership with the same people who helped them through what is often a physically and emotionally trying period for the caregivers as well as the patient. There are ways that hospice staff can be of service outside the standard practices without making exorbitant demands on time or duties.

Here’s how hospice staff can help:
1. Ask families on admission if they would like to explore funeral options rather than asking what funeral home to call
2. Provide information if solicited
3. Offer connections to home funeral resources
4. Recognize the family’s legal right to have a home funeral
5. Demonstrate confidence in the family to care for their own dead
6. Expedite processing of the death certificate
7. Assist next-of-kin in getting the death certificate signed by the doctor responsible
8. Assist with body care, if invited

Photo courtesy of Romina Vida Kani, Enhancity

National Home Funeral Alliance, www.homefuneralalliance.org
8 Ways Hospital Staff Can Support Home Funeral Families

We’ve all heard that the majority of us wish to die at home and that very few of us manage it. As more people become aware of and plan for home funerals, we will someday see similar statistics about how many of us planned to die peacefully in our beds expecting to then be laid out and waked at home vs. how many of us ended up serviced by professionals after a hospital stay or ER visit. One way we can prevent those statistics is to begin early to find ways to assist families who choose to bring the body of a loved one home, even after death in a hospital, including after autopsy, organ donation, or traumatic circumstances. Hospital staff can play key roles in helping families make their way through the body release process.

Here’s how hospital staff can help:
1. Ensure that your body release policy and other pertinent policies are in compliance with the laws in your state regarding the right of next-of-kin to take custody and control of the body, even in states that require hiring a funeral director for some aspect of care
2. Create policy that is easy to follow and that lays out the procedure for removal and release to the family.
3. Ask families what their funeral plans are, rather than asking what funeral home to call
4. Offer information about home funeral options and resources
5. Assist in completing appropriate paperwork in a timely manner so the next-of-kin will be able to meet time requirements for removal
6. Offer information about reliable removal services or home funeral-friendly funeral directors willing to file paperwork and transport to the home for a reasonable fee
7. Recognize the family’s legal right to have a home funeral throughout the experience
8. Demonstrate confidence in the family to care for their own dead

Photo courtesy of Olivia Barnburn, Sacred Crossings

National Home Funeral Alliance, www.homefuneralalliance.org
10 Ways Care Facility Staff Can Support Home Funeral Families

When a loved one dies in a care facility, it is common practice to contact a funeral director immediately. The need to fill the bed, to avoid disturbing other residents, the fact that many family members may take a considerable amount of time to arrive all add up to this practical solution. But this doesn’t preclude the possibility for families to conduct the care they choose.

More families are expressing interest in handling at least some of the after-death details, including bringing the body home or to another facility to bathe and dress, have visitors stop by, or plan a ceremony or funeral observance. They may or may not choose to hire a professional. Help in making that dream a reality lies with caring facility staff.

Here’s how care facility staff can help:
1. Ensure that your body release policy and other pertinent policies are in compliance with the laws in your state regarding the right of next-of-kin to take custody and control of the body, even in states that require hiring a funeral director for some aspect of care.
2. Create facility policy that is easy to follow and that lays out the procedure for removal and release to the family.
3. Ask families what their funeral plans are during admission, rather than asking what funeral home to call.
4. Offer information about home funeral options and resources and explain how your facility manages the details.
5. Assist in completing appropriate paperwork in a timely manner so the next-of-kin will be able to meet time requirements for removal.
6. Offer information about reliable removal services or home funeral-friendly funeral directors willing to file paperwork and transport to the home for a reasonable fee.
7. Assist next-of-kin in getting the death certificate signed by the doctor responsible.
8. Assist with body care, if invited.
9. Recognize the family’s legal right to have a home funeral throughout the experience.
10. Demonstrate confidence in the family to care for their own dead.

National Home Funeral Alliance, www.homefuneralalliance.org
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