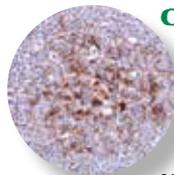


CJD: An Update



There has been much written about Creutzfeldt-Jakob disease, both accurate and inaccurate, as well as a continuing debate as to whether or not a confirmed or suspected CJD case can be safely embalmed and viewed. This article will bring clarity to this issue through an examination of OSHA law, the current science regarding CJD, the effect of CJD-contaminated waste on the environment and the handling of a CJD case by a funeral service professional.



CJD and OSHA

Edward M. Ranier

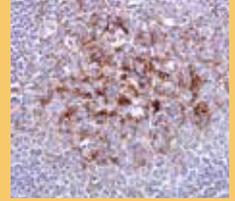
Found primarily in the body's cerebrospinal fluid, CJD presents the greatest potential for exposure to funeral professionals confronted by autopsied remains or remains with a non-intact skull with confirmed CJD. At the present time, the method to confirm the presence of CJD is by autopsy. There are instances, however, in which a funeral professional is presented with intact remains in which CJD is medically suspected but not confirmed by autopsy.

CJD resists disinfection and is not eliminated by formaldehyde or similar embalming chemicals. The most effective way to destroy the CJD prion is through cremation at or above 1,600 degrees. The recommended disinfection of instruments such as would be used in an autopsy or preparation is through the use of an autoclave, which is found in hospitals

but rarely in a funeral home. Another option is the use of disposable instruments that are then disposed of as hazardous waste. There is also a recommendation by the World Health Organization (WHO), which will be discussed in more detail, regarding the use of sodium hydroxide (lye), which creates its own safety and environmental hazards and requirements for use and proper disposal.

What is agreed on is that non-autopsied, intact remains present much less of a hazard to an embalmer in a suspected CJD case than autopsied remains or remains with a non-intact skull in a confirmed CJD case. There also appears to be little hazard, even with autopsied remains, in having the remains present, in a closed casket, for a funeral service. Direct burial or direct cremation also appears to be the safest method of disposition for a confirmed, autopsied CJD case.

The OSHA Bloodborne Pathogen Standard (29CFR1910.1030) applies to all oc-



Edward M. Ranier, Curtis D. Rostad, Carol Lynn Green and Kurt L. Soffe

cupational exposure to blood or other potentially infectious material and includes exposure to bloodborne pathogens, which are defined as pathogenic microorganisms present in blood that can cause disease in humans. These pathogens include but are not limited to CJD, as well as the more usually encountered hepatitis B virus and human immunodeficiency virus (HIV).

Occupational exposure is defined as reasonable anticipated skin, eye, mucous membrane or parenteral contact with blood or other potentially infectious materials that, in funeral service, would occur during a preparation or transfer of remains. Other potentially infectious materials include cerebrospinal fluid, where CJD may be found, as well as any body fluids that are visibly contaminated with blood and all body fluids in situations where it is difficult or impossible to differentiate between body fluids.

The Bloodborne Pathogen Standard requires that universal precautions be followed, which means that all human blood and certain body fluids should be treated as if known to be infectious with HIV, hepatitis B or other bloodborne pathogens, such as CJD.

The Bloodborne Pathogen Standard also requires a written exposure control plan that must be reviewed and updated at least annually and whenever necessary to reflect new or modified tasks and procedures that affect occupational exposure. It is strongly recommended that the written plan contain specific instructions as to what funeral personnel must do when confronted with a suspected or confirmed CJD case.

Because of the absence of an autoclave in the preparation room, if an embalming is to be done on a suspected CJD case, it is strongly recommended that disposable instruments be used, disposable plastic sheeting be placed on the preparation table and, per the Bloodborne Pathogen Standard, all personal protective equipment be worn, including gloves, goggles, face shield and surgical

gown. The personal protective equipment and the sheeting should be disposed of as hazardous waste, consistent with state and federal requirements. Plastic sheeting should also be used in the removal vehicle and similarly disposed of after the transfer of the remains to the funeral home.

The ultimate question, in either a confirmed or suspected CJD case, is whether or not the remains should be embalmed. The most recent update regarding CJD published by the Centers for Disease Control and Prevention (CDC), entitled "Information on Creutzfeldt-Jakob Disease for Funeral Home, Cemetery and Crematory Practitioners" (December 10, 2012), confirms that CJD patients usually die within one year following the onset of symptoms and that an autopsy is the best way to confirm the presence of the disease. The CDC also states that transmission can occur through invasive medical procedures involving the central nervous system due to exposure to contaminated brain tissue. The average age of death of CJD patients in the United States, according to the CDC, is 68 years.

It is the conclusion of the CDC in its update that standard disinfection procedures and routine embalming solutions are ineffective against prions such as CJD, but studies have shown that chemical solutions and physical processes involving bleach, sodium hydroxide or autoclaving can inactivate the prion. The CDC also concludes that if the bodies of CJD patients have not been autopsied, then transportation, preparation, disinfection and final disposition can be safely performed when standard precautions are strictly enforced.

The CDC recommends that individuals transporting a CJD patient to the funeral home wear personal protective equipment and place the body in a leak-proof pouch, which should be lined with absorbent material to prevent leakage of fluids.

Embalming of non-autopsied remains should include, according to the CDC, the placement of the body on a waterproof

sheet to collect body fluids and the use of disposable instruments. Body fluids should be collected in a suitable container and incision sites should be closed with a superglue, wiped down with bleach and the body washed prior to dressing. Cosmetic restoration work can also be undertaken.

For autopsied remains with confirmed CJD, the CDC states that adherence to standard infection control methods is paramount and that special precautions should be taken, including the placement of a plastic sheet with absorbent lining and raised edges underneath the head to ensure containment of fluids and prevent any spillage. Where sutures do not completely control leaking, the cranium cavity should be packed with absorbent material that has been soaked with bleach and then tightly sutured. The body of a CJD patient must be placed on a waterproof sheet to contain all fluids, and disposable instruments, masks, gowns and puncture-resistant gloves must be used whenever possible. The CDC also recommends that the body be washed with bleach, rinsed and sanitized before dressing and special care be taken to limit fluid leakage when performing restorative work.

The method of disinfection for a CJD case, according to the CDC, is 40 grams of sodium hydroxide pellets per liter of collected fluid, which will be discussed further in this article. Plastic sheets and other disposable items that have been exposed to body fluids must be incinerated, and mortuary working surfaces that have accidentally become contaminated should be flooded with sodium hydroxide or bleach, left undisturbed for at least one hour and then, with the embalmer wearing gloves, mopped up with absorbent, disposable rags. The CDC specifically cautions that the disposal of body fluids, tissue and hazardous chemicals be done in accordance with funeral home policies and state and federal regulations.

Despite the indication that a CJD case

may be embalmed, the CDC specifically warns that unnecessary manipulation of the body that would force purging of body fluids and risk opening incision sites should be avoided. It also recommends that the casket be lined with a leak-proof sheet.

The CDC specifically warns that if an autopsy has been performed, family members of CJD patients should be advised to avoid superficial contact with the remains, such as touching or kissing the patient's face. The inference is that a closed casket in the case of autopsied remains with confirmed CJD is the prudent way to proceed for the funeral service professional and for the protection of family and the public.

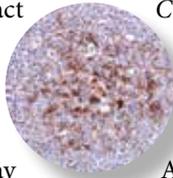
The presence of CJD, confirmed by autopsy or just medically suspected, presents a special dilemma for a funeral service professional dedicated to the service of a family that seeks assistance. Clearly, there are health issues for the funeral service professional, who must consider the protection of the funeral home staff, the family and the public. NFDA hopes this

article will provide the funeral service professional with sufficient information to fully determine the proper precautions and procedures to follow when presented with a confirmed or suspected CJD case.

Edward M. Ranier is NFDA OSHA and labor legal counsel.

CJD: The Disease

Curtis D. Rostad



It took almost 75 years from first discovery until most funeral directors had heard of a disease called Creutzfeldt-Jakob. And when they did hear about it, the information was incomplete, sketchy, mostly wrong and sometimes close to hysterical. It did not help that a related disease resulting from eating meat from cows infected with "mad cow" disease in Great Britain added to the misinformation.

Unfortunately, that hasn't changed much. The information is still sketchy and incomplete, and funeral directors' reactions to dealing with the disease range from paranoia to "no big deal."

CJD is one of a family of rare diseases known as transmissible spongiform encephalopathies (TSEs) that affect the brain and nervous system. CJD is a fatal neurological disease; there is no treatment that can control or cure it. Other TSEs are found in certain animals, including bovine spongiform encephalopathy (BSE, otherwise known as "mad cow" disease) found in cattle. CJD was first identified and described in the 1920s and is the most common of human TSEs. It can be 12 to 20 years or even longer from time of infection until onset of symptoms. Its symptoms mimic that of Alzheimer's except that the period from first symptoms to death can be as short as a few months.

CJD is infectious or transmissible, although it is not considered to be contagious in the usual sense. Spouses and family members who live with a CJD patient are at no greater risk of acquiring CJD than the general population.

There are three epidemiologic forms of CJD. Hereditary (or familial) CJD, resulting from a genetic mutation, comprises about 5 to 10 percent of all cases. Sporadic CJD (from unknown causes) is the prevalent form, occurring in at least 85 percent of cases. Iatrogenic (acquired) CJD is responsible for about 1 percent of cases and is transmitted by exposure to infected brain or nervous system tissue, usually through medical procedures such as neurological procedures using contaminated instruments, via corneal transplants, silver electroencephalograph electrodes, cadaveric dura mater transplants and human growth hormone administration.

Since the disease is neurological, the greatest risk of infection comes from exposure to brain, spinal column and cerebrospinal fluid. Fluids that normally leave the body, such as urine, semen, sweat and tears, are non-infectious. While blood is generally held to be non-infectious, there is some research to suggest that blood could indeed be infectious. Evidence suggests that caution in exposure to blood is warranted. A special panel of the National Heart, Lung and Blood Institute agreed that "an unqualified and irreducible risk of exposure to CJD through blood and blood products does exist."

The one unique aspect of CJD that distinguishes it from all other diseases an

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embalmer faces is that the causative agent of the disease, a rogue protein called a prion, is not killed or affected by formaldehyde or any other common embalming chemical.

The disease has no effect on the preservative and restorative aspects of embalming, but disinfection of the body does not take place. Extra caution should be used when there is exposure to the brain, spinal column and, to a lesser and unknown degree, blood. The problem is that little is known about how the disease is actually transmitted. While we know the risk

of infection from the deceased is small, we don't know how much risk there really is. We can assume the risk increases as we increase our exposure during the embalming process. We again assume that risk increases even more following cranial autopsy. But what we do not know is how great that risk is. Therefore, little can be said about how embalmers can protect themselves.

It's easy for the medical profession to tell embalmers that CJD does not pose a safety and health risk. Many medical organizations, including the World Health

Organization, do not see any particular concern with embalming a body with CJD (even one that has been autopsied) and simply advise universal precautions. Many embalmers take this to mean that CJD poses no risk.

Yet for those in the medical community, the story is quite different. Many pathologists simply refuse to perform autopsies on patients known or suspected to have CJD. When an autopsy is performed, the recommended autopsy procedures include verified negative pressure in the room, receipt of the body in a body bag placed inside a heavy crash bag, limiting admittance to the autopsy room once the body bag is opened, three layers of personal protective equipment and plastic sheeting covering the floor. The autopsy (head only is recommended) is done entirely within the body bags. Electric saws should not be used. Instruments are either discarded or soaked for one hour in bleach and then autoclaved for an hour. All personal protective equipment is removed while standing on the plastic sheet, with shoe covers removed as personnel step off the sheet. The sheet is then rolled up and discarded as a biohazard. None of this comes close to simple "universal precautions."

The body, two body bags and all, are then released to the embalmer, who is told that CJD is no big deal. Embalming that same body carries no risk. But no one can guarantee that embalming a CJD case is "safe." The odds of contracting CJD may be small, but we really don't know what they are, and it does not help that the medical community has one set of standards and recommendations for funeral service and a different one for themselves.

The second problem with embalming a CJD case is disinfection of instruments and the embalming room. An autoclave, which few funeral homes have, is the only safe way to disinfect instruments. While bleach is effective against the prion for general disinfection, it is not easy to know if the bleach really got to all contaminated surfaces with sufficient amount and concentration to provide complete disinfection. There is also the possibility of a second chance of exposure during cleaning. And if patients can contract CJD from improperly cleaned surgical instruments, that leaves open the possibility of ongoing exposure to the disease for the



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embalmer from incomplete disinfection of instruments.

Still, in most cases, the body can be removed from the place of death to the funeral home with minimal threat of exposure. As already stated, family members can live with a person with CJD and are not at risk of infection from normal contact, so there is no reason for a funeral home to flatly deny service to a family whose loved one has died from CJD. Yet there is plenty of good reason to hesitate or even decide against embalming, especially following an autopsy, when exposure to the prion is greatest. The embalmer is faced with a serious decision, even though it may go against their mindset to say no to a family.

Some within the profession have maintained that since the risk of disease from exposure to the prion is minimal, the embalmer should proceed as a matter of professional duty. Others have justified embalming by saying they may have already unwittingly embalmed an undiagnosed CJD case, so there is no way to avoid exposure anyway. Others have acknowledged that they have knowingly em-

balmed a body with CJD and suffered no ill effects (so far, anyway).

Yet voluntarily exposing oneself to a fatal disease that cannot be mitigated by modern embalming techniques and chemicals should not be taken lightly. Since symptoms of the disease may not show themselves for many years after exposure, a rash decision today to earn a few hundred dollars or better serve one family could have regrettable results for the embalmer's entire family a decade or more later.

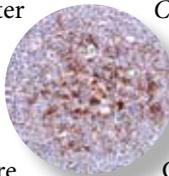
Since the incidence of CJD remains rare, it does not receive the attention of researchers, as do cancer and other serious diseases. We don't have all of the answers. Not much more is known today than we knew a decade ago. The decision to embalm remains a personal decision that should not be made because of peer pressure or a sense of professional duty. CJD is a fatal disease and not to be treated lightly. The advice has not changed: Approach with caution.

Curtis D. Rostad, CAE, CFSP, is a licensed

funeral director, executive director of the Indiana Funeral Directors Association and author of Creutzfeldt-Jakob Disease: A Comprehensive CJD Guide for Healthcare Personnel.

CJD and the Environment

Carol Lynn Green



This article, which originally appeared in *The Director* in 2001, has been updated here and highlights issues related to Creutzfeldt-Jakob disease and the environment.

Although much has been written about CJD, the potential risk it presents and the steps required to minimize (but not necessarily avoid) the potential for transmission, little appears to have been written about CJD in the environment, its short- or long-term viability and whether CJD survives over time in water, soil or air. The CDC recently stated that CJD is not transmissible through environmental contamination. According to the CDC, CJD is not spread by airborne droplets, as are tuberculosis and influenza, or by blood or sexual contact, as are

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hepatitis and HIV, although CJD transmission can occur during invasive medical procedures involving the central nervous system if exposed to contaminated brain tissue.

In Geneva in March 1999, the World Health Organization convened a three-day meeting of experts on CJD. Dr. Paul Brown, a senior research scientist at the National Institutes of Health in Bethesda, Maryland, and an author of a March 2000 article in this magazine, chaired the meeting. Guidelines on the prevention of exposure to CJD were prepared following the meeting (WHO Infection Central Guidelines for Transmissible Spongiform Encephalopathies, Report of a WHO Consultation).

The guidelines confirm that CJD is highly resistant to conventional chemical and physical decontamination methods and also document that CJD is not destroyed by formaldehyde, phenol, glutaraldehyde, alcohol, dry heat, boiling, ultraviolet radiation, autoclaving at 121 degrees C for 15 minutes or standard gravity sterilization.

In view of these conclusions about the resistance of CJD-contaminated wastes and other materials and equipment to treatment, WHO established an accepted practice for waste handling and disposal of CJD-contaminated fluids. With regard to embalming fluids, the WHO Consultation Report recommends that at the conclusion of the embalming procedure, the container of drainage fluids should be decontaminated by adding sodium hydroxide (lye) pellets at the rate of 40 grams per liter of fluid and “disposed of as for any other mortuary waste.” According to the CDC, the mixture should be stirred after a few minutes and care should be taken to avoid spillage, as the fluid will be hot. It should then be left undisturbed for at least one hour, after which it can be disposed of like other mortuary waste. Plastic sheets and other disposable items that have been exposed to bodily fluids should be incinerated. Preparation room working surfaces that have accidentally become contaminated should be flooded with sodium hydroxide or bleach, left undisturbed for at least one hour, then, using gloves, mopped up with absorbent disposable rags and the surface swabbed with water sufficient to remove any residual disinfectant solution.

The addition of the recommended

amount of sodium hydroxide to embalming fluids has the potential to dramatically change the regulatory character of the resulting fluid, causing it to be a regulated hazardous waste under the Resource Conservation and Recovery Act (RCRA). Ordinarily, embalming fluids discharged to sewers and septic systems are not regulated hazardous wastes. The addition of sodium hydroxide causes the pH of the fluid to become extremely basic, around 13 or 14, depending on the composition of the fluid to which the sodium hydroxide is added. This pH is highly corrosive. Because of the high pH – above 12.5 – the resulting solution and all other wastewaters with which it is mixed are considered to be RCRA-regulated hazardous waste.

Contrary to the previous statement in this article, this RCRA-regulated wastewater can no longer be disposed of “as for any other mortuary waste.” Because the liquid has become a RCRA hazardous waste, special handling, notification and other requirements must be met if the wastewater is to be disposed of in the sewer system. This high-pH wastewater may be disposed of in the sewer *only* if it mixes in the sewer with domestic sewage and only if specific notification (including a description of the nature and character of the waste) is provided to the federal Environmental Protection Agency, the state EPA and the local wastewater treatment authority. In addition, the local wastewater treatment authority may prohibit the discharge of this high-pH solution to the sewer system. A change in pH of this magnitude may be considered a substantial change in the character of the funeral home’s discharge, in which case advance notification must be given to the regulatory authorities prior to discharge. The wastewater may not be trucked or hauled to the sewer system because of the prohibition on such disposal of RCRA-regulated waste. If the mixture is trucked or hauled, it must be handled as a hazardous waste, transported by a licensed RCRA hauler and taken to a permitted RCRA hazardous waste facility.

Disposal of this high-pH solution into a septic tank is strictly prohibited; no RCRA-regulated hazardous waste may be disposed of in a septic system. Beyond that, disposal of the solution into a septic tank will most likely lead to process fail-

ure. A pH in this high range would be expected to kill system microbes.

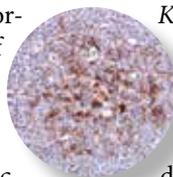
Both sodium hydroxide and sodium hypochlorite can be quite dangerous to handle. Neither of these chemicals – or other chemicals, generally – should be used without full knowledge of their properties, appropriate training and work practice or engineering controls for those who use or are otherwise exposed to the chemical. Sodium hydroxide is highly caustic and will cause the fluid to which it is added to become quite hot. Contact with sodium hydroxide or with sodium hypochlorite may cause severe burns to skin and eyes; all skin contact should be avoided. Special precautions must be observed when handling these chemicals to ensure that injury does not result from their use.

Putting in place funeral home procedures and training funeral home employees as to the appropriate handling of embalming wastewaters and the decontamination of preparation room surfaces that may have become contaminated with CJD is a critical first step that will enable the funeral home to serve families and protect the public when caring for a deceased known or suspected to have CJD.

Carol Lynn Green is NFDA specialty counsel for environmental compliance.

CJD: Care vs. Scare

Kurt L. Soffe



Though most Americans have never heard of Creutzfeldt-Jakob disease, they have heard of mad cow disease and fear it. They don’t know what it is, but they know it’s catastrophic.

In the spring of 1998, following the much publicized events surrounding mad cow disease in England and the confirmation of tainted beef consumed by humans resulting in vCJD or new variant CJD, a gentleman in our community selected our funeral home to serve his needs. His desire was to complete advance funeral plans for his wife, who was not expected to live more than 30 days. Upon completion of her arrangements, he informed the funeral director that his wife needed to be transported to University Medical Center at the request of her neurosurgeon for a cranial autopsy. He stated she was dying as a result of “mad

cow" disease. His wishes for his wife were to pay tribute to her with a public viewing in the evening, followed the next day with a second viewing and funeral service at their church.

Information relevant to funeral service and deceased care of those with CJD was in its infancy. We knew that only through education and discussion with the husband could we properly prepare for his wife's care and the tributes he had planned. Upon her death, his wishes were carried out as requested.

Our funeral home policy regarding the care of confirmed or suspected CJD cases is discussed and outlined with all staff interacting with the public. Second, and in my opinion the most crucial, is an open, informative discussion with family members, creating the opportunity to pay tribute to a life lived while providing safety to the family and funeral home personnel. Many family members have been caregivers of those either diagnosed or suspected of having CJD. Much of that familial care has been performed under acute circumstances. Many families are unaware of the CJD channels of transmission but are acutely aware of the devastating effect this prion has on the brain and bodily functions.

A critical key is educating family members about the pathways of transmission coupled with potential exposure to funeral home personnel, including family and friends who may come in contact with the deceased. This information results in the probable election not to perform embalming and have an open-casket viewing. Several have shared that the thought of exposing someone to this insidious disease is sufficient motivation to eliminate all doubt of transmission by not embalming the body following a cranial autopsy.

Following multiple discussions, the husband above elected not to open the casket, eliminating any possibility of transmission. He continues today as one of the foremost public authorities on CJD and has mentored many through the challenges this disease presents to victim and family.

The policy of our funeral home when a cranial autopsy has not been performed is to proceed with extreme universal precautions in the embalming and disinfection procedures. The body is prepared for viewing and funeral services, with burial or cremation as the disposition. However, when a cranial autopsy has been performed when CJD is present or suspected to be present, the funeral home cannot provide an absolute process to complete the disinfection of the remains or guarantee to the viewing family and public in attendance that the remains are not a potential hazard. We do not arterially embalm the body and restore the autopsied body for public viewing. We have requested that the pathology department restore the calvarium and suture the incision made during the autopsy, thus allowing the funeral home, upon receipt of the body, to apply topical disinfection and external embalming chemicals, minimizing risk to funeral home personnel. This request has not been granted.

Many questions remain regarding ensuring worker safety and adequate protection for funeral service professionals performing the embalming and restoration process required to repair the autopsy procedure. The only guaranteed process is to eliminate the potential for exposure. We recognize that some could argue that this decision may be in conflict with the Americans With Disabilities Act. We do not refuse to serve the fam-

ily but do require, based on our interpretation of the ADA, the option to alter our process and procedures to accommodate a given set of circumstances.

Every effort is made on our part to educate those making final arrangements and provide updated information to the deceased's personal representative and family members regarding CJD and the options of care for their loved one.

As of December 2013, our firm has assisted three families with loved ones who had confirmed cases of sporadic CJD. Unfortunately, confirmation was not immediately available and came several weeks following the funeral services.

It is my opinion that funeral homes in general are not seen as partners in the CJD information cycle. Medical providers have called our funeral home and ridiculed our policies without any information or background. The profession is ridiculed in the media following a declination of embalming of an autopsied CJD case. We have been told that transmission of CJD is unlikely if exposed to blood, yet the American Red Cross is denying blood donations from anyone who has spent more than six months or more in Europe from 1980 to the present, as well as that of any blood relative of a CJD victim. Although sporadic CJD is not believed to be transmissible through blood, the American Red Cross is taking strict precautions.

Our concern is for the safety of funeral home personnel and the families we serve by not placing them in harm's way. The federal surveillance system for monitoring CJD and BSE (bovine spongiform encephalopathy or mad cow disease) is modestly funded and fragmented. There is no uniform reporting mechanism in place, and every state has its own set of



The advertisement features a photograph of two white keepsake items, possibly funeral home cards or small booklets, resting on a bed of purple and yellow flowers. One card has a logo with the initials 'JF' and the text 'Jacobson Ferguson Funeral Home 223-450-7000'. The other card has a circular portrait of a woman and the text 'In Loving Memory of'. To the right of the photo, the text reads 'For Years to Come...' in a large, black, serif font. Below this, it says 'Remind your customers of their loved ones, and the thoughtful service you provided during their deepest time of need.' To the right of this text is a green stylized flower logo. Below the logo, it says 'HOPE GREETINGS' in a bold, black, sans-serif font, followed by 'Handwritten & Keepsakes' in a smaller, italicized font, and 'Call: 904.998.4299' in a bold, black, sans-serif font. At the bottom of the advertisement, there is a green banner with white text that reads 'SPECIALIZING IN UNIQUE AND PRACTICAL KEEPSAKE OPTIONS | www.hopegreetings.com'. At the very bottom of the banner, it says 'Call today to join our website affiliate program & begin earning effortless commissions!'.

rules. The detection and treatment of CJD is extremely limited and the incubation period lengthy, up to decades.

Until this information, detection and treatment gap is narrowed or closed, the

linkage between CJD, BSE and CWD (chronic wasting disease in deer/elk); the blood supply; and the lack of knowledge and reporting combines to fuel the fears of the public and caregivers. With oth-

er communicable disease, disinfection is guaranteed when protocol and universal precautions are followed. When presented with CJD, however, disinfection of instruments, the preparation room and the body itself cannot be guaranteed. The professional standard of care may not be achieved when embalming and having an open-casket viewing for an autopsied CJD body.

Knowing thousands of funeral professionals across the country, I am confident that not one of them desires to alter a family's wish or desire for a public open-casket viewing. Yet the very reason we are called upon is to safely "direct" that family through the loss of a loved one regardless of the cause.

From a public policy perspective, a deeper understanding of CJD – its causes, rate of incidence and options for care of the deceased – would provide direction for funeral service professionals in their search to better understand prion diseases and care for both the victims and their families.

Kurt L. Soffe, CFSP, is an owner of Jenkins-Soffe Funeral Chapels & Cremation Center in Murray and South Jordan, Utah; a fourth-generation funeral director; current member of the NFDA Spokesperson Team; past president of the Utah Funeral Directors Association; past NFDA Policy Board member; and a past board member of Intermountain Donor Service.

Embalming CJD Cases and the Americans With Disabilities Act

Funeral homes are considered public accommodations under the Americans With Disabilities Act (ADA) and as such, they may not withhold their services or impose additional expenses for those services to disabled individuals and other persons associated with disabled individuals, such as family members. This is the reason funeral homes may not refuse to embalm AIDS cases or impose surcharges for doing so. To deny embalming services would be discrimination against family members of disabled individuals.

While the ADA does require public accommodations to provide services to disabled individuals, there is an exception to that requirement when the provision of those services would pose a substantial risk of serious harm to the health and safety of others. This exception does not apply in embalming AIDS or hepatitis cases since we know that by employing universal precautions, the funeral home can avoid risk.

However, as explained in the accompanying articles, there is considerable uncertainty as to whether CJD cases can be safely embalmed in all circumstances. Questions surrounding how the disease is transmitted, under what conditions the prions are destroyed, the safe disposal of waste and the disinfection of equipment and the preparation room have not been definitely answered.

In NFDA's opinion, there is no absolute mandate under the ADA that requires a funeral home to embalm a CJD case. The ability to safely embalm a CJD case may depend on the condition of the remains, the funeral home's available equipment and the training and expertise of its embalming staff. While a funeral home that has an autoclave and embalmers who have been trained in handling CJD cases may feel it can safely embalm a CJD case that has been autopsied, a funeral home without the equipment or expertise may believe that offering embalming in such a case poses a serious health risk to its employees. After reviewing the circumstances of each case, the risks posed by the case and the funeral home's ability or inability to safely avoid those risks, funeral home management will have to make the decision on what embalming services it will provide and under what circumstances. That decision should then be clearly and expeditiously communicated to the family.

Conclusion

Information and knowledge regarding Creutzfeldt-Jakob disease, its transmission and exposure prevention continue to develop. NFDA will provide all new information it receives and any new direction and guidance received from such organizations as the Centers For Disease Control as it becomes available.

A funeral service professional must balance the desire to provide service to families in need with the equally important goal of protecting the health of the funeral home staff, as well as the family and the public.

For further information or for specific questions relating to the content of this article, NFDA members can contact John H. Fitch Jr., senior vice president of the NFDA Advocacy Division, at 202-547-0441 or jfitch@nfda.org. ★

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