

# **END OF LIFE CARE AND VERIFICATION OF DEATH**

## **PROBLEMS AND OPTIONS**

Notes on findings of a search for information by Mike Carter

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### **1. BACKGROUND**

Clearly, for a person who wishes to be cryogenically preserved after death, it is imperative that a verification (often called a pronouncement) of death be given as soon as possible after that person has died. However, this is not normally considered to be a priority by doctors, so there is a high risk of significant delays occurring.

These notes are for intended to provide background information to members of Cryonics-UK to help them understand the various options available for minimising delays in verification of death, so that they can make suitable arrangements for themselves. They are intended to provide background information only, based on my recent searches, and are not advice.

Following recent problems in making arrangements for rapid verification of death for a member of Cryonics-UK, I contacted various organisations to investigate the options available and to identify some of the companies that may be willing to provide suitable services. The notes are my best understanding of the situation but it has been extremely difficult to obtain definitive answers, and I have neither a medical nor a law background. These notes should be read in this context, and I should be grateful of any comments from members so that any errors can be corrected, and the notes improved.

### **2. REGULATORY REQUIREMENTS – WHO CAN VERIFY DEATH?**

This is a minefield, as there are so many bodies involved in regulating who can pronounce death, and under what circumstances.

Doctors can verify death but they must be registered practitioners with a GMC (General Medical Council) registration number. If there is any doubt, this can be checked on the GMC web site ([gmc-uk.org](http://gmc-uk.org)). Doctors must follow NHS guidelines and the guidelines of the local NHS Trust. For cremation, two doctors are required to pronounce death but this does not apply to cryonics any more than it would for embalming and burial.

Nurses can verify death within certain limitations but the situation is more complex than for doctors. The nurse must be registered with the NMC (Nursing and Midwifery Council), and must follow NMC guidelines in addition to NHS and NHS Trust guidelines. There are also RCN (Royal College of Nursing) guidelines which they may have to follow, although the RCN tend to defer to the NMC regarding regulatory procedures. Also, a nurse may verify death only where a doctor has seen a patient within 14 days prior to death and has completed a form to say that death is expected.

In addition, the nurse must have suitable training in the verification of death, and the company that employs him/her (agency, care home, etc.) must have a Verification of Death Procedure policy document in place.

As you can see, the situation with regard to a nurse verifying death is complicated so, given that there is normally no urgency attached, it is little wonder that most care homes and agencies are not aware of the regulatory requirements, and prefer to simply avoid the problems.

### **3. OPTIONS FOR THE CARE SITUATION ON DEATH**

#### **SUDDEN UNEXPECTED DEATH**

If death is sudden or unexpected and there has been no care situation in the period running up to death, then an autopsy will almost certainly be required. Under such circumstances, the chances of a good cryo-preservation are extremely slim. Thus, death by heart attack or an accident represents a very bad situation for anyone wishing to be cryogenically preserved.

#### **NHS HOSPITALS**

You will be here only if there is a medical reason for you to remain in hospital up to the time of your death. Clearly, medical staff, including doctors, will be present, and it will be a matter of persuading them to minimise delays on pronouncement of death. Medical staff have a duty, under NHS guidelines, to respect your beliefs, so should agree to your wishes. It is all a matter of forming a good relationship with staff. However, there is still no guarantee they will be as quick as we would like, so you may still want to make other arrangements for verification of death (see below), subject to agreement with hospital staff.

#### **PRIVATE HOSPITALS**

These are mainly equipped to carry out specific medical procedures such as hip operations and cosmetic surgery, and are unlikely to accept a patient for end-of-life care. They are therefore not normally an option.

#### **HOSPICES**

These are similar to hospitals but specialise in palliative care for end-of-life situations. They will have medical staff available, so the possibility of obtaining reasonably prompt pronouncement is fairly good. The same comments apply as for NHS hospitals, above. However, to be admitted to a hospice you will need to be suffering from a recognised terminal disease such as cancer, and will need to be referred by a consultant. Simply dying of old age will not get you into a hospice.

Unless you can be referred in such a way as to have fees paid, then costs could mount up, especially for anybody who remains in the hospice for several weeks or months.

#### **CARE HOMES**

A few care homes have registered nurses with the necessary training to verify death. However, most do not, and staff generally do not understand the regulations so they may tell you that nurses cannot verify death. It is therefore a matter of checking in your area to find a home that has both the trained nurses and vacancies. Clearly, whilst checking well ahead would be useful, the situation is likely to change over years or even months, so to some extent final checks would have to be carried out by your family or friends nearer the time.

If you can find a home without nurses who have undergone training in verification of death but which is still sympathetic to your wishes, they may agree to have one or more nurses trained for this, especially if you would arrange and pay for the training. This can be accomplished by use of an agency that can send out a trainer at short notice to give the appropriate training at the nursing home, and can also provide a pro-forma Verification of Death Procedure document that can be put in place quickly – see section 4 for details of Fairway Training, a training agency that will give this service.

You can get into a care home as a private patient without going through the usual referral procedure, although the home will vet you to see whether they think they can accommodate you. See section 4 for how to contact care homes.

Care homes cost typically around £1,000 to £1,400 a week, so costs could mount quickly, but a suitable care home, which is able to arrange for rapid verification of death at any time, may be one of the best options in terms of reliability.

## **LIVE-IN OR VISITING NURSES**

As far as I can determine, nurses are able to make a pronouncement of death in a home situation but I found only one company, Fairway Training, who understood the regulations properly and might do this (see section 4 below).

Nurses cost around £20-£25 per hour and a live-in nurse would normally charge for a 12-hour day but should be available at any time to verify death. Thus, the total daily cost would be around £240-£300, making this the most expensive option, but probably the most reliable one.

## **VISITING DOCTORS**

The patient's GP is an obvious choice, and may be prepared to give some urgency to coming to pronounce death if he/she is approached and is sympathetic. However, there are still likely to be delays, even during normal surgery hours. Out of hours (when death is most likely), an agency doctor would be used, with possibly several hours' delay.

Private doctors are available, usually through agencies, but the agencies are reluctant to send a doctor just to verify death, as they are unsure of the regulations. I have found only one agency that is prepared to do this; Ambition24 (see section 4, below), who were used and performed well during a call-out in 2013.

There would still be no guarantee of a maximum response time, as this will depend on where the doctor is when called, and would vary with individual doctors, but it should be much quicker than using an NHS GP. Fees would be in the region of £2,000 (including doctor's fee, agency fee and VAT), and would have to be paid in advance but should be refundable in the event of no call-out, or the inability of the doctor to respond.

Clearly, there is still a risk of a delay, but the response should at least be significantly quicker than relying on the GP service, especially out of normal surgery hours, and the risk of mounting payments associated with most other alternatives is avoided.

## **EUCRIO**

Eucrio was set up to provide services are similar to those provided by CUK, but operating on a commercial basis and using healthcare professionals. Thus, they ought, in theory, to be able to provide professionals who can verify death without delay, as part of an overall package to give a complete call-out service from verification of death to transportation to a cryonics provider. As such, this note would not be complete without reference to them.

Unfortunately, Eucrio never seems to have functioned reliably, and Nuno Martins, who runs Eucrio (in Portugal) advised me that they are planning a 'substantial jump in size' and a major advertising campaign, but asked that Eucrio be not considered as an option in CUK's notes for now. For the moment, therefore, there is no commercial organisation available for people who would like a call-out service but do not want to be members of CUK, with its reliance on members to participate in call-outs.

Should they ever provide a service we can feel confident with, it seems likely that costs would be in the region of €60,000 for a simple cool-down with water ice to perhaps €120,000 or more for full perfusion, including transport to the US.

## **4. ORGANISATIONS THAT MAY BE USEFUL**

### **AGENCY TO PROVIDE A PRIVATE DOCTOR AT SHORT NOTICE**

Ambition24 is an agency that normally provides nurses and doctors to healthcare organisations but agreed to provide a doctor at short notice on a private client basis for a CUK patient in late 2013. In the event, the doctor arrived within about 40 minutes of being called out, in the early hours of the morning, and gave verification of death; not as quick as we would have hoped, but still far better than any other arrangements we could have made.

Their fee for the call-out was £1,740. They have stated that they are agreeable to working with CUK for future call-outs, but fees may be a little higher, perhaps around £2,000. This is steep, but is a one-off fee, unless for some reason the doctor would be called out more than once.

Contact details are: 0871 8733 300 or 0207 112 4510. Contacts: Marius or Aiden. Further details on their web site.

#### **NURSES WHO CAN GIVE VERIFICATION OF DEATH FOR HOME CARE OR IN A NURSING HOME**

Fairway Training, based in Solihull, just north of Birmingham, specialise in giving training courses for medical professionals. They are able to help in two ways: by giving Verification of Death training to nurses who work at nursing homes; by giving similar training to live-in nurses supplied by an agency; and possibly by supplying a live-in nurse directly. They will also prepare a pro-forma Verification of Death Procedure document that can be readily adapted to the care home or nursing agency's needs.

The training course, which is for registered nurses, takes three hours and could be given at the care home or other premises. It costs £350 + expenses + VAT, regardless of the number of trainees, so total costs would probably be of the order of £800-1,000.

Contact details: 0845 450 3971 Edd O'Neil (his brother, Alex O'Neil, owns the company).

#### **CARE HOMES**

If you decide to use a nursing home you will need to contact homes local to your area to check whether they have vacancies and whether they have nurses with training in verification of death, and a Verification of Death policy document, or whether they are prepared to get these – possibly with help from Fairway Training.

Care homes can be located via Google or Yell, and the Bupa website will show you Bupa care homes in your area. When phoning a care home via Bupa, select option 2, 'all other enquiries', as this will put you directly in touch with the care home. Selecting option 1, 'initial enquiries and bookings', will direct you to the central Bupa bookings office, who will not be able to help you.

### **5. WHAT TO DO IF THERE IS A DELAY IN VERIFYING DEATH**

A delay in getting verification of death represents a serious setback to getting a good cryo-preservation, and should be avoided wherever possible. However, as discussed above, some delay is virtually unavoidable but there are mitigating actions that can be taken.

The regulations and guidelines that have to be followed are complex, but a lot appears to depend on the intention of the actions taken, not just the actions themselves. In this regard, discussion with the patient's GP is vital, as this will decide just what actions can be taken without fear of prosecution. Below is my understanding of the various options, having talked to a doctor and a legal adviser and read through various sets of guidelines by the NHS, NHS Trusts, the Royal College of Nursing and the Nursing and Midwifery Council. However, all this must be clarified and agreed with the patient's GP or other health professionals involved, and the following comments should not be taken as legal advice.

- Chest compressions can be viewed as an attempt to revive the person, using CPR, so should be acceptable.
- Cooling could be viewed as an attempt to limit ischemic damage, especially to the brain, but the extent to which this applied needs to be carefully discussed with the GP so that it could not be construed as hastening death. In a recent call-out, the doctor agreed to cooling of the neck (specifically, the carotid arteries) using ice bags.
- Administration of medications, even just heparin, will almost certainly not be allowed. However, some pre-death medication could be acceptable, using non-prescription medications: vitamin E; aspirin; and a dexamethorphan-based cough suppressant such as Benylin Dry Coughs – see CUK call-out manual for details.

The advice I have received is that, from a legal point of view, any of the above procedures could be performed on a cadaver or on a living person; it is a question of degree, so that there is no risk of death being diagnosed as being caused by, for instance, broken ribs due to chest compressions or by excessive cooling. This could be a problem if there is doubt about the cause of death but if death is expected and the GP has been consulted and has no objections then it should not be a problem. However, it would mean that the degree of cooling may have to be less than we would really like, and we would have to be careful with chest compressions.

It seems that the intent of the actions we take is important. If our actions were viewed as being intended to hasten death then there would be a problem but if they were viewed as being intended to resuscitate and/or minimise ischemic damage prior to the arrival of the attending doctor or nurse then there should not be a problem. Above all, the actions we take must be acceptable to the patient's GP and agreed in advance.

Ideally, the patient should also have agreed to the treatment, although this is not a requirement. Nevertheless, it would greatly help if the patient had already given a clear indication of his/her wishes on death; for instance, by lodging a letter or note with the GP, to be kept on file. This could make a difference to the amount of treatment we could give.

Lastly, it must be emphasised that all the above comments apply to the case of expected death; the most important element is that the patient is "attended during his/her last illness" by a medical practitioner. For sudden or unexpected death, the situation is much more difficult, and bleak in terms of a satisfactory cryo-preservation.