

END OF LIFE CARE AND CONFIRMATION OF DEATH

OPTIONS AND PROBLEMS

The arrangements for the final days or weeks of life are an important consideration for a cryonics patient because of their impact on the delays that can occur between clinical death and start of cool-down procedures. Various options are discussed below. In all cases, it is assumed that death is expected. For sudden or unexpected death, the situation is more complicated and much more detrimental for the cryopreservation process. More details are given in a separate note that is normally handed to the patient's GP.

Please note that the discussions and comments given in this note represent our best understanding of the various situations but are based on experience with a fairly small number of call-outs so, whilst they are given in good faith, they should not be assumed to be accurate.

THE MAIN CONSIDERATION

The single biggest factor in determining the quality of initial cool-down and perfusion of a cryonics patient is the speed with which the cool-down process can begin after clinical death. This means that a call-out team needs to be present when the patient dies and is allowed to begin cool-down and perfusion procedures without delay. Since full procedures cannot start until the patient has died, it is essential that confirmation (sometimes called verification or pronouncement) of death is given quickly.

There is some vagueness about who can legally verify death and, in strict legal terms, it seems that it can be confirmed by any competent adult but attending medical staff must abide by the recommendations of their respective professional bodies in addition to any legal considerations. Because attending professionals will not normally have attended a cryonics patient before, they are often uncertain what is permissible and tend to err on the side of caution. A separate note is provided by Cryonics UK which sets out our understanding of what is permissible, with references to the recommendations of various professional bodies regarding confirmation of death.

If cryonics arrangements are to proceed smoothly, then the co-operation and goodwill of the patient's GP, the attending doctor and other medical and care staff are needed, which means having regard for what they feel they can agree to in terms of arrangements. Because of the uncertainties discussed above, this inevitably leads to variations in the way we can proceed in each case, and unwanted uncertainty that arrangements will work smoothly.

The implications for obtaining a rapid verification of death for each of the end-of-life locations listed above is discussed in the following sections, along with the options available to minimise delays.

STAYING AT HOME

This will be the situation for most people since it provides many advantages, minimises costs and is usually the preferred option for both the patient and family.

However, it usually presents difficulties in obtaining rapid verification of death, depending on the views of the patient's GP.

As noted above, our understanding is that any competent person (typically a relative) may verify death, and the GP may be happy to allow this. This is unusual, however, and the GP may require a suitably qualified medical professional to verify death. Some possible options are:

- The GP agrees to a relative verifying death and for the cool-down process to proceed immediately. In this case, the doctor will usually want to view the body at some stage before certifying death (i.e. issuing the death certificate).
- The GP insists that verification of death is given by a medical professional; usually a private on-call doctor or a suitably qualified nurse or paramedic. In this case, the GP will normally agree to Cryonics UK giving chest compressions, lung ventilation and cooling of the neck before verification.

Where the GP insists on death being verified by a medical professional, relying on the GP practice is not satisfactory, as they will not prioritise the call-out to confirm death over the needs of their living patients. Therefore, alternative arrangements will be needed, as discussed below.

AGENCY DOCTORS

Private doctors are available through agencies, but very few agencies are willing to send a doctor to verify death at short notice. Even where this is arranged, doctors will generally not guarantee to come immediately, and a short list of several doctors may be needed to minimise the risk of unacceptable delays. Even then, there is no guarantee that any doctor on the short list will be available quickly. Even where arrangements go smoothly, there may still be a delay of half an hour or more before the doctor arrives at the patient's home.

The cost of this service is quite high, typically in the region of £2,000, which has to be paid in advance. If, for some reason, the agency doctor service is not subsequently used, most of the fee will be returned, less an agency administration fee of several hundred pounds.

The response should at least be significantly quicker than relying on the GP service, and the risk of mounting payments associated with most other alternatives is avoided. However, there is clearly a risk of delay, so this arrangement is not ideal.

PRIVATE NURSES

A suitably experienced nurse can confirm death provided the patient has been seen by the GP within 14 days prior to death, and Cryonics UK have been in discussions with an agency that is willing to provide these. However, this is an option we have not yet tried on a real case.

Unlike an agency doctor, the agency nurse could attend prior to death and stay in the vicinity of the patient's home, effectively as a part of the Cryonics UK team, so would be available rapidly on death. Charge rates are lower than for doctors but costs can become high if death occurs later than expected, resulting in the nurse attending for a lengthy period.

OTHER POSSIBILITIES

Ambulance crews can verify death but calling out an ambulance specifically to verify death is not really what the ambulance service is for, and it is likely that the service would refuse to attend a call if it were just for this purpose.

However, this raises the possibility of having a paramedic (perhaps a retired ambulance crew member) on standby, rather than a nurse.

CARE HOMES

Most care homes approached by Cryonics UK are either unwilling to undertake the arrangements needed for rapid verification of death or will not commit until a specific case arises. However, a major care home group, with care homes across the UK, has been helpful in a past case, which opens up the possibility of using a care home for the final weeks of life.

From our experience, care homes will have a doctor who would be willing to act as the attending doctor prior to death, and will usually allow trained care home staff to verify death. The doctor or patient's GP (whoever will certify death) may or may not wish to view the body after death under these circumstances.

Care homes are often fully booked, so need to be researched and booked well in advance to ensure that there is a place available reasonably nearby. Also, liaison with both the care home and the patient's GP will be essential.

The main disadvantages of care homes are that the patient is away from the home setting with relatives having to travel for visits, and the cost of typically around £1,000 to £1,400 a week, so costs could mount quickly. However, care homes may offer the most reliable way of obtaining rapid confirmation of death minimising delays.

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. 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, and it is unlikely that treatment of any kind will be permitted in the hospital. This means that delays will occur while your body is taken to the hospital mortuary and then discharged, after completing the necessary paperwork.

So, while a hospital may seem a good place to be for a cryonics patient, hospital procedures make it not ideal.

PRIVATE HOSPITALS AND HOSPICES

Private hospitals 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 specialise in palliative care for end-of-life situations and will have medical staff available, so the situation for a cryonics patient is broadly similar to that for an NHS hospital. However, to be admitted to a hospice you will normally need to be suffering from a recognised terminal disease such as cancer, and will need to be referred by a consultant. This makes the hospice option unlikely to be possible for most people.

Because of the above restrictions, Cryonics UK have no experience of using private hospitals or hospices.

BACKGROUND INFORMATION

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, various 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 is 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.

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.

COMMENTS ON WHAT IS NORMALLY ACCEPTABLE

Confirmation (verification, pronouncement) of death is a statement that a person is dead. It may be carried out by a range of healthcare and care professionals and others.

Certification of death is a statement (in the form of a death certificate) of the cause of death. It normally may be given only by the patient's GP or with his consent.