

Case review of C for Welsh Government

The background

This report is written following a paper-based case review of case notes regarding one particular patient C, who was born in 1970, suffered a major accident in 1994 and died in 2017.

For reasons of confidentiality and to protect the privacy of surviving relatives and others concerned with his welfare throughout the years he was cared for, only minimal details of the case are given here.

Following a major industrial accident and cardiac arrest, the patient 'C' sustained severe hypoxic brain damage and became tetraplegic. He was also thought to be blind and was in a severe minimally conscious state (a profound persistent disorder of consciousness).

As part of his longer-term care, he had a tracheostomy in place and was fed via a gastrostomy tube. For most of the years after the accident his care was at home.

Historic context

When reviewing the specifics of C's case, it is also vital to look at the case in its historical legal context, particularly in relation to the law on medical treatment and cessation of artificial nutrition and hydration.

The term 'persistent vegetative state' was coined in 1972 by Jennett and Plum to describe the unresponsive wakefulness syndrome seen in survivors of catastrophic brain injury.¹

Then, in 1989, the Hillsborough football stadium disaster occurred when 93 football fans were crushed to death and three died later. One of these initial 'survivors' with anoxic brain damage was Tony Bland. After a high-profile Court case the Law Lords ruled that his feeding by nasogastric tube could cease and he died on 3rd March 1993. An important part of the Court of Appeal ruling and the authorisation, granted by the House of Lords², for the withdrawal of his naso-gastric feeding, was that in ceasing the clinically assisted nutrition and hydration, the doctors would not be committing murder. This event was widely publicised, not least because it was the first of its kind. Prior to this case, withdrawal of treatment was only available to neonates who had no chance of survival.

The authorisation was additionally complicated by the issues around the cause of Bland's brain anoxia, and possible criminal charges, for which the relatives of the victims of Hillsborough were campaigning. Following Bland's death, a priest and anti-abortion campaigner tried unsuccessfully in 1994 (a few months prior to C's accident) to have the doctor who withdrew the treatment (nutrition and hydration via nasogastric tube) charged with murder. Thus, at the time, there was a general consensus that all life-prolonging interventions would be expected to be continued without question, and doctors certainly knew that they risked accusations of murder if they even raised the topic of treatment cessation.

¹ Jennett B, Plum F. Persistent vegetative state after brain damage. A syndrome in search of a name. *Lancet*. 1972;1:734–737. doi: 10.1016/S0140-6736(72)90242-5

² *Airedale N.H.S. Trust v Bland* [1993] A.C. 789 House of Lords

It is also important to note that, while the technique of percutaneous endoscopic gastrostomy tube insertion was described first in 1980 by paediatricians in the USA, the technique took some time to be rolled out into adult practice and to become routine. It is also worth noting that at the time of Bland's death in 1994 he had not had a PEG, only a nasogastric tube for feeds.

The Mental Capacity Act of 2005 was not developed until the following century.

Additionally, in Wales prior to 2005 there was no capacity to provide assessment of prolonged disorders of consciousness, which meant patient had to be transported to England (usually to The Royal Hospital for Neurodisability in Putney) for assessment.

In 2008 in Wales a review of palliative care was published and the Implementation Plan, instigated by the Minister for Health and Social Care, was accompanied by funding to expand services and to provide education for health care professionals across Wales in communication skills for difficult conversations and core palliative care skills. However, it must be remembered that such training is not yet mandatory across Wales in any of the healthcare disciplines. Thus, although many senior clinicians have, of their own volition, undertaken training in breaking bad news and conducting other difficult conversations, there is no universal requirement for such conversations to be part of routine clinical practice.

Another contextual difficulty for clinicians has been the emphasis on patient confidentiality and the restrictions that this poses on conversations with family and close friends who are concerned for and important to a patient. Despite the Mental Capacity Act now being in place with its current code of practice since 2008, the understanding of the details of the Act remains patchy. Many clinicians are unclear about the legal status of relatives in decision making, about the role of a Court Appointed Deputy or a Lasting Power of Attorney and about how extensive consultations should be over best interest decisions and whether the primary decision maker is a clinician or the Deputy/Attorney.

C's care in outline

From the outset, C was unable to take fluids or nutrition by mouth. Dieticians were involved in care as he was fed by gastrostomy tube and all medications were given via the gastrostomy tube. Regular medications in the long-term were aimed at controlling seizures and ensuring comfort, with medications available if he showed signs of distress, pain or agitation.

The longer term Nursing Care Plan focused on:

- (1) Tracheostomy
- (2) Gastrostomy tube & nutrition
- (3) Incontinence
- (4) Personal Hygiene
- (5) Immobility – waterlow score /skin care
- (6) Medication
- (8) Potential problem of symptom control
- (9) Potential problem of managing epilepsy
- (10) Monitor signs of awareness & record

The care plan in the community seemed to be more specifically focused to C's needs and was less 'paper heavy' than the hospital records, where some assessment forms were incomplete, often as they seemed less relevant to C's situation.

Over many years C was looked after at home by family with regular nursing and carer input, and appropriate home adaptations, some at the family's own expense. There was evidence of ongoing clinical review about his immediate physical care, including blood tests.

Significant conversations

Records of discussion with relatives focused on practical issues, but there was little recorded concerning major significant conversations with the family.

Over the years, a gastroenterologist paid domiciliary visits to manage his PEG tube, often changing the tube at home. Throughout his letters there is a sensitive and caring tone from this doctor who appeared to go out of his way to care for C, as did his GP. Overall the notes provide an atmosphere of each person going in and doing what they could, focused on the physiological care of the patient.

Over 20 years after the accident, the decision to stop all life-prolonging interventions and stop clinically assisted nutrition and hydration (CANH) was instigated by his family in discussion with the GP. The GP had a long discussion about C before going to review him.

Discussions about cessation of interventions were far less frequently held in the early years after C's accident, as outlined above in the historic context. Within society, media attention gradually increased over decisions at the end of life. These were highlighted by the inquiry into the Liverpool Care Pathway, case reports of court cases over CANH decision in the UK and the US, and public discussions over advance decision to refuse treatment (colloquially referred to as 'living wills'). Additionally, the book "The Last Act of Love" was nominated for the Wellcome Book Prize. This gradual change in society meant there was no clear point over the years that such discussions could have been expected to be instigated by professionals, who may have felt reluctant to raise treatment cessation lest it imply to the family that there would be a withdrawal of support at any level.

Grief and loss

In the initial shock of such a tragedy having occurred, those close to a patient experience profound and overwhelming grief and anxiety. In a search for some clinical direction, it can be difficult to come to terms with the uncertainty that surrounds prognosis, both in the time course and in any possibility of functional recovery. For clinicians, whose priority is the patient, it is difficult to convey such uncertainty while neither engendering false hope nor overwhelming despair.

This is made all more difficult for clinicians looking after a patient in the immediate aftermath of such an accident because their social context and values are completely unknown. To try to assess these at this time of distress is particularly difficult as relatives' reactions can be altered by feelings of guilt and questions of 'what if?' or 'if only ...' when faced with life changing injuries in the person they love.

The role of the GP

The GP can be uniquely placed when he or she knows a family over many years, although such a pattern of general practice is becoming increasingly rare. However, the ability to have conversations with a family in their own home, rather than in the stressful atmosphere of a hospital or clinic room, can allow for more open discussion regarding values, wishes and feelings as the asymmetry of the relationship is lessened by relatives being in their own environment, as evidenced in C's case.

Additionally, the GP is better able to liaise directly with district nurses and other carers who often have very important insights into such a situation and how the family are coping.

The role of Palliative Medicine

A consultant in palliative medicine is trained to have conversations about the end of life, is trained in the legal frameworks applicable to such a situation and, in Wales, also has a network of colleagues who can provide support with reflective practice over difficult decisions. However, their involvement will only be at a later stage when hopes of meaningful improvement of any sort have been lost. Thus, such a consultant may be well-placed to lead a Best Interests meeting with a comprehensive overview of the relevant steps that need to be taken prior to deciding to cease artificial nutrition and hydration, and how such a decision might be enacted.

RECOMMENDATIONS

Information giving

From the time of acute care, it is essential that the family and those close to the patient are **kept informed** of what is being done, why and what is expected. In those families where one person takes on the role of lead communicator (e.g. the spouse), it is still important that others such as siblings, parents etc are kept informed unless there is a clear and compelling reason not to speak to them. Despite family rifts, all those linked emotionally to the patient will be affected by the events. If anyone is to be excluded, it must be clearly documented and explained why. Therefore, it is important to lay out the pathway for communication to avoid confusion or dispute later, as well as ensuring that staff are not taken away from their primary duty of patient care.

If this is a **police** case it will be important to work closely with the allocated family liaison officer too, whilst respecting confidentiality and taking care not to provide any comment that could be misleading.

From the outset, family need to know **who is in overall charge of care** and, therefore, heading the clinical team at a particular time, which means responsibility for coordinating both medical care and nursing care. Whenever care is handed over to another clinical lead this must be made explicit to the family, who should be supplied with contact details.

The **family need information about what they can do to try to encourage recovery**, including stimulation with favourite music playlists or other forms of sensory input (e.g. animal sounds etc) that are meaningful to the patient. They also need to know what they can do, and conversely should not do, to be involved in as much care as they wish.

It is difficult for all involved to focus on the patient's probable or known wishes and feelings and **avoid such sentiments as 'if it were me...'**. It is also difficult for clinical staff to openly acknowledge the uncertainty involved in such cases and the unpredictability of recovery, yet early conversations need to outline uncertainty and explain prognostic indicators as they appear.

Each planned conversation should **start by exploring what the relatives have already understood** and what they have observed, before imparting new information. In an emergency, it is still important to briefly recap on warnings of deterioration that were given, before imparting further bad news.

Opening conversations can be difficult for staff. A simple framework is the Cardiff six-point toolkit:

1. **Comfort** – ensure the physical environment is as comfortable as possible, such as being seated. Consider other factors such as whether an interpreter is needed, or if any family members have particular difficulties.

2. **Listen** – listen actively with undivided attention to what relatives think is happening and to their concerns.
3. **Use open questions** – to help explore their understanding of the situation; only use focused questions to explore specific areas for clarification.
4. **Non-verbal clues** – remember about 4/5 of all communication, both ways, is non-verbal.
5. **Reflective phrases** – using the family's own words is far less threatening than any medical jargon; it can allow them to feel able to ask questions and express concerns.
6. **Summarise** – ensure everyone present agrees about what has been covered in the conversation; make sure it is written down clearly.

In the first days after a catastrophic brain injury of any cause, family need to be warned of the uncertainty that now exists, of the inability to know how much recovery will occur and that the trajectory over time is the best indicator of the chances of any recovery. It is also important early to **avoid raising false hope or being unduly pessimistic** in relation to care being given.

Care should be provided as early as possible in **specialist centres in Wales** to avoid inaccurate diagnosis of the disorder of consciousness, complications that can arise and which slow recovery, maximise prognostic accuracy and improve clinical decision making. Specialist centres must be staffed by multi-professional teams bringing together the necessary skills to optimise recovery.

The wishes and feelings of the person should be ascertained early, through as wide consultation as possible, as they will be important whenever best interests' decisions are made. Those consulted at different times will change over time as care staff (at every level) may pick up changes in the patient and may also obtain important information from friends and family who visit in hospital.

From the outset, **the welfare of the family** must form part of the clinical assessment and the emotional impact of their loss must be explicitly recognised. The hospital chaplaincy team can be of specific assistance, irrespective of particular faith or no faith.

After 4 weeks there may be some indication of the trajectory and possible course. This should trigger a formal review with family whose emotional needs must be taken into account. These conversations are very difficult as they balance between realistic hope and grieving for the person who is severely injured and who will probably never be as before, even if there is functional recovery.

No conversations should occur in corridors etc. If the family by chance encounter a clinician of any grade and make any sort of enquiry, the appropriate response must be to immediately take them to a private area for a proper conversation or to immediately fix a time to speak with them later that day or whenever possible. Casual remarks can be extremely damaging to trust and may traumatise unnecessarily.

Clinical reviews

Further routine formal patient 'best interests' and family reviews should be held *at a minimum on a three-monthly basis*. Much more frequent reviews may often be required, with arousal enhanced as much as possible. It is important to recognise that although some patients can regain awareness after a head injury, over time the chances of such an event dwindle. However, **up to 20%** show functional improvement within five years, to the extent of undertaking some activities of daily living

and possibly holding some form of employment. For others, their trajectory of recovery will be ‘flat’ from the outset and show no improvement even at one year.

Allowing family access to case notes or clinical summaries can help them understand what is happening.

Timing of each review should be **explicitly planned** and recorded.

When a patient is being cared for at home, **family may observe important changes**. They should be encouraged to record these as part of the clinical record; to exclude them undervalues their important contributions to care.

Clinical notes are easier to interpret if there is a **continuous on-going log** of results, key events and major reviews. The current structure of case notes should be considered by NWIS as they move to computer held records.

Standardised assessment tools should be used by those with **specialist training** to improve diagnostic accuracy and consistency of assessments.

The slow timeframe of such recovery needs to be explained and the family need to feel they are part of the care system without feeling decisions are being dumped on them. **Open conversations**, although very difficult, can form a foundation for future decisions.

Whether on a ward or at home or in a nursing home, the **front-line care-providers** should also be engaged in decision-making, not least by being consulted about how they find the patient, what changes they have observed in the patient and other issues they may have observed in family and friends, such as who particularly needs support. The conclusion from formal assessments should be fed back to all involved in care in order to avoid mixed messages – either unduly pessimistic or over-optimistic with false hope. The importance of emotional awareness should be stressed to all staff.

At each review **all aspects of the care plan should be comprehensibly reviewed**, including consideration of any agreed limits in possible anticipated interventions that may be life-prolonging, such as deciding not to attempt cardiopulmonary resuscitation in the event of cardiac arrest (DNACPR) or using intravenous antibiotics in the event of a chest infection. All such conclusions must be **clearly communicated** to staff providing the hands-on care.

Decision making

When people lack mental capacity to make their own treatment decisions at the time they need to be made, those decisions must be made in accordance with the Mental Capacity Act 2005 (MCA). This means clinicians must be familiar with the MCA’s statutory principles, how to assess and record capacity, how to make and record best interests decisions, and how to identify situations when people other than clinicians are the decision-makers.

Family members often believe, wrongly, that anyone regarded as the ‘next of kin’ has decision-making powers regarding a patient lacking capacity to make their own treatment decisions. While there are no such powers, the Mental Capacity Act does make it mandatory for a decision-maker to consult people ‘interested in the person’s welfare’, which will of course be their relatives or, sometimes, close friends.

Where a person is facing a decision about serious medical treatment or where to live (for example, whether to move into a nursing home), *and* lacks capacity to make relevant decisions at the time they

need to be made, *and* has nobody, apart from paid carers, to be consulted as part of reaching a best interests decision on such an important matter, it is a mandatory legal requirement that an NHS body or local authority who is in the role of decision-maker must instruct an **independent mental capacity advocate** (IMCA). The IMCA does not become the decision-maker but their views must be taken into account in reaching the decision. An IMCA cannot be instructed simply because there are different opinions (whether among relatives and friends or among professionals) about what course of action is in the best interests of the patient: such differences must be resolved within an open-minded process of conflict resolution.

A **Lasting Power of Attorney** (LPA-H&W) for Health and Welfare may be in place, or a **Court Appointed Deputy**. LPAs give anyone aged over 18 the power to choose someone they know and trust to be their decision-maker if they should lack capacity in the future. LPAs are of two kinds; (1) the better-known LPA for financial and property matters and (2) the Health and Welfare LPA, which is completely separate.

Within the **Health and Welfare LPA**, the 'donor' (person creating the LPA) has to state clearly whether or not they are giving their 'donee' (or attorney) the right to make decisions about consenting to, or refusing, life-sustaining treatment. No attorney can demand a treatment that clinicians decide would be burdensome to the patient and of no therapeutic benefit. But, if the donor has given them the specific power to do so, they can make a best interests decision to consent to or refuse treatment offered, even if it is likely to lead to the death of the person.

Just as clinicians who are decision-makers are bound to make their decisions in accordance with the MCA, in particular the **statutory best interests check-list**, and to have regard to the MCA code of practice, health and welfare LPA attorneys are similarly bound to make decisions having regard to the MCA code of practice. Clinicians must be clear about the provisions of any LPA for health and welfare, and assist any attorneys by providing information in an accessible and helpful way.

Deputies appointed by the Court of Protection can never be authorised to make the decision to refuse or cease treatment intended to be life-sustaining: apart from this, they can make decisions as laid out in the deputyship order. Again, it is essential that clinicians are clear about what powers are given by the Court. It may be evident that there will be the need for an application to the Court of Protection for a Court Appointed Deputy. Financial planning and social work input for future care must be considered early. Ensure that social workers are aware of any LPAs or deputyships and the extent of the powers given by these.

LPA attorneys and deputies are overseen by the Office of the Public Guardian (OPG). If any clinician has **concerns that an attorney or deputy is failing to act in the best interests of the person**, they must notify the OPG and, where appropriate, also raise a safeguarding alert using local multi-agency procedures. If they suspect that a criminal act has been committed, or is about to be, they must also urgently inform the police.

Deciding on limitations in interventions

When no further improvement is occurring, and all reversible causes of a continuing minimally conscious state have been excluded, the rationale for agreeing limitations in anticipated possible interventions should be introduced, if such limits have not already been considered.

Each decision must be taken in **the patient's best interests**, giving as much weight as possible to what is known about his or her wishes and feelings, and considering the burdens and risks associated with

each management option. Where such a decision concerns potentially lifesaving treatment, it **must never be motivated by a desire to bring about the patient's death** (see Mental Capacity Act section 4.5).

It is also important to remember that the interests of a person pertain to the living experience of the person, however profoundly disabled. When the person dies they cease to have intrinsic interests. They may have bequeathed their material interests, their organs or tissues, or have left messages for others, but when dead they no longer have intrinsic personhood.

At each review **all possible anticipated scenarios** should be considered and their management planned. For example, how will fits be managed, when should 999 be called, how aggressive will antibiotic therapy be in the event of a chest infection, when will respite be planned, will CPR be appropriate?

Specific recommendations in relation to Clinically Assisted Nutrition and Hydration (CANH)

When considering CANH, the question should be ***"Is there an overriding reason not to continue CANH?"*** – i.e. the default position should be to continue, unless an agreement is reached that it is failing to achieve its goal and is unduly burdensome.

Deciding to cease CANH is only the first step in the last phase of the patient's life. Before CANH is withdrawn, all involved must have a chance to speak openly about what they believe the patient would have wanted and what their own feelings are about his or her care. These decisions must not be rushed as an error is catastrophic.

Palliative care must be meticulously planned, with early involvement in the process at the time the decision is being contemplated. The checklists below, from the case notes of C, may be of help.

"Is there an overriding reason not to continue CANH?" a checklist if this time is reached:

Initially

- Weigh up the benefits versus the risks and burdens of CANH continuing;
- Ascertain beyond doubt that the patient is in a prolonged profound disorder of consciousness or PPDc (previously referred to as Persistent Vegetative State - PVS);
- Consider evidence from carers and family about his/her condition and all aspects of his/her life and
- Evidence from clinicians who have looked after the patient over recent years, particularly at home;
- Obtain an expert opinion
- Use formal testing tools such as the Sensory Modality Assessment and Rehabilitation Technique (SMART) testing, or other tests (Wessex Head Injury Matrix, Coma Recovery Scale-Revised); currently SMART is the most likely to be used
- Keep at the forefront the paramount importance of 'what the patient would want'
- Ascertain whether there is any disagreement over the decision and the reasons for such disagreement

Subsequently

- Seek agreement on a way forward before proceeding to initiate processes
- It can be helpful to seek legal advice from the legal advisor to NHS Wales

Limitation of possible interventions

- Define the decisions to be taken, which must be clearly documented and communicated, concerning expected events for which the limits of intervention need to be determined. These include but are not restricted to DNACPR (Do Not Attempt Cardio-Pulmonary Resuscitation), the management of any intercurrent infections with or without antibiotics, and other crisis episodes such as fits, difficulty with suction of secretions, sudden gastrointestinal haemorrhage.
- The limits in possible interventions (sometimes colloquially called 'ceilings') and the rationale behind these decisions must also be very clearly and explicitly communicated to all the carers involved in the day-to-day care and to the district nurses if the patient is at home. The difficulty of this and the propensity for misunderstanding must not be underestimated.

Progress of discussion

- Long-term paid carers will have an opinion too. They will have observed the patient and may find that it is a difficult decision to make. They will also need to formally state the patient's condition. The difficulties about speaking with them must be considered in detail.
- Consider discussion with other relatives.
- The summary of discussions should be agreed by all and the date for the next review meeting fixed as this is an ongoing process.

Possibility of going to Court

The recent ruling about the cessation of CANH (NHS Trust v Y; Lady Justice Black 2018) has clarified that court agreement is not needed if all parties involved are in agreement that CANH should not continue. However, if there is any disagreement whatsoever, or any person (whether professional or part of the patient's family) has a particular concern then the Court of Protection should be consulted.

- All concerned need warning that the Court might not permit cessation of CANH
- The Court of Protection is public but there are reporting restrictions and the patient is not named in the final judgement statement
- The family need contact details of the Trust solicitor as well as the lead clinician(s)
- The ongoing care of the family and others needs planning as part of the overall care plan for the patient
- The family should be informed that organ donation is not possible
- The coroner will need to be informed of the death and may require an inquest.

When the decision to withdraw /CANH has been confirmed

- The wellbeing of the patient is paramount, including plans for any aspect of symptom control that may need management at any time
- Open discussion, with relatives/others who want to be present near the time of death, that the physical appearance of the patient is likely to change
- Awareness of the social and emotional distress of the family even when they have agreed unanimously and apparently unreservedly with the decision. Doubts will inevitably emerge in their minds and they must not feel they 'made the decision' or carry responsibility for it. It is

a clinical decision with which they agree. The family, and others close to the patient, may need very careful support. This is particularly true when a relative or friend with powers under an LPA for health and welfare has been the decision-maker about cessation of a treatment that has been sustaining life, having consulted clinicians, carers and others close to the person.

- There is also need for careful support to the carers/nurses and medical staff who have provided home care for a long time. They need time to be able ask questions and to know they are being consulted and that their day-to-day responsibility is recognised and respected. In the community this is best led by the GP or by a specialist palliative care nurse who has been party to all the discussions.

Additional factors to plan

- Bereavement support services need planning, recognising that the grief and associated emotions from the original accident will re-surface at this time
- How and when equipment will be removed from the house
- How the death will be announced to friends and family
- Consideration of important rituals around death for the family and of handing the body after death – one of the chaplaincy team may be best placed to open such questions
- Questions of cremation or burial may be best handled after discussion of organ donation or after death has occurred

Overall

- It is essential that all discussions are clearly documented so they can be referred to rapidly and easily and to avoid repetitive duplicate conversations
- Support to the staff may need to be increasingly flexible to care for the family, as their anxiety rises and goals become shorter term

Legal steps

- The legal steps that need to be undertaken must be clearly laid out in an All Wales document for clinicians to follow. (It would be helpful for such a document to be developed by a small working group including the legal advisor to the Welsh Government, the consultant in palliative medicine involved in C's care, senior nurses involved, other social care support staff involved, the general practitioner, the lead district nurse involved and the community carers' manager).
- Such a document could then be shared with relatives if they wished to have an input, but approaching them would need to be done very sensitively.
- The different tests to assess minimally conscious state/PVS should also be laid out clearly in the document.
- Portability of key assessments is essential – the all Wales Clinical Record should be planned to allow for portability of all complex data and long-term assessments. Nursing records of routine observations are also important as they provide an indication of the 'normal' for the patient (such as BP, pulse rate etc) because alterations can be an indication of pain or distress.

Cessation of CANH and euthanasia

After an accident such as this, the patient would have died without the CANH provided and without all the other interventions provided. When a treatment intervention, whatever it is, has no therapeutic or other benefit, is burdensome to the patient and carries risks which are greater than the benefit that has the aim, then continuing the intervention – whatever that intervention is – needs to be carefully considered.

When an intervention is not continued this may either be because it is withdrawn or because the steps to continue it are not renewed. For example, an event may have happened such as the feeding tube needing replacing, but all involved have agreed that this procedure would not be in the patient's best interests. To cease interventions in this situation is lawful and the reasons for this decision must be clearly and fully documented in accordance with the MCA statutory best interests check-list, along with details of who has been consulted.

If the patient then dies, they will die of the underlying condition (in this case the catastrophic brain injury) from which they would have died some time earlier (in this case years earlier) without the interventions. Their conditions are all irreversible and deteriorating.

This is different from euthanasia, which occurs when a patient with full mental capacity voluntarily requests lethal drugs to deliberately end their life months or years earlier than it would have otherwise ended. Euthanasia is illegal in the UK. Even in those jurisdictions that license doctors to provide lethal drugs, such as the Benelux countries, a patient without capacity (such as C with PDoC) would not be eligible. Additionally, the cocktail of drugs used for euthanasia is a massive overdose of barbiturate or other short acting anaesthetic agent with or without curare, so the patient dies of asphyxia.

For the family and carers, it is very important that explanations make clear that the cessation of CANH as in C's case is not euthanasia or killing, but that it is an acceptance that the person has been artificially maintained and would have already died without the CANH for their underlying condition.

Lessons in the legal and clinical practice framework

It will be important to have a mandated feedback mechanism to audit all such cases in Wales. This will allow Welsh guidance to be updated regularly and will provide important data on the number of cases and trends.

Such cases should be subject to specific death reviews to enable any difficult aspects of care to be openly discussed and for all those involved to have support from sharing their experiences.

In addition to the processes being fully and thoroughly undertaken and completed, all cases of the cessation of CANH (other than when a person is terminally ill and in the last days to weeks of life) should be reported to a central All Wales register. This should be audited annually and reported in a completely anonymised format to the Minister for Health and Social Care in Wales. The audit should explicitly assess all records of decision-making for compliance with the MCA.

All Coroners in Wales should be involved in consultation on national guidelines for Wales.

Review of BMA guidelines

The BMA guidelines have been widely scrutinised and will contribute to Welsh guidance.

They should be read in conjunction with the American Academy of Neurologists' recent revision of guidelines on the management of disorders of consciousness that are based in a comprehensive literature review, albeit in a different funding system.

It is recommended that the BMA guidelines are looked at carefully in relation to Wales and in conjunction with the American guidelines, to ensure NHS Wales' guidelines recognise the emerging literature, can contribute to knowledge in the field and can provide longitudinal clinical data through academic input and overview of the care of these patients.

In conclusion

The term in 'Persistent Vegetative State' (PVS) could be abandoned as it has qualitative judgemental overtones that may be offensive to relatives and may subliminally skew clinical thinking. It would be better replaced by a term such as **'profound prolonged disorder of consciousness' (PPDoC)**.

The difficulties in timing key conversations means that **no rigid rules** can be laid down. Each family will be different. Within the family, it may be that each person comes to terms with the reality that recovery is increasingly unlikely at different times. Therefore, clear clinical information about what is being done and why can be helpful in order to avoid family conflict.

Welsh guidelines should lay out a clear assessment schedule that **involves families early** and shares with them as much of the information on prognosis as they wish to access. The burden of responsibility they may feel when any decisions are made must be recognised and acknowledged so as to avoid them feeling as though they have 'signed away' their relative's life. The schedule must explicitly ensure that all enquiries are made to ascertain all that is known of the **patient's wishes and feelings**.

Guidelines should also explicitly involve the full range of therapists, including speech and language, music etc, early on in order to maximise brain function in the light of emerging evidence about neuronal plasticity.

It is very important for Welsh Government to know **how many patients in a minimally conscious state and in PPDoC are living in Wales today**. As they will almost certainly all be receiving continuing care, a record should be available in each health board.

It is also important that any such list is kept totally confidential as some may fear it is being collated with a view to cessations of CANH. All deaths from cessation of CANH should be subject to formal annual review to ensure the guidance is adhered to and decision making is appropriate.

Reference documents

Managing prolonged disorders of consciousness, a summary of the publication, "Practice guideline recommendations: Disorders of consciousness," can be found on line at: <https://www.aan.com/Guidelines/home/GetGuidelineContent/929> . It was developed through a collaboration of the American Academy of Neurology (AAN), the American Congress of Rehabilitation Medicine (ACRM), and the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). The article was published in *Neurology*[®] and in *Archives of Physical Medicine and Rehabilitation* online on August 8, 2018, and in print on September 4, 2018.

British Medical Association – Confidential draft. Clinically-assisted nutrition and hydration (CANH) and adults who lack the capacity to consent. Guidance for decision making in England and Wales. June 2018.

Mental Capacity Act 2005: can be found online at

https://www.legislation.gov.uk/ukpga/2005/9/pdfs/ukpga_20050009_en.pdf

Mental Capacity Act code of practice: can be found online at

<https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice>

Office of the Public Guardian: how to report a concern about an attorney or deputy: can be found online at <https://www.gov.uk/report-concern-about-attorney-deputy>

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