THE HIGH COURT

WARDS OF COURT

IN THE MATTER OF THE APPROPRIATE CARE

OF A WARD OF COURT

JUDGMENT of Mr. Justice Denis McDonald delivered on 31 May, 2019

1. These proceedings relate to the care of a Ward of Court ("*the ward*") who is in a permanent vegetative state ("*PVS*"). In order to ensure that the identity of the ward is kept confidential I will avoid making any reference by name to any person or institution connected with the proceedings. This does not extend to the independent medical experts who provided reports or evidence to the court. Unlike the general practitioner treating the ward, they have no ongoing relationship with her. Accordingly, identifying such experts will not put the anonymity of the ward at risk.

2. The proceedings have come before the court in an informal manner in circumstances where the Committee (comprising the parents and a sibling of the ward) have run out of funds to continue the current regime of care of the ward. The court has heard evidence and submissions from the Committee and from the Health Service Executive ("*HSE*") as to the appropriate care to be put in place for the ward in the circumstances. Directions are also sought as to the terms of a "*Do Not Resuscitate Direction*".

Background

3. The ward is a woman in her early forties. She has one child. When she was in her early thirties she was diagnosed with a brain tumour. Up to that time, she presented as a perfectly normal woman of her age. According to her father, she was a bright happy person with her own home and a promising career. She was fiercely independent and devoted to her child.

4. Following the diagnosis of a brain tumour, she underwent brain surgery at a local hospital and was cared for in a high dependency unit there. While in the hospital, she suffered a cardio-respiratory arrest. This led to significant brain damage. In particular, it led to paralysis. A tracheostomy was performed so that the ward could continue to breathe. Initially, she was fed through a nasogastric tube. Subsequently, a Peg feeding tube was inserted in her abdomen.

5. According to her father, at this stage, the ward was aware of everything around her. She communicated by blinking, by the use of the alphabet and by facial expression. Her father explained that, in order to communicate with her, the family would speak to her and she would respond by going through the alphabet. The way this was done was that the family would hold up letters of the alphabet to her. She would blink when the right letter was held up. In that way, she was able to form words and have a conversation. Her father says that the family and some of the nursing staff became accustomed to communicating with her in this way and that they became familiar with the ward's responses. In addition, a physiotherapist in the hospital taught the ward to stick out her tongue when she wanted to be left alone and she mastered this very quickly.

6. Sometime later, the ward was transferred to a specialist neuro-disability facility in London for further treatment. Tragically, the ward suffered a further respiratory arrest while undergoing treatment in London. As a consequence, she suffered further brain damage. In the aftermath of this incident, the Committee and other family members believed that the ward suffered from "*locked-in syndrome*" but they now accept that she is in a PVS condition which is consistent with the medical evidence which I heard during the course of the hearing in March, 2019.

7. After the second respiratory arrest, the ward returned to Ireland and was cared for, initially, in the hospital where the first arrest had occurred. After a period of time at that hospital, the ward was transferred to a Community Nursing Unit in the same locality. It appears that there were disagreements from time to time between the family and the Nursing Unit in relation to the level of care afforded to the ward while she was in the unit. However, it is unnecessary, for the purposes of this judgment, to consider those disagreements in any detail.

8. While the ward was in the Community Nursing Unit, her family secured funding from a housing organisation to build a facility adjoining their family home where the ward could be cared for. Once that facility was constructed, it was possible for the ward to return home from the Community Nursing Unit for periods of time. Nonetheless, she remained a patient of the Unit.

9. In the meantime, proceedings were taken on behalf of the ward against a number of parties in which it was claimed (*inter alia*) that there had been untoward delay in diagnosing the brain tumour. Those proceedings were settled in 2013 by the payment, without admission of liability, of €2.4 million. This sum was lodged in court for the benefit of the ward.

10. Care of the ward, while in the home facility, was undertaken by a private home care service provide engaged by the family. Separately, the HSE provided its own regime of care while the ward was in the Community Nursing Unit. In early 2015, the family was informed by the Community Nursing Unit that there had been an outbreak of the vomiting bug at the unit and it was not in the ward's best interests to return there just then and be exposed to infection. Thereafter, the outbreak continued for a relatively prolonged period. During this period, the private home care service provider continued to care for the ward at the home facility. After a number of weeks, a decision was taken by the family to keep the ward permanently at the specially constructed home facility. This occurred in March, 2015. For a period of approximately one year, care at the home facility was provided by the private home care service provider. However, in an attempt to save costs, the Committee subsequently decided to engage a care team directly to look after the ward thereby reducing costs and the agency fees involved. This home care was paid for out of the proceeds of the settlement of the proceedings taken by the ward (as described above).

11. The home facility (in which the ward is currently housed) comprises a ground floor extension to the home of the ward's parents. It is a self-contained clinical space with a range of medical equipment available. There is an oxygen supply; a suction machine; there is also an Ambu bag for manual respiratory resuscitation available. The ward is maintained in a hospital bed with a pressure relieving mattress. She continues to breathe through a tracheostomy tube. This is changed regularly by the care staff who have been trained for this purpose. She has a Peg tube or gastrostomy tube in her abdomen through which she is fed. She also has a suprapubic catheter which is changed every six weeks by her general practitioner. She is completely immobile. She is transferred using a hoist (with assistance from two carers) to a modified chair every second day for a number of hours. She has never developed pressure ulcers while being cared for at the home facility.

12. There are two carers present at all times. As I understand it, they attend in two shifts of twelve hours each. From my observations of a video taken by the ward's father, it is clear that two people are required if the ward is to be moved in position in her bed to any significant degree. It was also common case at the hearing that, if she is to be moved by hoist, the assistance of two persons is required. On the basis of the evidence which I heard, two people would ordinarily be required to assist with hygiene in the event of a bowel motion. Such assistance would be required promptly in order to avoid infection.

13. Remarkably, during all of the time that the ward has been cared for at home, she has not suffered any chest infection notwithstanding the tracheostomy and the fact that she is prone to the build-up of secretions in her lungs. The only infections which the ward has suffered have been some minor urinary tract infections. In order to keep the ward breathing properly it is necessary to carry out suctioning from time to time of the tracheostomy tube. In addition, the ward receives physiotherapy treatment twice daily by her care staff at her home. This assists in relieving the build-up of secretions on the ward's lungs.

14. There is no doubt but that the ward has enjoyed an exemplary level of care in the home facility with her family at hand. This was acknowledged by all of the witnesses who gave evidence before me and who have visited the facility at the ward's home.

15. Thanks to the exceptional level of care at her home, the ward has lived for much longer than had been expected at the time of the settlement of the proceedings described above. As I understand it, the settlement figure was based on an estimate of the ward's life expectancy at the time of the settlement. Sadly, the proceeds of the settlement have now been exhausted and a significant issue arises as to how the ongoing cost of care of the ward is to be funded. The Committee desperately wish that the HSE may come to their aid and fund the existing care regime of the ward at her home. The Committee makes the case that this is, by far, the best method of care of the ward. The Committee also maintain very strongly that this is in the best interests of the ward.

The position of the HSE

16. The HSE does operate a Home Support Service which is funded by the Government to deliver a certain volume of service each year as approved in the HSE National Service Plan. According to the HSE, this is a discretionary service and there is no automatic entitlement to such a service. This service is mainly used by older people. It is also provided (to a more limited extent) to younger people with disabilities and other identified care needs. This includes services for people leaving hospital who need ongoing support.

17. In broad terms, there are three levels of service available under the Home Support Scheme. These are: -

> (a) The most basic service is the Home Help Service which is designed to assist people with personal care and domestic duties;
>
> (b) There are also Home Care Packages available. These packages aim to help people with medium to high support needs. They are designed to allow people to continue to live at home independently. Such packages may also include nursing, physiotherapy, speech and language therapy and occupational therapy together with respite care and aids or appliances;
>
> (c) The third form of package available is an Intensive Home Care Package. Such a package allows people who require a very high level of assistance to be discharged home from hospital or possibly to avoid admission to hospital. According to the evidence available to me, it is a limited service that includes supports over and above those provided as part of a standard Home Care Package.

18. Although very significant sums are spent by the HSE every year on the Home Support Services, the level of services available cannot keep up with demand. As a consequence, there is a significant number of people on waiting lists for home care.

19. According to the Head of Social Care of the HSE Community Healthcare Service for the region in which the ward lives, the level of home care requested for the ward by her Committee is on a scale that the Home Support Service was never designed to meet. There is currently a waiting list of people assessed as requiring a Home Support Service in the region. According to this witness, to address the needs of the 321 people on the waiting list today would cost in excess of €2 million per anum. In the absence of additional funding to expand the level of Home Support Services in the region, those on the waiting list are dealt with on a priority basis when hours become available through the cessation of Home Support Packages for those for whom care at home is no longer appropriate. The evidence of this witness was to the effect that the provision of a package of care of the scale previously provided by the Committee out of the proceeds of the settlement would result in a complete cessation of recycling of Home Support hours for a significant period of time in the region. The recycling of such services could not resume until such time as the value of Home Support hours no longer required met the value of the package required to be put in place for the ward. Thus, a large number of people on the current waiting list would have to wait for a considerable additional time period for a Home Support Service potentially resulting in a deterioration in their conditions. This witness also said that new referrals would face longer waiting times to access a service.

20. Against the background described above, the initial position taken by the HSE on this application was that the most appropriate service that could be provided for the ward was in a residential setting at the Community Nursing Unit in which the ward was cared for following her discharge from hospital several years ago. In taking this position, the HSE has, very fairly, acknowledged that the Committee and family of the ward have worked for a very long time to ensure a very high standard of care for the ward. The HSE also acknowledges the desire of the Committee and family of the ward to ensure that she continues to receive the same high level of care.

21. In adopting the position that residential care would be more appropriate, the HSE emphasised that there are risks inherent in providing care to the appropriate level in a domiciliary setting. The provision of 24 hour, 7 day a week care services is considered by the HSE to be more appropriate to an institutional setting, where there is consistency and certainty in staff provision and training. In addition, according to the HSE, a decision to fund service in the ward's home facility in the circumstances of the present case would, as the summary in para. 19 above illustrates, create an inequitable opportunity cost in respect of others in need of health services.

22. A further factor influencing the approach taken by the HSE is that the Home Support Services are designed to support people capable of living productive lives in the community in partnership with their families. Given that the ward is in a PVS condition, the HSE questioned whether it is appropriate to put in place a costly home care package for a person in that condition. A different approach might possibly be taken (subject to cost constraints) if the ward had some level of consciousness sufficient to allow her to appreciate her surroundings, actively participate in family activities and if she had the ability to express some form of consent or refusal in relation to how she would wish to be cared for.

23. In the circumstances described above, the initial position adopted by the HSE in these proceedings was to recommend that the ward should be moved back to the Community Nursing Unit. In taking that position, the HSE accepted that there would have to be a significant increase in the number of registered nursing hours and healthcare assistant hours made available at the Unit so as to

ensure that the ward's needs would be appropriately met in a residential setting. The HSE estimated that the cost of this proposed package of care for the ward is in the region of €315,198 per annum. In my view, this is an important factor to keep in mind – namely that, even if no homecare package is made available to the ward, there will inevitably be a significant annual cost for the HSE in caring for the ward.

24. Although care in the Community Nursing Unit was regarded by the HSE as the most appropriate care plan for the ward, the HSE subsequently put forward an alternative proposal under which the ward would continue to be cared for in the home facility. This alternative proposal was prompted by the views expressed by Professor Conor Burke in a report obtained following a direction given by Kelly P. (as described in para. 25 below).

25. During the course of the proceedings, Kelly P. directed that an independent report be obtained from Prof. Burke. In a report dated 5th January, 2019, Prof. Burke indicated that the normal standard of care for PVS patients is in a nursing home rather than a family home environment. He explained that this is because of governance and cost issues. However, in the case of the ward, he suggested that it might be possible that she could be maintained at home in circumstances where the focus of care is comfort only. I should explain, in this context, that Prof. Burke expressed the view that the current resuscitation measures that are in force are not appropriate and that a new approach should be taken which would confine the ongoing care of the ward to comfort measures. In such circumstances, he suggested that her needs could be met by a permanent carer rather than a permanent nurse and carer.

26. Following receipt of this report from Prof. Burke, the HSE put forward a new proposal for the care of the ward by way of an alternative to care in the Community Nursing Unit. The HSE made it clear that this was an exceptional measure which goes beyond anything that the HSE would ordinarily consider. This alternative proposal envisages that the ward could be cared for at the home facility adjoining her parents' home on the basis of the following services:-

> (a) the availability, two hours per day of a registered general nurse to attend to the nursing needs of the ward;
>
> (b) 24 hours per day availability of a single healthcare assistant to support the ward's family to maintain and provide comfort for her in the home facility; and
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> (c) the parents of the ward would have to maintain 24 hour responsibility for all of her care needs and would need to be present at all times in the absence of the registered general nurse.

27. The provision of this care package would be achieved through an agency service provider appointed (following a procurement process) by the HSE. It was made clear, during the course of the hearing that the HSE would have to have overall governance and control over any care provided by them or at their expense at the ward's home. The estimated annual cost of this comfort care plan is in the region of €283,796.24. It will be noted that this is approximately €20,000 less than the annual cost of care in the Community Nursing Unit (under the first HSE proposal summarised in para. 23 above).

The response of the Committee

28. Following receipt of Prof. Burke's report, the Committee of the ward also revised their position. In light of the recommendations made by Prof. Burke and having discussed the matter in detail with the ward's general practitioner, the Committee proposed that the minimum level of care required for the ward would comprise the following:-

> (a) the provision of two healthcare assistants to be present to care for the ward on a 24 hour basis per day (this would involve a total of four healthcare assistants providing care over a twenty-four hour period divided into two twelve hour shifts with two assistants per shift); and
>
> (b) the parents of the ward, under the guidance of the general practitioner would assume the duties of a registered general nurse in terms of administering medication, nutrition and hydration and carrying out any further medical requirements.

29. According to this proposal on behalf of the Committee, it was stressed that two carers were required on a daily basis at all times. It was suggested that two capable and experienced carers are necessary for the turning and handling of the ward which it was suggested can be quite difficult given the intubations *in situ*. The Committee also expressed the desire that, given the level of experience and knowledge of the ward which her current carers possess, it would make sense that the carers currently employed should be retained to continue their work. On behalf of the Committee, an accountant initially estimated the weekly cost of this regime at €5,454.59 which would equate (approximately) to an annual cost of €283,639. This estimate is on the basis that the current carers would continue to be directly engaged by the Committee of the ward. It was suggested that this would involve a saving in agency fees and commissions. It should be noted, however, that the estimate of €283,639 does not include additional pay for bank holidays which would add a further sum of €12,630.82 per anum bringing the total annual estimated cost to €296,269.82. It will be noted that this is still less than the annual cost of maintaining the ward in the Community Nursing Unit.

30. It will be necessary, in due course, to consider the evidence available to the court in more detail. At this point, it should be noted that the HSE has stressed, throughout the hearing, that if it is to be involved in underwriting the cost of any care for the ward, it would be essential that an appropriate governance structure would need to be in place which would be nurse led and under the control of the HSE. It was strongly urged that it would not be possible for the HSE to simply fund the existing care that is in place or the alternative proposal outlined in paras. 28-29 above. The HSE also suggested that, as a public body, it would have to observe all of the usual requirements of public procurement. Inevitably, this is likely to increase the overall cost in that agency rates would have to be paid in respect of carers and there will also be an agency fee paid to the service provider.

31. It will be necessary, in due course, to consider, in more detail, the evidence available to the court. It may also be necessary to address the legal submissions of the parties. Before doing so, it may be helpful, at this point, to outline the one area where the parties are now *ad idem*. This relates to the terms of a "*Do Not Resuscitate Direction*".

The Do Not Resuscitate Direction

32. During the course of his visit to the home facility, Prof. Burke spoke to the ward's parents about the terms of the Do Not Resuscitation Direction ("DNR") at the time of his visit in January 2019. The parents confirmed to him that on 30th August, 2018, in consultation with their advisors and in particular with the general practitioner treating the ward, that they had signed a formal DNR which stated that in the event of a full cardio-pulmonary arrest, cardio-pulmonary resuscitation ("CPR") should not be attempted. However, the DNR also stated that, in the event of a respiratory arrest without a cardiac arrest, relief was to be provided by "*bagging*". This was a reference to the use of the Ambu bag. This had been originally supplied as an aid to facilitate physiotherapy. In the context of the DNR then in place, it was envisaged that the Ambu bag would be used to stimulate respiration if there was a

respiratory arrest without any corresponding cardiac arrest. The DNR then in place stated that CPR should not be applied if respiration had not been restored after five minutes use of the Ambu bag.

33. Professor. Burke, in his report, records that, in his conversation with the ward's parents, they emphasised that they had absolutely no wish to prolong her life unnaturally. They confirmed to him that, in circumstances where, regrettably, there is no chance of recovery, they see no point whatever in artificially prolonging her life by use of the Ambu bag or by any other resuscitation measures. They were, understandably, quite concerned that all appropriate comfort measures should be taken. In this context, Prof. Burke explains that the ward had some respiratory difficulties in late December 2018 at which point morphine in the form of Oramorph-10mg per 5ml was prescribed at a dose of 1.5 ml three or four times daily. This had a welcome palliative and soothing effect on the ward such that her respirations are now quiet and comfortable and she remains on the Oramorph treatment to date. The parents confirmed to Prof. Burke that the current low dosage could be increased to any level necessary to control any distress which the ward may experience in the future.

34. The terms of a new DNR were discussed between Prof. Burke and the ward's parents and they advised him that they now wished to amend the current DNR and to replace it with one in the following terms:-

> *"No cardiac or pulmonary resuscitation or use of Ambu bag or any other extraordinary measures should be instituted in the event of a cardiac arrest or a respiratory arrest or a cardio-pulmonary arrest. However, all comfort measures including morphine as required should be continued".*

35. At the hearing before me, both sides confirmed that they were in agreement with the terms of this proposed DNR. In addition, I was provided with a document signed by each of the parents of the ward and her general practitioner in which they signified, in writing, their assent to the above terms of the proposed DNR.

36. In his report, Prof. Burke strongly recommended a DNR in these terms. He stated that he was emphatically of the view that any resuscitation attempts (including Ambu bagging) are not indicated in the event of a cardiac or respiratory or a cardio-pulmonary arrest in circumstances where there was no prospect of recovery of any meaningful or functional status for the ward. He considered that any such measures were not only futile but would not be in the best interests of the ward.

37. Professor Mark Delargy gave evidence at the hearing and he also strongly supported the terms of the proposed DNR quoted above. In light of this medical evidence and in light of everything that I have heard about the condition of the ward (including that she is in an irreversible PVS condition) I have come to the conclusion that it is in the best interests of the ward that the proposed DNR should be adopted. I will therefore make a declaration and order to that effect. In my view it is very clearly in the ward's best interests that this approach should be taken.

The legal debate

38. Although the parties had no dispute about the terms of an appropriate DNR, there was a significant divergence of views in relation to the ongoing care of the ward and in relation to the extent of the legal obligations on the HSE in relation to her care. In the submissions made by counsel on behalf of the HSE, very significant emphasis was placed on the separation of powers mandated by the Constitution. It was submitted that, having regard to the separation of powers doctrine, courts are prohibited from making orders with respect to issues which are properly within the remit of the legislature or the executive, including, in particular, questions of distributive justice and the allocation of finite resources. The case was made that it is not sufficient to look at the issue before the court by reference to the needs and circumstances of the ward alone. One must also have regard to the needs and circumstances of the other possible recipients of the finite resources which fall to be distributed. Reliance was placed on the classic statement of this principle made by Costello J. (as he then was) in *O'Reilly v. Limerick Corporation* [1989] ILRM 181 at p. 194 where he said:-

> *"It is the Oireachtas or officials acting under the authority of the Oireachtas which under the Constitution determine the amount of the community's wealth which is to be raised by taxation and used for common purposes and the Oireachtas or officials acting on its authority determine how the nation's wealth is to be distributed and allotted. The Courts' constitutional function is to administer justice but I do not think that by exercising the suggested supervisory role it could be said that a Court was administering justice as contemplated in the Constitution. What could be involved in the exercise of the suggested jurisdiction would be the imposition by the Court of its view that there had been an unfair distribution of national resources.* ***To arrive at such a conclusion [the court] would have to make an assessment of the validity of the many competing claims on those resources, the correct priority to be given to them and the financial implications of the plaintiffs' claim****. As the present case demonstrates, it may also be required to decide whether a correct allocation of physical resources available for public purposes has been made. In exercising this function, the Court would not be administering justice as it does when determining an issue relating to commutative justice but it would be engaged in an entirely different exercise, namely, an adjudication on the fairness or otherwise of the manner in which other organs of State had administered public resources. Apart from the fact that members of the judiciary have no special qualification to undertake such a function, the manner in which justice is administered in the Courts, that is on a case by case basis, make them a wholly inappropriate institution for the fulfilment of the suggested role. I cannot construe the constitution as conferring it on them. So I must hold that I am not empowered to make the adjudication which the plaintiffs ask me to make. I should add that I am sure that the concept of justice which is to be found in the Constitution embraces the concept that the nation's wealth should be justly distributed (that is the concept of distributive justice), but I am equally sure that a claim that this has not occurred should, to comply with the Constitution, be advanced in Leinster House rather than in the Four Courts." (Emphasis added).*

39. That principle, as outlined by Costello J., has since been approved in a number of Supreme Court decisions including *MacMathúna v. Attorney Genera*l [1995] 1 I.R. 484, *Sinnott v. Minister for Education* [2001] 2 I.R. 545 and *T.D. v. Minister for Education* [2001] 4 I.R. 259.

40. An analogous principle is also well established in the specific area of healthcare decision making. In this context, my attention was drawn to the decision of the Court of Appeal in England in *Re. J. (A Minor)* [1993] Fam. 15, the decision of Kelly J. (as he then was) in *D. H. v. Ireland* (High Court, unreported, 23rd May, 2000) and the decision of Charleton J. in *E.T. v. Clinical Director, Central Mental Hospital* [2010] 4 I.R. 403 where the judge accepted the approach taken by the Court of Appeal in England in *R. v. N.W. Lancashire Health Authority* [2000] 1 WLR 977. In the *Lancashire* case Buxton L.J., at p. 997, set out a number of propositions as follows:-

> (a) A health authority is required to make choices between the various claims on its budget when (as is usually the case) it does not have sufficient funds to meet all of those claims;
>
> (b) In making those decisions, the authority can legitimately take into account a wide range of considerations including

the efficacy of any proposed treatment, the seriousness of the condition of the patient and the cost of that treatment;

(c) It would be inappropriate for a court to substitute its decision for that of the health authority, either in respect of the medical judgments that the authority must make or in place of the authority's view as to where the priorities lie.

(d) The only role of the court is to require that such decisions are taken in accordance with the well-known principles of public law.

41. In the context of the competing demands for services faced by health authorities, my attention was also drawn to the decision of the Court of Appeal in England in *R. v. Cambridge Health Authority* [1995] 1 WLR where Bingham M.R. (as he then was) said:-

> *"It is common knowledge that health authorities of all kinds are constantly pressed to make ends meet. They cannot pay their nurses as much as they would like; they cannot provide all the treatments they would like; they cannot purchase all the extremely expensive medical equipment they would like; they cannot carry out all the research they would like; they cannot build all the hospitals and specialist units they would like. Difficult and agonising judgments have to be made as to how a limited budget is best allocated to the maximum advantage of the maximum number of patients. That is not a judgment which the court can make. …".*

42. The HSE also made the case that the fact that we are here dealing with the position of a ward of court makes no difference. It was submitted that the wardship jurisdiction exists to vindicate and protect the existing rights of wards of court. It does not create or confer any new substantive rights or entitlements on such persons as against third parties. In support of that proposition, the HSE referred to the judgment of Finnegan P. in C*.K. v. Northern Area Health Board* [2002] 2 I.R. 545 at p. 558 where he said:-

> *"I can find nothing in [the wardship] jurisdiction which would enable me to compel a third party to make provision for a ward unless an obligation to make such provision can be found in the Constitution, by statute or at common law…. Further, it seems to me that where a statute makes provision for a ward in a matter which would otherwise be subject to the parens patriae jurisdiction the court should not exercise that jurisdiction in relation to duties or discretions vested by statute in a statutory authority…"*

43. In the context of that observation by Finnegan P. in *C.K.,* the HSE drew attention to the provisions of s. 61 of the Health Act, 1970 ("the 1970 Act") which is in the following terms:-

> *"61.—(1) A health board may make arrangements to assist in the maintenance at home of—*
>
> *(a) a sick or infirm person or a dependant of such a person,*
>
> *(b) a woman availing herself of a service under section 62, or receiving similar care, or a dependant of such a woman,*
>
> *(c) a person who, but for the provision of a service for him under this section, would require to be maintained otherwise than at home,*
>
> *either (as the chief executive officer of the board may determine in each case) without charge or at such charge as he considers appropriate.*
>
> (2) In making a determination under subsection (1), the chief executive officer of a health board shall comply with any directions given by the Minister."

*44. The HSE makes the case that s. 61 is permissive only. It provides that the HSE "**may** make arrangements…" (emphasis added). It empowers the HSE to provide or fund homecare services but does not impose a statutory obligation on the HSE to provide or fund such services. The HSE suggests that this was confirmed by Finnegan P. in C.K. at p. 557 when he said:-*

> *"Section 61 is regulated by the word 'may' rather than the word 'shall'. In these circumstances it is a matter of policy for the Respondent and having regard to the terms of the section for the Minister if any such services should be provided and if provided to what extent. There is no statutory right to such services. In these circumstances it is inappropriate that the court should intervene insofar as a claim under this section is made."*

45. On appeal, the Supreme Court took a similar view of the interpretation of s. 61 of the 1970 Act. However, the HSE submits that s. 61 is not the only potentially relevant statutory provision. Section 7 of the Health Act, 2004 ("the 2004 Act") is also relevant. As amended by the Health Act, 2007 ("the 2007 Act"), s. 7 of the 2004 Act provides as follows:-

> "(1) The object of the [HSE] is to use the resources available to it in the most beneficial, effective and efficient manner to improve, promote and protect the health and welfare of the public
>
> ….
>
> (4) The [HSE] shall manage and shall deliver, or arrange to be delivered on its behalf, health and personal social services in accordance with this Act
>
> *….*
>
> *(5) In performing its functions, the [HSE] shall have regard to—*
>
> *…*
>
> *(d) the resources, wherever originating, that are available to it for the purpose of performing its functions,*
>
> *(e) the need to secure the most beneficial, effective and efficient use of those resources and*

(f) any standards set by the Health Information and Quality Authority, in so far as practicable and subject to the resources available to the Executive…".

46. The HSE also emphasised the statutory obligation imposed on it to operate within its allocated budget. In this context, my attention was drawn to the provisions of ss. 30A and 34A (1) of the 2004 Act. Under s. 30A, the Minister for Health is under a statutory obligation to determine the maximum amount of net non-capital expenditure that may be incurred by the HSE for a financial year (or any part of a financial year). In turn, under s. 34A (1), the Director General of the HSE is under a statutory obligation to take steps to ensure that net non-capital expenditure for a financial year or part of a financial year does not exceed the amount specified in the s. 30A determination for that financial year (or part of a financial year – as the case may).

47. On behalf of the Committee, it is argued that the court is obliged, in the exercise of its *parens patriae* jurisdiction, to determine what care plan is in the ward's best interests. The Committee rely on the decision of Kearns P. in *Re S.R.* [2012] 1 I.R. 305 where Kearns P., at p.p. 53 – 55, stressed that, once a person is made a ward of court, the court is vested with jurisdiction over all matters relating to the ward's person and estate. If any decision requires to be made, that decision no longer lies with the family of the ward or the ward's doctors. Although the views of the family and doctors must necessarily be taken into consideration in determining the correct course of action, the decision is now solely one for the court.

48. The committee also relies on the decision of Baker J. in *Governor of X Prison v. McD* [2015] IEHC 259 where the court's inherent jurisdiction to protect vulnerable adults was discussed in detail. It was submitted by the Committee that the court is not only entitled but is obliged to consider whether there has been a failure on the part of the HSE in its duties with respect to the ward.

49. Insofar as the HSE relies on the separation of powers doctrine, the Committee submits that there have been many cases where, notwithstanding the decisions cited by the HSE, the courts have made mandatory orders directing State parties to provide particular services to a plaintiff. By way of example, the Committee refers to the decision of Laffoy J. in *Cronin v. Minister for Education* [2004] IEHC 255 where a mandatory injunction was granted against the Minister for Education to fund 29 hours per week tuition for the plaintiff. The Committee also draws attention to a number of cases where the courts have been prepared to grant declarations against State parties where a plaintiff's constitutional rights have been infringed. By way of example, the Committee refers to the decision of Kelly J. (as he then was) in *O'Donoghue v. Legal Aid Board* [2006] 4 I.R. 204 where the court granted a declaration that there had been a breach of the plaintiff's constitutional rights by failing to provide her with legal aid for a period of more than two years notwithstanding that she was a person entitled to free legal aid pursuant to the Civil Legal Aid Act, 1995.

50. With regard to s. 61 of the 1970 Act, the Committee argues that there is a significant distinction, on the facts, between the present case and *C.K. v. Northern Health Board* [2003] 2 I.R. 544 (on which the HSE relies). In making this argument, the Committee draws attention to the fact that, in contrast to other cases seeking relief in respect of homecare, there is, in the present case, a purpose-built self-contained care facility specifically constructed for the ward which has been fully operational and has been used to care for the ward, albeit outside the remit of the HSE. The Committee submits that this makes the case unique and brings it outside the normal considerations that apply to the provision of homecare under s. 61 of the 1970 Act. In making this argument, the Committee draws attention to the provisions of s. 51 of the 1970 Act where "*in-patient services*" are defined as follows:-

> *"institutional services provided for persons while maintained in a hospital, convalescent home or home for persons suffering from physical or mental disability or in accommodation ancillary thereto".*

51. The Committee submits that this definition more closely accords with the care setting provided to the ward at the facility than to any concept of care in the home (as envisaged by s. 61). The Committee also argues that s. 51 must be read in conjunction with s. 52 of the 1970 Act under which the HSE has an obligation (as opposed to a mere power) to provide in-patient services to persons with full eligibility (of whom the ward is one). It is argued that the home facility here falls within the definition of "*in-patient services*" set out in s. 51 of the 1970 Act in circumstances where it is a specially constructed and adapted facility providing medical treatment to the ward.

52. Quite apart from the argument based on ss. 51 and 52 of the 1970 Act, the Committee also argues that, in any event, the HSE, in the exercise of its duties and powers, is obliged to act in a rational and reasonable manner. Reliance is placed on the decision of Flood J. in *County Meath VEC v. Joyce* [1997] 3 I.R. 402. In addition, the Committee relies on the decision of the Supreme Court in Meadows v. Minister for Justice [2010] 2 I.R. 701 where Murray C.J. said at p. 723:-

> *"In examining whether a decision properly flows from the premises on which it is based and whether it might be considered at variance with reason and common sense I see no reason why the Court should not have recourse to the principle of proportionality in determining those issues…*
>
> *The principle requires that the effects on or prejudice to an individual's rights by an administrative body be proportional to the legitimate objective or purpose of that decision. Application of the principle of proportionality is in my view a means of examining whether the decision meets the test of reasonableness."*

53. In the event that the court is of the view that it is constrained within its inherent jurisdiction from making mandatory orders as against the HSE, the Committee submits that, in the alternative, the court should permit the Committee to seek judicial review of the decision of the HSE.

Discussion

54. The legal issues that arise in these proceedings are very important and potentially complex. Essentially, the court is being asked to consider the limits that exist to its *parens patriae* jurisdiction in wardship matters. In addition, difficult issues potentially arise in relation to the separation of powers doctrine and, in particular, in relation to the extent (if at all) to which a court can involve itself in making decisions which trench upon the manner in which State bodies decide to allocate scarce resources. As outlined in para. 19 above, any decision in relation to the resources to be provided to the ward may have significant consequences for others in need of home support services. The case law cited demonstrates that courts have, traditionally, been reluctant to intervene in such cases. A decision of a court in an individual case could have the potential to seriously skew the fair allocation of available resources in a manner which would undermine and destabilise the equitable provision of health services in accordance with the needs of the community.

55. On the other hand, as the recent decision of the Supreme Court in *Kerins v. McGuinness* [2019] IESC 11 shows, there are circumstances (albeit rare) where the courts may have to intervene and make declarations as to legal rights even in areas which the courts ordinarily regard as being outside their province.

56. However, I believe it is premature to attempt to resolve the legal issues that were debated in the course of the hearing. In the first place, having had an opportunity to consider the evidence in the case, I believe that it would be wise, if I were first to set out my views arising from that evidence so that the parties can have an opportunity to consider them further. Thus, for example, I am of the view, on the basis of the evidence, that it would be wise for the HSE to reconsider the question of funding the alternative care package proposed by the Committee (as summarised in paras. 28-29 above). Having had an opportunity to reflect on the concerns voiced by the HSE in the course of the hearing, it seems to me that these should be well capable of being addressed in an acceptable manner. I set out my views on this issue in more detail below. Secondly, even if, after further consideration, the HSE comes to the conclusion that it would not be possible for it to fund the care package proposed by the Committee, it nonetheless seems to me, on the basis of the evidence which I have heard, that the alternative care package proposed by the HSE will require to be adjusted in a number of respects. The reasons why I have come to that view are addressed further below.

57. In my view, it would be undesirable to determine the legal issues until the parties have first had an opportunity to consider this judgment. If the HSE is prepared to take either of the courses considered below, then it would be unnecessary to make any findings on the legal issues debated at the hearing. To my mind, a court should not involve itself in deciding legal issues of this importance in the event that it is not, strictly speaking, essential to do so.

58. Before setting out my views in relation to the matters discussed in para. 56 above, it may be helpful, at this point, to draw attention to certain aspects of the evidence which was given in the course of the hearing which took place in March, 2019.

The evidence

59. In the course of the hearing, I had the benefit of evidence from the ward's father, her general practitioner, the accountant providing pay roll services in respect of the care team currently caring for the ward, the Head of Social Care within the HSE responsible for the delivery of services to people with disabilities in the area in which the ward resides, and the director of nursing of the Community Nursing Unit. I also heard evidence from Doctor John McFarlane, a consultant in rehabilitation medicine at the Mercy University Hospital, Cork, Prof. Mark Delargy a consultant in rehabilitation medicine and also the Clinical Director of the National Rehabilitation Hospital. In addition, I had the benefit of a report from Prof. Conor M. Burke a consultant respiratory physician at the Mater Hospital in Dublin. By agreement of the parties, the report of Prof. Burke was admitted in evidence without the need to call him as a witness. Both Dr. McFarlane and Prof. Delargy also provided written reports.

60. Doctor McFarlane was called as a witness on behalf of the HSE. Most of his report is concerned with the question of an appropriate DNR. Dr. McFarlane was firmly of the view that the ward is in a PVS state. He explained that, physically, she has no active movements in any of her four limbs. He stated that, because she has no voluntary movements, she is immobile and is transferred using a hoist with the assistance of two people. He also described how the ward is transferred to a modified chair every second day for a number of hours and he drew attention to the fact that she has no pressure ulcers which is a well-recognised risk for individuals in a PVS condition.

61. In his evidence, Dr. McFarlane referred to the National Clinical Guidelines of the Royal College of Physicians 2013 ("*the 2013 guidelines*") where a vegetative state is described as:

> "*Characterised by a complete absence of behavioural evidence for self or environmental awareness".*

Doctor McFarlane contrasted this with "*locked-in syndrome*" which usually results from brain stem pathology which disrupts the voluntary control of movement without abolishing either wakefulness or awareness. Dr. McFarlane explained that consciousness and a person's ability to understand and make decisions is preserved in the case of those suffering from locked-in syndrome. Professor Delargy agreed with this evidence. He explained that people in locked-in syndrome have full mental capacity and are competent to instruct medical practitioners and others as to what they want and whether they wish to have medical treatment or not. People suffering from this syndrome have damage to the brain stem. In contrast, in the case of the ward, Prof. Delargy said that she has suffered widespread global hemispheric brain damage.

62. In his evidence, Dr. McFarlane also addressed the issue as to whether a PVS patient might experience pain. His evidence was that this is a controversial issue. There is conflicting research on the issue with the result that there is no firm body of evidence to conclude either way. He referred to the 2013 guidelines where, at p. 59, it is stated:-

> *"Patients in PVS are believed to lack any capacity to experience the environment, internal or external, but complete certainty that primal sensations, such as pain, are absent is impossible to know".*

63. At p. 60, the guidelines state that preliminary findings (based on a very small sample) suggest that in PVS patients, although painful stimuli reach the primary somatosensory cortex (the area of the brain that senses pain and coordinates reflex responses) they do not reach the higher-order associative cortices (i.e. those areas that are responsible for perception and awareness of pain). Although further research has taken place since 2013, Dr. McFarlane said that the research is inconclusive.

64. Under cross-examination, Dr. McFarlane conceded that there is a spectrum of PVS conditions. PVS patients might be diagnosed as being in the same state but they may not all have the same manifestations or conditions. He also conceded that one can never be certain as to the reality or extent of perception of a person with a severely impaired brain function.

65. Professor Delargy was called as a witness on behalf of the Committee. He had earlier prepared a detailed report on the joint instruction of the solicitors for the HSE and the Committee. This report is very comprehensive and it is clear that Prof. Delargy had a very full opportunity to consider the condition of the ward and the question of an appropriate care regime for her. According to Prof. Delargy, the ward may well be blind although she appears to be photophobic. He also observed a startle reaction to noise. However, he explained that a reflex startle reaction is a primitive response which does not imply consciousness. She showed little evidence of facial movement. He carried out a number of basic tests to determine whether the ward suffers pain. From his assessment, he considers that it is a reasonable approach for her care team to treat the ward on the basis that she may perceive discomfort from known painful stimuli even though his assessment did not elicit any clear evidence of awareness to pain. In terms of PVS patients generally, Prof. Delargy was of the view that there is a realm of uncertainty as to whether the patient will experience pain. He described it as an outside possibility but he nonetheless drew attention to the fact that, in those cases where a decision is made to withdraw nutrition and hydration, it would be normal practice in the United Kingdom that the patient would receive substantial amounts of pain and other medication (even to anaesthetic levels). Professor Delargy also explained that it was part of his practice to prescribe analgesics to PVS patients on the outside chance that the individual may be aware of some element of pain. His evidence was that we do not have the technology to determine with absolute certainty that the individual cannot experience something. Under cross examination, Prof. Delargy also explained that there have been some investigations, such as functional MRI and EEG tests that have been performed on patients considered to be in a vegetative state which has shown that, contrary to a previous PVS diagnosis,

they had some limited or minimal awareness.

66. In terms of the numbers required in any care team, Prof. Delargy explained that a fully dependant hoisted patient who, for example, needs to be changed during the night would typically require the assistance of two staff. This evidence of Prof. Delargy is borne out by the video evidence provided by the ward's father. It was quite clear from that video evidence that it would be virtually impossible for a single person to manage a change of the ward without the assistance of another person. While the director of nursing (who gave evidence) suggested that there would be "*significant challenges*" for one carer to change a patient without assistance, she suggested that the task would be "*difficult but not impossible".* Having observed the immobile condition of the ward in the video and in light of the evidence of Prof. Delargy, I am very definitely of the view that it would be well nigh impossible for one person to successfully effect a change of an incontinence pad for the ward in the event of a bowel movement.

67. More generally, Prof. Delargy made clear in his report that it would be most appropriate that the ward should continue to be cared for in a calm, caring and gentle manner with all care activities explained to her in a calm manner so that startle responses are kept to a minimum. Professor Delargy considered that the use of soothing voices to introduce the care team's physical interaction with the ward is an appropriate approach (albeit that it does not infer that she can understand the language used by staff when interacting with her in this way).

68. Insofar as care in the Community Nursing Unit is concerned, Prof. Delargy considered that the level of care needed for the ward would require a major increase in the staffing intensity. In addition, the staff would have to be competent in delivering the level of care which the ward requires. Professor Delargy expressed the view that specific training would be required. In contrast, Prof. Delargy noted that, an advantage of care in the home environment is protection from cross-contamination with organisms contracted by other patients. In addition, as the only responsibility of the current care team is to provide for the ward's needs, the care team is not challenged by delivering care to other patients as is normally the situation in a hospital or a community nursing unit. Following his assessment of the ward's current care and his review of the Community Nursing Unit, Prof. Delargy expressed the view that her current needs would require a substantial investment in staffing and training time to enable her to return to that unit.

69. On the other hand, Prof. Delargy accepted that there could be some reduction in the current level of care given to the ward without a significant deleterious effect. In particular, he explained that he did not believe it was essential to have a skilled nurse available. As I understand it, this view was put forward by Prof. Delargy in circumstances where the ward's life expectancy is now limited; where there will be a very clear DNR in force, and where the regime of care for the ward is centred on comfort measures only. However, he was reluctant to express any view on the suggestion made by the HSE (as part of its alternative care package proposed for the ward if she is to remain at home) that there would be one care provider 24 hours a day with support from a registered nurse for two hours a day. When asked, in the course of cross examination, whether he had a view on that proposal his answer was:-

> *"I think that my preference would be that the expertise in nursing care is a nursing matter".*

70. In the course of his cross examination, Prof. Delargy was also asked about the HSE policy that, if homecare is to be made available, there must be a greater hands-on care role involvement from the ward's family. In particular, he was asked whether that is a reasonable element of any care package and he agreed with that proposition.

71. One further aspect of Prof. Delargy's evidence should be noted. Contrary to the understanding of the HSE witnesses in this case, Prof. Delargy drew attention to the fact that there are at least two other PVS patients being cared for in the State at home. He explained that his understanding is that the majority of care in each case is provided by the family (with the support of an outside care team) but the difference is that the patients concerned are not tracheostomy dependant. They are not on supplementary oxygen and do not require the frequent suctioning which is such a feature of the care required for the ward. Insofar as the United Kingdom is concerned, Prof. Delargy said his understanding was that it is very unusual for people in a PVS state requiring the level of care that the ward requires to be managed at home.

72. Professor Burke did not give evidence. It was unnecessary for him to do so in circumstances where the parties agreed that his very comprehensive report of 5th January, 2019 could be admitted in evidence without formal proof. In his report, Prof. Burke dealt with the DNR. Based on the discussions which he had with the ward's parents, he was in a position to record that they were prepared to amend the DNR in the terms outlined at an earlier point in this judgment. Prof. Burke complemented the ward's family on the extraordinary devotion and care they have shown to the ward since 2008. However, he expressed the view that, in circumstances where the ward is in a PVS condition, she is not capable of perceiving any sensory input and therefore the benefit to her of being maintained at home is questionable. On the other hand, Prof. Burke acknowledged that there were significant benefits to the ward's family by the knowledge that the ward is being maintained at home.

73. Professor Burke explained that the accepted standard of care of patients similar to the ward is in a nursing home setting such as the Community Nursing Unit. He drew attention to the concern that governance of care is not at all clear in a home environment. He also expressed the strong view that healthcare budgets could not sustain the management of fully dependant patients routinely managed at home with all of the attendant costs impacting on other areas of care. For those reasons, Prof. Burke expressed the opinion that patients like the ward should ordinarily be managed in appropriate nursing home environments rather than at home and he suggested that this was in the interests of the greater good of the community as a whole. Notwithstanding this view, Prof. Burke suggested that, as an exceptional measure, it might be possible to maintain the ward at home at no greater cost than in the Community Nursing Unit. He expressed himself in the following terms:-

> *"…with particular regard to this individual case and absolutely not as a general rule or precedent and entirely at the discretion of the Court, it is possible to suggest that [the ward's] care could be maintained at home with no community disadvantage in the following circumstances. In a comfort only scenario, her needs could be met by a permanent carer as opposed to a permanent nurse and carer ….This would save 168 hours of nursing time and given holiday and other considerations this would amount to approximately five nursing salaries….furthermore, there is no need for ongoing bedside monitoring (with the possible exception of oxygen monitors) which would be a further cost saving. Further savings would accrue if the appropriate facilities were not required in a nursing home. Under these circumstances, the financial difference between home and nursing home care would be effectively zero. In addition, [the wards] life expectancy is now very limited for all the reasons outlined …and she is now maintained …on palliative morphine. The [family] themselves note a significant deterioration in her status over the past two months. Under these circumstances the excess (if any) financial cost of home maintenance may be insignificant. Given the misunderstandings over the past few years between the …family and the HSE, and given the extraordinary love and devotion shown by [the ward's parents], the court might take the view that maintaining her at home in these unique circumstances is worthy of consideration…."*

74. It was this expression of opinion by Prof. Burke that led the HSE to put forward the alternative proposal summarised in para. 26 above. As noted in para. 27 above, the estimated annual cost of this comfort care plan is approximately €20,000 less than the annual cost of care in the Community Nursing Unit. In this context, it should be borne in mind that, as noted in para. 23 above, moving the ward to the Community Nursing Unit will involve a significant increase in the number of registered nursing hours and healthcare assistant hours that will require to be made available at the unit so as to ensure the ward's needs are appropriately met in a residential setting. Thus, the cost of maintaining the ward in a residential setting (which will be necessary if it is not possible to maintain her at home) will inevitably give rise to significant cost for the HSE. Thus, the cost of caring for the ward will be significant, irrespective of the course which is ultimately taken in these proceedings.

75. The director of nursing at the Community Nursing Unit gave evidence to the effect that care of a PVS patient must always be nurse led. Her view was that while carers provide an invaluable service, they are not registered practitioners. She was very firmly of the view that care has to be governed, audited, monitored and supervised by registered practitioners such that governance by a registered nurse is essential. For that reason, the homecare package proposed by the HSE (as an alternative to placing the ward in the Community Nursing Unit) is nurse led involving two hours of nursing care per day. According to this witness, the carers under the homecare plan would report to the nurse who will perform the daily personal care in conjunction with the carer then on duty. The homecare package proposed by the HSE envisages that, where required, the single carer on duty would be supported by a family member at those times during the 22 hour period when the nurse is not present. In addition, the expectation would be that the carers would be given a break during their twelve-hour shift, during which time a family member would take over the care of the ward.

76. The director of nursing accepted that the hoisting of the ward is always a two person manoeuvre (both for the safety of the patient and also for the health and safety of those involved in performing the manoeuvre). There is a full ceiling tracking hoist available at the homecare facility adjoining the ward's family home. The director of nursing was of the view that the repositioning of the ward in her bed could be accomplished by one person alone. However, she accepted that the "*ideal*" is to have two people to do it. Having seen the video taken by the ward's father I believe that a full repositioning of the ward requires the involvement of two persons. Under the care regime currently in place for the ward, she is repositioned at regular intervals night and day. Her father gave evidence that she would usually be repositioned every three hours. The director of nursing was of the view that it should not be necessary to reposition the ward every three hours over the course of a night. She gave evidence that for the night time portion of care, it would be appropriate for the ward to be repositioned last thing at night. Her view was that a pressure relief mattress would be sufficient to maintain the ward's skin integrity until she is repositioned again in the morning. She also suggested that, where necessary, some minimal repositioning could be undertaken during the course of the night that could be achieved with one person through the use of pillows, wedges and a turning sheet. She offered that the HSE would be prepared to provide a new bed incorporating the latest technology to relieve pressure and avoid ulcers. This would include what was described as a low air loss therapy system with lateral positioning function which would include a pressure sensor with an acoustic and visual alarm. It would also include a pulsation mode, an alternating pressure mode, a power failure alarm and an intelligent default detection with an LED indicator.

77. Under cross examination, the director of nursing was asked whether it was safe for a patient to go through the night without being turned. The director responded by saying that a patient needs rest as well and that the patient will already obtain pressure relief from the effect of the "*high-tech*" mattress which the HSE would be willing to provide. She explained that during the day, it would be appropriate to effect a full repositioning of the ward at four hourly intervals. She was asked, in that context, for how long she thought the carer would require the assistance of a family member in connection with this periodic turning exercise. Her response was that repositioning was a three-five minute procedure unless there has been a bowel movement in which case, the patient will require further care.

78. The ward's father, in contrast, suggested that one carer could not possibly care for the ward. He explained that, turning the ward, is a difficult procedure because she is a dead weight. His evidence was that one would need to be "*fairly fit*" to assist in this procedure. He explained that he had undertaken a twelve hour shift himself from time to time (and that by the end of the evening he was "*absolutely shattered*"). In his evidence, he also dealt with the proposed HSE comfort care plan (under which the family would be required to be available to assist on a 24 hour basis). His evidence was:-

> *"We can't do that. I can't do that. I couldn't. I physically couldn't do it myself. If I could I would. I would. I would do anything for my daughter. When we got that from the HSE of course it wasn't ideal but we want to keep [the ward] at home now because she is coming to a stage now where she won't be with us for much longer I would say".*

79. The ward's father explained that in 2013 he had a significant cardiac incident and now has three stents. He said that the family are in a position to administer morphine, assist in suctioning, and to change the tracheostomy tube, assist with PEG feeding and all of the other care needs of the ward (with the exception of the periodic changes of the catheter which are undertaken by the general practitioner treating the ward). However, in the course of his cross examination by counsel for the HSE, the ward's father explained that he had never been involved in changing his daughter's incontinence pad. He was strongly of the view that this would involve an affront to her dignity. His evidence was:-

> *"That's all that she has got left now is that little bit of dignity. So how, could you tell me, how could one carer change [the ward]?"*

80. According to the ward's father, changing the ward is not the only care task which requires the involvement of two carers. He also explained that two carers are required for washing and dressing the ward and, as previously mentioned, for repositioning the ward in her bed. The ward's father suggested that this involves particular care given the three forms of intubation in place. It also seems likely (although this was not specifically addressed) that the twice daily physiotherapy would require the involvement of two carers.

81. While the Committee, in the course of the hearing, strongly submitted that more than one carer was required, the Committee questioned whether it was necessary to have the level of involvement for a registered nurse currently envisaged under the homecare package proposed by the HSE (as an alternative to placing the ward in the Community Nursing Unit). This was explored in the course of the cross examination of the director of nursing. It was put to the director of nursing that, if there are suitably qualified and experienced carers in place, governance by the nurse could be undertaken on the basis of a weekly visit rather than a daily visit. This was rejected by the director of nursing. She strongly maintained that it was essential that there should be a nurse with ultimate responsibility. She said that:

> *"There is no shades of grey in my opinion on that".*

She was asked to explain how the HSE arrived at the view that two hours nursing care per day was required, her response was as follows:-

"I suppose two hours I would consider as an appropriate period of nursing hours and that is to review the resident on a daily basis; to guide the carer; to audit the care; to ensure safe care and quality care; and also to have a clear governance structure in place".

82. When pressed further, the director of nursing explained that the nurse would be in a position to discuss any issues that might come up on a daily basis or that might need to be addressed. The nurse would be in a position to provide advice to carers. The nurse's function would also be to ensure supervision of the DNR (albeit that the DNR is ultimately a medically-led decision). When it was put to her on cross examination that this could be undertaken on a weekly basis (once carers were properly instructed) her response was:

"I don't think the presence of nursing every day is for that role alone…"

83. The Head of Social Care for the relevant Community Healthcare Area also gave evidence. I have already summarised the effect of some of her evidence in paras. 16 -24 above. She explained that, following receipt of Prof. Burke's report, the HSE, as an exceptional measure, prepared the comfort care plan summarised in para. 26 above. This witness explained that, although Prof. Burke proposed care by a single carer present at all times, the HSE added two hours of nursing care per day to ensure appropriate clinical governance and to maintain quality and safety. She also explained that the comfort care plan has been prepared on the basis that assistance would be provided by the family of the ward who she said clearly have appropriate knowledge and expertise for this purpose. The witness was cross examined closely as to the necessity for the involvement of a nurse. Her evidence was that the daily involvement of the nurse would be critical:-

"…for the knowledge of the person being cared for and in order to, I suppose, apply their knowledge and expertise appropriately to that care to lead the healthcare assistant in how they should carry out their tasks; to monitor [the ward's] condition and to be in a position to give appropriate advice based on knowledge of her clinical status and her care needs".

84. The witness stressed the importance of the requirement for clinical governance in the context of a body such as the HSE and she said that:

"We feel that it needs to be applied on a daily basis, as we have outlined. So, I don't see it as a lack of flexibility on our part because we see that as a requirement in order to ensure the care plan works".

85. When pressed by counsel for the Committee as to the necessity for the number of nursing hours proposed under the HSE care plan, the response of this witness was that it was a matter of clinical judgment. On re-examination, the witness was asked about the reporting requirements that the HSE would envisage. The witness explained that a Nurse Manager in the HSE would review reports in relation to the ward on a weekly basis.

86. In response to questions from me, the witness explained that the nurse would come on duty more or less as the first care assistant of the day came on duty. I asked her would the nurse interact with the night time carer before that carer signed off. The witness explained that the nurse would review the notes and the records and she would expect that spot checks might be made on occasion. However, she stressed that the two hours per day envisaged under the care plan would normally take place at the start of the day shift in the morning when the ward would receive daily personal care and hygiene including the checking of the intubations. The nurse would also read all of the notes made by the care assistant who had been present during the night shift.

87. With regard to input from the family of the ward, the evidence of this witness was that it is the family's choice to try to maintain the ward at home; that the role of the HSE is to provide support for that. However, the involvement of the family was a crucial element of the comfort care plan. Thus, if there was a need to change the ward or if there was a need to assist with repositioning, the HSE would expect that arrangements would be made for the family to assist the single carer on duty.

88. It was put to this witness, on cross-examination that if the ward is to be maintained at home, this will essentially make the bed, which had previously been earmarked for her in the Community Nursing Unit, available for use by another patient. As noted in para. 72 above, a similar point was made by Prof. Burke in his report. However, the witness explained that this was not the case. The proposal in relation to the Community Nursing Unit was to open an additional bed there. Thus the proposal would not deprive anybody of an existing bed. It would be a newly opened bed specifically for the ward. Save for the purposes of providing care to the ward, there is no intention of increasing the beds at the Community Nursing Unit. It was also put to this witness that the HSE has been saved the cost of providing fulltime care to the ward over the past number of years in light of the fact that she was cared for entirely at her own expense at home. The witness responded that this would not be taken into account by the HSE.

89. The remaining witness who gave evidence was the accountant who costed the alternative care proposal put forward by the Committee (as summarised in paras. 28-29 above). In the course of his direct examination, he explained his calculations. He drew attention to the fact that he had omitted to factor in the cost of nine bank holidays in the year which would add a further €12,630.82 to the estimate mentioned in para. 29 above. He explained that there were significant advantages to employing the carers directly. There had been a significant saving when the Committee (acting on behalf of the ward) switched from using a home care service provider to direct employment of the carers. He also explained that, in terms of what the carers received into their hand per hour, it was on a par with the hourly rates offered by private employers. His evidence was that the net pay to the carers was, in fact, slightly higher than the net pay received by the carers when they were previously employed by an agency. Where an agency is involved, there are significant overheads which are reflected in the rate charged by the agency to clients such as the HSE.

90. In light of the evidence before the court, my next task is to make appropriate findings. Before doing so, it is necessary to identify the appropriate test to be applied by the court in considering an issue relating to the welfare of a ward.

The legal test to be applied

91. In *Re A Ward of Court (withholding medical treatment) (No. 2)* [1996] 2 I.R. 79 at p. 106, Hamilton C.J. explained the role of the court in relation to the welfare of wards as follows:-

"When a person is made a ward of court, the court is vested with jurisdiction over all matters relating to the person and the state of the ward and in the exercise of such jurisdiction is subject only to the provisions of the Constitution: there is no statute which in the slightest degree lessens the court's duty or frees it from the responsibility of exercising that parental care.

That duty includes giving directions with regard to the care, maintenance and well-being of the ward. While a Committee

of the person of a ward is appointed by the court, such Committee is subject to the directions of the court and all decisions with regard thereto are made by the court….

In the exercise of this jurisdiction the courts prime and paramount consideration must be the best interests of the ward. The views of the Committee and family of the ward, although they should be heeded and careful consideration given thereto, cannot and should not prevail over the court's view of the ward's best interest.

As stated by Balcombe L.J. in Re J. a Minor…[1991] Fam 33 at p. 50:-

> *'In deciding in any given case what is in the best interests of the ward, the court adopts the same attitude as a responsible parent would do in the case of his or her own child; the court, exercising the duties of the Sovereign as parens patrieae, is not expected to adopt any higher or different standard than that which, viewed objectively, a reasonable and responsible parent would do'.*

It is quite clear from the judgment of the …trial judge that he accepted that in dealing with the application before him he was exercising the parens patrieae jurisdiction …now vested in the President of the High Court or at his direction, by an ordinary judge of the High Court for the time being assigned…".

92. At p. 107, Hamilton C.J. noted that, in that case, Lynch J. in the High Court had also made clear that the views of the family and the carers of the ward would carry weight with the court. It is important to put that observation in context. That case was not concerned with the cost of ongoing care for a ward of court. It was concerned with the question whether a much more drastic step should be taken – namely the withdrawal of nutrition and hydration from a near PVS patient.

93. For the purposes of the task which I must now undertake, it seems to me that the approach which I must adopt is to put myself in the shoes of an objective reasonable and responsible parent. In taking that course, I will, of course, have regard to the evidence of the ward's father but I cannot allow his subjective view to replace or unduly influence the purely objective approach which I am required to take.

94. All of the witnesses who gave evidence in this case were agreed that the family of the ward have at all times acted in the ward's best interests and have ensured that the ward has received an exceptional level of care. The fact that the ward has never had a pressure ulcer or a serious infection is testament to the excellent level of care which the ward has received. In an ideal world, a court exercising its *parens patriae* jurisdiction would wish to continue this level of care. However, as the evidence summarised in paras. 18-19 above demonstrates, any decision in relation to the level of care may have adverse consequences for others hoping to avail of the home support services provided by the HSE. Against that backdrop, I do not believe that the court, in approaching the matter objectively from the perspective of a reasonable and responsible parent, could properly ignore the potential impact of its decision on the ability of other deserving cases to secure assistance from the HSE. In my view, in deciding what is in the ward's best interest, I must bear in mind the knock-on consequences of any decision in relation to the level of care to be devoted to the ward. Given the limited funds available to the HSE, and given the extensive demands on those funds for services of this kind, I believe that the court, wearing the hat of the objective reasonable and responsible parent, should properly take this factor into account.

95. Accordingly, in considering what is in the ward's best interests, I do not believe that I can reasonably take the approach that money is no object. It seems to me that I must bear in mind the likely level of cost that will arise. On the other hand, I cannot lose sight of the fact that if the ward were to be transferred to the Community Nursing Unit, this would cost an estimated €315,198 per annum. This figure is an important touchstone when considering whether it is reasonable to continue to maintain the ward at home. As Prof. Burke has observed, the additional financial cost of home maintenance may not be significant when compared to the inevitable costs that will arise if she is moved to the Community Nursing Unit and additional staff have to be specially trained and assigned to that unit for the purpose of caring for the ward there. As Prof. Delargy has observed (and as the HSE appear to accept) the level of care needed for the ward at the Community Nursing Unit would require a major increase in staffing intensity. In addition, the staff would have to be specially trained and competent in delivering the level of care which the ward requires.

96. Furthermore, as Prof. Delargy has said, there are significant advantages in continuing the care of the ward in the home environment. Uniquely, the home facility is in a position to provide a very quiet and calm environment for the ward. As noted in para. 66 above, Prof. Delargy was clear in his evidence that the ward should continue to be cared for in such an environment. There is also protection from cross-contamination (both from other patients and from the significant number of visitors who will inevitably attend a facility such as the Community Nursing Unit). In these circumstances, it seems to me that I should first consider whether it would be possible to maintain the ward at the home facility at a cost that would not be excessive (relative to the cost of maintaining her at the Community Nursing Unit). In this context, it would be a great pity if the HSE did not give further consideration to the option of funding the care regime proposed by the Committee (as summarised in paras. 28-29 above). That would not involve the HSE appointing its own team of carers. Instead the HSE would provide the funds to the Committee (through the Registrar of Wards of Court) in order to continue to pay for the presence of two carers for the ward around the clock.

97. On the basis of the estimated annual cost of this option as measured by the accountant appointed by the Committee, it would be less costly than maintaining the ward in the Community Nursing Unit. It would only slightly exceed the estimated annual cost of the alternative comfort care plan proposed by the HSE (which would involve putting in place a new care team under a procurement process).

98. I appreciate that the Head of Social Care has said that the HSE does not provide funding to private individuals to employ carers. However, I would not characterise the proposal in that way. The circumstances of this case are unique. There is an existing care regime in place for the ward which has been universally praised and what is now proposed will be less costly for the HSE than the cost of care at the Community Care Unit.

99. The Head of Social Care explained that the HSE has a framework through which it provides care either directly (through staff employed by the HSE) or by funding a care services provider which has gone through a procurement process. According to this witness, if the HSE were to pay the rates currently paid by the ward, this would: *"be completely unfeasible because we would be literally bringing in staff who would be paid with a lesser rate with lesser conditions than people doing comparable work in other settings".* However, in my view, if the HSE were to fund the alternative proposal made by the Committee, this would not involve the HSE in "*bringing in staff*" at all. The ward (through her Committee) would remain as the employer. The terms and conditions of the carers have already been the subject of a negotiated agreement between the carers directly and the Committee. The evidence of the accountant made this very clear.

100. I also appreciate that the HSE has understandable concerns about governance if it is to be involved in any form of funding of a home care package for the ward. I have already summarised the evidence given by the Head of Social Care and the director of nursing to that effect. This appears to be the principal reason why the HSE proposes two hours of nursing care per day to ensure appropriate clinical governance and maintain quality and safety. On the other hand, it cannot be gainsaid that there is, at present, a safe system of care in place for the ward at the home facility. Everyone who has visited the facility has remarked on the standard of care and on the excellence of the facilities available there. Several of the witnesses went so far as to compare the level of service and the facilities available to an intensive care unit. Furthermore, there is already an established care regime in place with fully trained carers who are accustomed to treating the ward and who fully understand what is required. The ward is also cared for by her general practitioner who attends her regularly to change her catheter and to attend to her medical needs. I can well appreciate that the HSE would wish to carry out verification inspections or audits to ensure that the high standard of care currently in place continues into the future. Thus, for example, the District Nurse could visit on a regular basis and, if necessary, this could be supplemented by periodic inspections of a more intensive kind. In addition, it could be made a condition of any care plan approved by the court that the ward's general practitioner should attend at agreed periodic intervals to confirm that the care of the ward is satisfactory.

101. I am conscious that the care plan now proposed by the Committee would no longer have daily nursing involvement. It is clear from the evidence of the HSE witnesses that they regarded nursing supervision as an essential element of any care plan. However, I was very impressed by the evidence of Prof. Delargy who has unparalleled experience of the treatment of PVS patients. As noted in para. 69 above, his evidence was that it was not necessary to have a skilled nurse available in circumstances where (a) the ward's life expectancy is limited; (b) there is a clear DNR agreed and in place; and (c) where the care regime is centred on comfort measures only. I accept his evidence on this issue. It might be different if the ward was coming into the care of a new care team unfamiliar with the ward's needs and with the routines of her care. I can well understand how, in those circumstances, it might be necessary to have some element of nursing supervision at least at the outset.

102. I also fully appreciate that the HSE could not accept liability in respect of the care provided on the instructions of the Committee. If the care is not being provided at the direction of the HSE, then the Committee (acting on behalf of the ward) could not have any proper basis on which to hold the HSE liable in respect of the care regime place. If necessary, an appropriate hold harmless agreement (under which the Committee would acknowledge that the HSE will have no liability) might require to be put in place on terms to be subject to the sanction of the court. I can see no reason why the details of such an arrangement could not be addressed in a manner satisfactory to both sides.

103. While I can understand the policy considerations underlying the approach taken to date by the HSE, I would ask the HSE to give further consideration to this option. In my view, there is no scope to suggest that, by doing so, the HSE would be in breach of the arrangements described by the Head of Social Care (as summarised in para. 99 above). It is important to keep in mind that the HSE would not be engaging the services of the carers directly. The HSE would simply, as a practical and pragmatic measure, be funding the provision of ongoing care. The ward (acting by her Committee) would remain as the employer. The funds would be paid through the office of the Registrar of Wards of Court. I cannot see how any procurement issues would arise in circumstances where the appointment of the care team has previously been made by the Committee (with the sanction of the court) and where the HSE would not itself be engaging or employing the care team itself. It would simply be using its resources in a sensible manner to protect the health and welfare of the ward while at the same time minimising the level of outlay required. There are significant benefits in taking this course particularly in circumstances where, in light of the evidence given by the accountant acting for the Committee, it is clear that the carers currently caring for the ward do not charge a higher rate for night work as opposed to day work. By taking this course, the need to train new staff (with all of the additional training costs involved) could be avoided. It would also be possible to avoid the adjustment difficulties that are likely to arise in the event that a wholly new care team is appointed by the HSE. Any such new care team will be entire strangers to the ward and will have to learn how to care for the ward. In this context, it is important to bear in mind the evidence of Prof. Delargy that one cannot rule out the possibility that the ward may perceive discomfort and that it is a reasonable approach for a care team to deliver care to the ward on that basis.

104. Furthermore, in circumstances where the accountant's estimate is less than the cost of maintaining the ward in the Community Nursing Unit, it would appear to me that this would secure for the HSE (in the context of s. 7(5)(a) of the 2004 Act quoted in para. 45 above) a more beneficial and efficient use of its resources than the alternative of funding residential care with all of the attendant costs that would arise in that event.

105. I appreciate, however, that the HSE would need to carefully reflect on these issues. All I do, at this point, is to ask the HSE to give serious consideration to proceeding on this basis. I would also ask the HSE to bear in mind that this would clearly be an exceptional measure which arises only in the very unique circumstances of this case and against a background where, sadly, the remaining lifetime of the ward, on the basis of the evidence before the court, is likely to be short. I also believe it is relevant to bear in mind that, by taking this course, the outlay by the HSE would be less than the cost of care at the Community Care Unit and would not be significantly greater than the outlay on the alternative care plan proposed by them. This would ensure that there is minimal impact on its ability to continue to satisfy the demands of its home care services in the local area. This proposal would effectively involve a very similar arrangement to the current *ad hoc* measure in place, while these proceedings are ongoing, under which the HSE provides funding to cover the cost of the current regime of care for the ward.

106. In light of the considerations discussed above, I believe that the concerns of the HSE in relation to funding the care proposal made by the Committee can be appropriately addressed. In the event that, notwithstanding my views, it transpires that there are genuinely insuperable difficulties for the HSE in taking that course, I next consider what level of care would be appropriate for the ward under a care regime put in place and governed by the HSE directly. For reasons which will become apparent, it seems to me that the alternative care regime proposed by the HSE will require adjustments that will inevitably add to the cost of the care package (to some extent). This seems to me to be a further reason why it makes sense for the HSE to seriously consider the suggestion discussed in paras. 95-105 above.

107. If the care team has to be engaged by the HSE, this will inevitably increase the overall cost. This is clear from the evidence of the Head of Social Care. In those circumstances, it becomes important to consider what adjustments can reasonably and safely be made to the level of care. In this context, the medical evidence suggests that there could be some reduction in the current level of care without a significant deleterious effect. This was the view expressed by Prof. Delargy (as summarised in para. 69 above). Prof. Delargy was of the view that it was not essential to have a skilled nurse available. Similarly, Prof. Burke was of the view that the ward's needs could be met by a permanent carer as opposed to a permanent nurse and carer. This is in circumstances where the parameters of the care regime are now well established. Going forward, the regime will be limited to comfort only measures. No resuscitation measures will be attempted. The evidence available to the court also suggests that appropriately trained carers without nursing qualifications can undertake the tasks of suctioning, feeding, hygiene, and monitoring of the ward.

108. There are, however, a number of tasks that cannot reasonably be undertaken by one person alone. These include the following:-

(a) In my view, a full repositioning of the ward in her bed cannot reasonably be undertaken by one person alone. While the director of nursing expressed the view that the repositioning of the ward could be accomplished by one person alone, her evidence to that effect was quite tentative. Furthermore, as noted in para. 66 above, the video taken by the ward's father demonstrates very clearly why two persons are required for this task.

(b) I am also of the view that two persons would be required to effect a change of an incontinence pad for the ward in the event of a bowel movement. I have already summarised the evidence given by the director of nursing on this issue above. Her evidence was that there would be significant challenges for one carer to change a patient without assistance. Although she suggested that one carer could manage the task with difficulty, I do not believe that this is the appropriate standard of care to apply. If the task is difficult to achieve by one person alone, that must increase the risk that something may go wrong.

(c) It was agreed by all witnesses that the use of the hoist (to move the ward from her bed to a chair) requires the assistance of two persons.

(d) It is also clear that the daily hygiene and dressing of the ward requires the intervention of two carers.

(e) Given the difficulty involved in a full repositioning of the ward without the assistance of two persons, I cannot see how the physiotherapy given to the ward during the day could be safely accomplished without the participation of two carers.

109. On the other hand, the tasks summarised in para. 108 above do not require the presence of two carers at all times. Most of these tasks could be accomplished at set periodic intervals. For example, in the context of a full repositioning of the ward during the day, that can be undertaken (as recommended by the director of nursing) at four hourly intervals. As explained above, the ward is also currently repositioned at periodic intervals during the night. The evidence given by the director of nursing on this issue (which was not significantly challenged) was that it should not be necessary to reposition the ward every three hours over the course of a night. I accept her evidence that it would be appropriate for the ward to be repositioned last thing at night and that the "*high-tech*" mattress which the HSE has offered to supply should be sufficient to maintain the skin integrity of the ward until she is repositioned again in the morning. The "*high-tech*" bed proposed by the HSE will include a pressure sensor with an acoustic and a visual alarm. Obviously, if the alarm sounds, steps would have to be taken to relieve the area of pressure and, in that case, reposition the ward to some extent. In those circumstances, the director of nursing gave evidence that minimal repositioning could be undertaken by one person alone through the use of pillows, wedges and a turning sheet. I accept that these would assist in altering pressure points on the ward's body which should ordinarily be sufficient to maintain the integrity of the ward's skin until the ward is fully repositioned in her bed in the morning.

110. Nonetheless, there are, at least two circumstances, where a second carer may be required during night time hours. In the first place, there may be circumstances where a carer forms the view that a minimal repositioning will not be effective and that a full repositioning of the ward is, in fact, required. Secondly, the ward could have a bowel motion overnight which would require a timely change of the incontinence pad. Regrettably, there is no way to predict whether events of this kind might occur and in those circumstances, the on-call availability of a second carer to assist would be necessary.

111. Thus, in addition to the need to have a carer available during the day at periodic intervals to deal with the matters outlined in para 109, there would also be the need to have a carer on call to assist with unscheduled events such as those described in para. 110 above. It is therefore clear that, notwithstanding the views expressed by Prof. Delargy and Prof. Burke, the care of the ward could not be achieved wholly by one carer alone.

112. However, in the context of the need for a second carer to be available (as outlined above) the HSE has strongly made the case that this is a matter for the family. As noted above, the Head of Social Care stressed that it is the family's choice to try to maintain the ward at home. While the HSE is prepared to support the family, this is on the basis that the family will play an active part in the care of the ward. Under cross examination Prof. Delargy agreed that, if homecare is to be made available, it is a reasonable element of such a care package that there would be a greater hands-on care role involvement from the ward's family. In fact, there already is significant input from the family in the care of the ward. As outlined above, the family are fully trained to assist in a whole range of tasks. The ward's father has also undertaken twelve hour shifts himself from time to time. However, his evidence was that he could not physically be available to assist on a 24 hour basis.

113. It is important to keep in mind that the role envisaged by the HSE for the family is not that they would undertake twelve hour shifts when they would be present at all times by the side of the ward's bed. What is envisaged is that they would be available at periodic times during the day to assist in those tasks that require the involvement of two carers. Insofar as the night time hours are concerned, a member of the family would need to be on call in the event that the involvement of a second carer is required to assist with an unscheduled task which might potentially arise. While this cannot be guaranteed, there are likely to be some nights when the family member on duty will not be, in fact, be called upon.

114. I fully appreciate that the ward's father believes that two carers should be present at all times during the day and night. If this could be achieved at reasonable cost, it would obviously be the ideal solution. That is one of the factors that leads me to conclude that it is in everyone's interests for the HSE to fund the care plan proposed by the Committee (which could be done at less cost than the care of the ward at the Community Nursing Unit).

115. However, if it transpires that, contrary to my belief, the care has to be provided by a team procured by the HSE, the cost of engaging two carers will be significantly higher. In such circumstances, insisting on two carers being present all of the time for 365 days a year would make the cost of maintaining the ward at home significantly higher than the cost of maintaining her at the Community Nursing Unit. In that scenario, the cost of a second carer becomes highly material. In so far as the day time hours are concerned, all of the professional witnesses who gave evidence (including Prof. Delargy) accepted that one carer should be sufficient save for those tasks that require the involvement of two carers. With the exception of a change of the incontinence pad, those tasks requiring the involvement of more than one carer can be scheduled for particular times of the day. The additional carer from the family would therefore be required to attend at pre-set times during the day to assist in carrying out the scheduled tasks but a family member would also need to be on hand to be on call for any unscheduled requirements such as a change of the incontinence pad. A family member would also have to be on call at night.

116. With regard to the cost of a second carer, I wish to make it quite clear that the ward's father (who is utterly devoted to his

daughter) is genuinely convinced that two carers should be present at all times. Even while the ward was a patient in the Community Nursing Unit, the ward's father was present for very long periods during the day. This level of concern by a father for his daughter is, in many ways, both admirable and affecting. However, the medical evidence is to the effect that the ward is in a PVS state and, while one cannot rule out the possibility that she is capable of experiencing some level of pain and discomfort, there is no evidence to suggest that she has any level of appreciation for the extent of the care which is currently afforded to her. It is therefore, in my view, unnecessary that any member of the family be present at all times with the carer on duty. What is required is that a family member be present at those times when tasks requiring two carers are to be undertaken. In addition, there would also be a constant need for a family member to be present nearby to be on call to assist with any unscheduled events.

117. I fully appreciate the burden which this imposes on members of a family who have already shown great devotion and care for their daughter and sister. Nonetheless, wearing the hat of the objective reasonable and responsible parent (who would not take the approach that money is no object and would be conscious of the impact on others of the cost of care for the ward) I have come to the conclusion that, if it is not genuinely feasible for the HSE to proceed on the basis outlined in paras. 95 -105 above, it would be reasonable that the homecare package to be procured by the HSE should involve the active participation of the family in the care regime in place of an additional carer.

118. On the other hand, I am very conscious that it would be very gruelling for members of the family if they were required to be constantly available to participate in the care of the ward during the day and also to be on call (in the event that they are required) day and night on a seven day a week basis without any respite. With that in mind, I believe that the HSE should consider an adjustment to its proposed homecare package to provide some respite for the ward's family. It would be unwise, at this point, to be unduly prescriptive about the form of respite that should be available. It seems to me that this would involve careful consideration by the HSE. However, one could envisage, for example, that a second day time carer could be made available from time to time and that a second night time carer could be available every second week for eight hours during the night time period (in order to ensure that family members have some opportunity to have an unbroken sleep).

119. I fully appreciate that, in making this suggestion, there would be an additional cost for the HSE. However, as noted in para. 73 above, Prof. Burke (whose views have significantly influenced the approach taken by the HSE) appears to concede that it would be preferable to maintain the ward at home even where the financial cost of home maintenance might, to some extent, be greater than the cost of care in the Community Nursing Unit. The extent of this additional cost could be minimised in the event that the nursing hours envisaged by the HSE can be reduced over time. On an hourly basis, the rate for nursing care will be greater than the hourly rate for carers. While I appreciate that both of the witnesses who gave evidence on behalf of the HSE stressed the importance of the nursing role, I find it difficult to see that it will be necessary in the long term to have a nurse present for two hours every day. I can well understand why this might be necessary at the start of a wholly new care regime in order to ensure that the HSE can be satisfied that the level of care being provided by the new team of carers is appropriate and sufficient. However, once the HSE care regime is up and running, it is hard to see that it should be necessary to have the nurse attend every day. I am not persuaded by the evidence that daily attendance by a nurse is required. Thus, for example, insofar as it is suggested that the nurse would be involved in the daily care and hygiene of the ward, that task seems to me to be well capable of being undertaken by a carer. Equally, to the extent that it was suggested that the nurse would check the notes of the night time carer, that is a task that could be undertaken on a periodic basis and plainly does not require daily attendance.

120. It is, of course, important that there should be an appropriate level of oversight. This would involve the attendance of the nurse from time to time to check on the quality of care being provided. It would also involve appropriate reporting by the carers to the nurse. Once the care regime is in place, that seems to me to be a task that could be undertaken on a periodic basis rather than a daily basis.

121. Furthermore, all of the difficulties outlined in paras. 109-120 above could be avoided if the HSE was in a position to proceed on the basis suggested in paras. 95 -105 above. The great advantage of the approach outlined in paras. 95 -105 above is that it provides round the clock care for the ward by two carers at all times at a cost very close to the cost of the package proposed by the HSE involving only one carer present with a nurse available two hours per day.

Conclusion

122. For the reasons outlined above, I have come to the conclusion that it would be premature at this point to determine the legal issues that were debated at the hearing. I believe that it is important in the first instance that the parties should have an opportunity to consider the views expressed in this judgment which I have formed following a review of the evidence.

123. While I acknowledge the concerns of the HSE in relation to the care plan proposed by the Committee, I have sought in paras. 98 to 103 above, to address those concerns. I believe that appropriate safeguards and protections can be built into the Committee's care plan for the ward which, if necessary, can be incorporated into an order of the court. In my view, it makes sense to proceed in that way. By taking that course, it will make it possible to care for the ward at home at less cost than the alternative of residential care in the Community Nursing Unit. It will also avoid some of the obvious practical difficulties (outlined above) that will arise in the event that the HSE were to procure its own home care package.

124. If there are genuinely insuperable difficulties for the HSE to take the course suggested in para. 123, I am of the view that any care plan procured by the HSE requires adjustment to provide for an appropriate level of respite for the ward's family.

125. In these circumstances, I ask both parties to carefully consider the views expressed in this judgment. I hope that the views expressed by me (on the basis of the evidence) will assist the parties in resolving the issue. In the event that such a resolution cannot be achieved, I will rule on the legal issue as to whether the HSE can be compelled by court order to fund a care package for the ward to a level set by the court.

126. Accordingly, I propose to adjourn this matter for mention to a date early next term to give the parties an opportunity to consider this judgment and to reflect on the views expressed by me.