IN THE HIGH COURT OF JUSTICE **FD17P00103**

FAMILY DIVISION

IN THE MATTER OF THE INHERENT JURISDICTION OF THE HIGH COURT

AND IN THE MATTER OF CHARLES GARD (DOB 04/08/2016)

B E T W E E N:

GREAT ORMOND STREET HOSPITAL FOR CHILDREN NHS FOUNDATION TRUST

Applicant

and

CONSTANCE YATES (1)

CHRIS GARD (2)

CHARLES GARD (3)
(a Child by his Guardian)

Respondents

GOSH'S POSITION STATEMENT
HEARING ON 25 JULY 2017

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1. Following yesterday's hearing, there remains the most delicate and difficult task of finalising an end of life care plan. A carefully formulated draft plan has been sent to the parents for their possible consideration and discussed with them by specialists. Here, as throughout the case, there remain two aspects to be balanced: Charlie's best interests and his parents' needs. The care plan must be safe, it must spare Charlie all pain and it must protect his dignity. At the same time, the plan must honour his parents' wishes about two matters in particular namely the time and place of his passing.

2. GOSH received notification of the parents' decision on Saturday and immediately offered mediation via a mediator. That offer of mediation has been reiterated several times since, a mediator has been identified and a mediation agreement sent. The offer has not been accepted and the discussions that have taken place yesterday and today between lawyers have, at the parents' request, been between solicitors for the parents and the hospital with no direct contact between the hospital and the parents. Today, palliative care consultants at the hospital have had a lengthy, difficult and (sadly but understandably in the dreadful circumstances) unconstructive meeting with the parents. There remains no agreed plan.

3. Charlie's parents want him to be with them and ventilated at home for several days before receiving palliative care. Above all, GOSH wants to fulfil that last wish and has considered it very carefully. The key obstacle, and one which the hospital cannot see a way around, is the reality of the invasive ventilation that Charlie requires.

4. So far as GOSH is aware, invasive ventilation is only provided in a hospital setting. It requires air to be forced into the lungs. For reasons that are obvious, that process and the correct, safe positioning of the tube have to be monitored by an ITU trained nurse at all times, with an ITU doctor on call and close at hand. Those resources cannot be provided by GOSH to Charlie at his parents' home. GOSH is aware that there are other practical problems one being that the ventilator does not fit through the front door. There are then stairs to negotiate and corners to turn. The physical lay-out of the route between the ambulance on the pavement and their home would require Charlie to be taken off the ventilator and provided with only "hand-bagging" until he was inside.

5. Charlie is a child who requires highly specialised treatment. His care cannot be simplified. It must be provided in a specialist setting by specialists. It is in Charlie's best interests, and everybody's, that the risk of a precipitate, distressing or disordered death is removed so that he may be assured of a peaceful and dignified passing. Yesterday, the hospital consulted the Director of Specialised Commissioning NHSE London who stated that it would not be possible to transfer Charlie whilst invasively ventilated for end of life care at home.

6. No specific or practical suggestions about private transport or nursing/medical care have been forthcoming from the parents' team.

7. Charlie's parents do not wish him to pass away at the hospital. Despite enormous efforts (these included enquiries through the Children's Hospital Alliance which comprises all dedicated children's hospitals nationally as well as large paediatric units) GOSH has been unable to find any other hospital, whether in the NHS or the private sector, prepared to accept Charlie for end of life care.

8. The other possibility is a hospice. After very many enquiries by the paediatric palliative care team, GOSH has found an excellent hospice willing to assist that would afford Charlie and his parents the space and privacy necessary to protect them all. A special area would be made available to them with the option for friends and family to visit. It would offer the opportunity to create memories and, perhaps, to begin a time of healing. Specialist support for the parents and the wider family might start there.

9. Because of the nature of some of GOSH's patients, its palliative care team is highly experienced and regarded and members of the team have cared for many parents who have made the same impossible decision as Charlie's have made so recently. A hospice plan brings with it considerations of time, since hospices in the UK lack the resources and trained staff to provide invasive ventilation for more than a period of hours and because they are not licensed or insured to deliver intensive care. Further, the expectation would be that extubation in a hospice would be under the care of the transfer team. Despite that, the wisdom accumulated by the team suggests that there are many advantages to hospice care for patients, parents and wider family alike.

10. In all the uniquely difficult circumstances of this case, the Court is asked to approve the hospice care plan for as long as that is on offer and, in the profoundly unwished for eventuality that the current offer is withdrawn, for end of life care to be provided at the hospital.

KATIE GOLLOP QC

25 July 2017

Serjeants' Inn Chambers