Northern Lincolnshire and Goole Hospitals NHS
NHS Foundation Trust

Directorate of Diagnostics & Therapeutics

POLICY FOR THE MANAGEMENT OF PERSONS REFUSING BLOOD & BLOOD PRODUCTS

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Contents

1.0 Introduction / Purpose

1.1 The administration of blood and blood products requires consent from the patient. Administration without valid consent may be considered to be an assault on the patient and could lead to criminal charges and/or proceedings for a civil claim against the persons involved and/or the Trust. The majority of patients will accept blood and blood products if their use is necessary as part of their treatment and the clinical reasons are fully explained.

1.2 However there are some people who may refuse blood products on the grounds of religious or personal beliefs. All members of the multidisciplinary health care team must respect the wishes of individual patients and it is imperative that the individual's wishes in respect of specific medical treatments are determined as soon as possible in order that a plan of management may be formulated.

1.3 This policy aims to ensure the wishes of patients with regard to the transfusion of blood and blood products, (especially those of a Jehovah's Witness faith), are acknowledged and respected. However it should be remembered that the refusal of blood products is not just limited to Jehovah's Witness patients and as transfusion transmitted infections such as HIV/vCJD are highlighted by the media, other patients may also refuse blood products. This policy aims to provide information regarding the management of all such patients.

1.4 This policy takes into account the provisions of the Mental Capacity Act 2005 ('the MCA 2005') which came into force in 2007, and the accompanying Code of Practice, and should also be considered alongside other relevant Trust policies, including the Policy for Consent to Examination or Treatment, and the Policy for Advance Decisions (Living Wills).

2.0 Area

2.1 This policy is to apply Trust wide across all Trust premises.

2.2 This policy will apply to patients who are under the care of the Trust. The policy distinguishes between adult patients (aged 18 years and over), 16 and 17 year olds and children under the age of 16 as the legal issues vary depending on which category the patient falls into.

3.0 Duties

3.1 This policy applies to all staff employed by or seconded to the Trust, including:

- Medical Staff
- Registered Nurses/Midwives
- Operating Department Practitioners
- Pharmacy
- Blood Transfusion laboratory

3.2 The duties are detailed in the subsequent sections of the policy.

4.0 Background information

Jehovah's Witnesses are a well-informed group of people, and have often made decisions regarding treatment in advance. Those baptized in to the faith will carry an "Advance Decision Document" which directs that blood transfusions should not be given under any circumstances. They are also encouraged to take this one step further, and ensure they clarify their own personal choices regarding fractions, transplants and autologous products, using the Advance Decision document. Jehovah's Witnesses are encouraged to update these advance directives yearly. This ensures that if the person's beliefs change, the advance decision reflects their current beliefs.

N.B. For the purposes of this document, where the wording 'Advance Decision Document' is used, this should also be taken to mean Living Will, Advance Directive, or Advance Statement. Good practice is now to refer to all advance statements to refuse treatment as 'Advance Decisions Documents' in line with the terminology of the Mental Capacity Act 2005.

5.0 Actions

5.1 Initial contact

5.1.1 Patients who refuse blood or blood products should be identified on initial assessment and documentation of this should be made in their health care records. At this initial assessment it should be established whether the patient fully understands the potential implications of their refusal of blood products, the circumstances in which they would refuse blood/blood products, and whether this refusal extends to emergency and/or life-saving treatment. All discussions should be fully documented in the healthcare record.

5.1.2 If there is any doubt as to the patient's capacity, then an assessment of capacity should be undertaken and documented in the healthcare record.

5.1.3 It should be possible, after the initial consultation, to determine which category the patient falls into, i.e.:

- Adult with capacity
- Adult without capacity but with valid Advance Decision
- Adult without capacity or valid Advance Decision
- Young person (16 or 17 year old) with capacity
- Young person without capacity
- Child (aged 15 and below) with capacity
- Child without capacity

5.1.4 It should also be possible to identify those third parties who will have a role in the decision making process including those with PR, Attorney's appointed under a LPA and Court Appointed Deputies. Thereafter the clinical team will be able to identify which decision making process to follow as set out in this policy.

5.1.5 The Hospital Transfusion Team should be contacted as soon as possible following initial contact with the patient. The patient's details and proposed treatment should be disclosed.

5.1.6 Adult Jehovah's Witness patients (aged 18 years and over) will carry an Advance Decision Document indicating their refusal to accept blood transfusion. This could also indicate which other blood or fractionated products or procedures such as cell salvage they may be willing to accept or refuse, and a copy of this directive should be placed in the patient's health care records.

5.1.7 It is essential to establish the views held by individuals as certain forms of blood salvage techniques and use of fractionated and clotting factors are acceptable to some but not others. Documentation of this discussion should be made in the patient's health care record and the treating healthcare team made aware.

5.1.8 If the patient's refusal to have a blood transfusion conflicts with the clinician's medical and ethical responsibility to save life then the clinician has the right to refer the patient to another clinician who is willing to accept these limitations in the patient's management but must ensure that the patient's care is in no way compromised.

5.1.9 The Hospital Liaison Committee (HLC) for Jehovah's Witnesses may be contacted for advice via the hospital switchboard (or see Section 7.5). Staff should not divulge any information to the HLC without the prior consent of the individual.

5.2 Jehovah's Witnesses with parental responsibility for children

5.2.1 If a child/young person is assessed as being 'Gillick competent' they will be competent to give consent to medical treatment. However, even if a child/young person is assessed as being Gillick competent, a refusal to consent to treatment can be overridden by a person with Parental Responsibility who is acting in their best interests. This power to override the competent child's wishes should be treated with caution and advice should be sought in all cases before preferring the wishes of the parents over those of the competent child.

5.2.2 Parents should be kept informed of all intended action by medical practitioners and given the opportunity to discuss their views on the use of alternatives to transfusion.

5.2.3 The care and well-being of the child is the paramount concern. Whilst the parents' wishes must be taken into consideration, if after parental consultation, blood is refused, which is considered by healthcare professionals to be in the best interests of the child, and the consequences of a refusal are potentially very serious then the Trust may need to make an application to the court for a declaration as to what is lawful

5.2.4 If it is thought to be in the best interests of the child to transfuse blood products, then before preceding down the line of obtaining a court order it is useful to:

- Ensure the Hospital Liaison Committee have been approached for advice
- Ensure all non-blood medical management options have been explored
- Consider the risks of giving the blood products
- Explore if there is another hospital that could treat the patient without blood products

5.2.5 If having weighed up all the advantages and disadvantages, transfusion is still essential, it may be necessary to seek a Court order. It should be noted that Court Orders can be obtained at short notice, whether during 'office hours' or out of hours (including weekends and bank holidays). Ideally the decision to seek a Court order should be supported by two consultants who are fully informed of the situation and are aware of the alternative forms of treatment; again ideally this should include the Medical Director of the Trust. The parents need to be informed of the plan, and involved in any meetings or hearings, which will affect the outcome. In exceptional emergency life threatening circumstances there may not be enough time to apply to the court. If is felt that a delay in the administration of blood may be fatal, a decision to treat can be made against the parent's wishes. Two Consultants who are fully informed of the situation and are aware of the alternative forms of treatment must make this decision. These consultants must accept accountability for their decision.

N.B. this situation should very rarely happen in practice as it should be possible to anticipate these situations and plan for them accordingly. It must be remembered that if necessary, a Court order can be obtained at very short notice (i.e. within an hour).

5.2.6 For further information on when/how to seek a court declaration please refer to Annex D of the Trust's Policy for the Consent to Examination or Treatment.

5.3 Practical Issues applicable to all cases

5.3.1 Patients who require surgery and refuse blood products should complete the "Refusal for blood transfusion" section of consent form 1 (WQN943), witnessed by the doctor and another witness.

5.3.2 The quality of written records is vital at all times and particularly if legal proceedings follow. An accurate account of the patient's management and decisions to treat (including all discussions with the patient and their family if appropriate) must be fully documented within the patient's healthcare record.

6.0 Management of Surgical patients refusing blood products

6.1 Elective pre-operative preparation

6.1.1 The transfusion team should be informed about the patient at the earliest possible opportunity preferably when a patient is placed on the waiting list for an operation, or at pre-assessment. Any other specialists likely to be involved in the patient's care (e.g. haematologists, anaesthetists) should also be informed of the patient as soon as possible and well in advance of the date of planned surgery (see para 6.2.7 and 6.2.8 below).

6.1.2 A copy of the Advance Decision should be obtained from the patient to clarify what is or is not acceptable to them. Operative treatment patients who refuse blood products should complete the "Refusal for blood transfusion" section consent form 1 (WQN943) witnessed by the doctor and another witness. If the surgeon is not willing to perform 'no blood' surgery, a referral should be made as soon as possible to a surgical team willing to undertake the patient's care.

6.1.3 Optimisation of the patient's general condition prior to surgery is paramount. Preparation of the patient should wherever possible be commenced immediately following initial contact and proposed dates for surgery planned to enable effective preparation of the patient.

6.1.4 The patient's haemoglobin should be checked and the result reviewed as soon as possible following initial patient contact.

6.1.5 In addition to the above, blood samples should be taken for serum ferritin, serum folate, serum vitamin B12 and a clotting screen performed. All blood sampling should be kept to the minimum necessary that will still allow close monitoring of the patient's haematological status.

6.1.6 Unless contra-indicated, oral iron therapy should be commenced to maximise the patient's iron stores. Concomitant administration of ascorbic acid and oral iron may enhance absorption from the gastrointestinal tract.

6.1.7 The patient should receive advice on their dietary intake. This may necessitate referral to a Dietician.

6.1.8 The Consultant haematologist should be contacted about the considering use of parenteral iron and erythropoeitin for patients who fail to respond to oral therapy and in patients whose haemoglobin is required to be increased rapidly.

6.1.9 Ascertain the patient's medical and drug history, and identify medications that may adversely affect haemostasis such as aspirin, non-steroidal anti-inflammatory agents and platelet aggregation inhibitors and wherever possible, and if clinically appropriate, discontinue their use prior to surgery.

6.1.10 Patients who refuse transfusion of blood and/or blood products should wear a hospital identity bracelet indicating this whilst an inpatient.

6.1.11 If cell salvage is acceptable, and appropriate, arrangements should be made to ensure that a machine and the relevant equipment is available with a fully trained operator, for the planned date of surgery.

6.2 Peri-operative preparation

6.2.1 All members of the multidisciplinary care team should be notified regarding the patient's decision on the refusal of blood and blood products along with their acceptance of specific techniques and products, which may assist in establishing homeostasis.

6.2.2 Patient positioning can influence the amount of pressure and subsequent blood loss from the operative area.

6.2.3 Maintain normothermia of the patient by employing the use of forced air warming, fluid warmers and heated mattresses.

6.2.4 Maximise tissue oxygen delivery by maintaining:

- Intravascular volume – note Hetastarch may adversely affect coagulation
- Cardiovascular support
- Ventilation and oxygenation – note Nitrous oxide and hypercapnia may increase the risk of bleeding

6.2.5 Minimise oxygen consumption by the use of:

- Adequate and appropriate analgesia
- Sedation
- Mechanical ventilation
- Techniques to maintain or restore normothermia

6.2.6 Employ surgical techniques which help prevent blood loss:

- Use of minimally invasive techniques if possible
- Use of electrocautery, laser or ultrasonic dissection to minimise blood loss
- Use of local infiltration
- Extra vigilance and lower tolerance for bleeding during procedure
- Staged surgery for complex procedures

6.2.7 Point of care monitoring may be useful where available (but only if the equipment has been fully approved via the POCT testing committee), however this should only be used as a guide and a laboratory tested sample is preferred.

6.2.8 Estimate and document blood loss from operative procedure.

6.3 Postoperative management

The key to effective management is vigilance.

- Observe patient closely for any signs of bleeding and employ early intervention as necessary
- Maintain strict fluid balance
- Consider intensive therapy/high dependency care if close observation is required
- Maintain oxygenation
- Restrict phlebotomy to prevent iatrogenic blood loss
- Continue iron therapy and stimulation of red cell production if required. It is recommended that iron therapy be maintained for a minimum of three months from restoration of normal haemoglobin values
- Avoid and promptly treat infections to reduce secondary postoperative haemorrhage
- Ensure prompt consultation with specialists experienced in non-blood management if complications arise
- Consider transferring a stabilised patient, to a major centre before the patient's condition deteriorates

6.4 Surgical Emergencies

6.4.1 If possible, discussion should take place with the patient (and their family if appropriate) pre-operatively to discuss the nature of their wishes and beliefs, and to ascertain what blood products (if any) they would be willing to accept in an emergency/to save life.

6.4.2 If the person has capacity and refuses blood / blood products, this decision must be respected. If the person lacks capacity (whether temporary or permanent), has no valid and applicable Advance Decision Document and there is no substitute decision maker with the requisite authority to consent to or refuse consent to the proposed treatment (either an attorney appointed under a personal welfare LPA or a Court Appointed Deputy), then the healthcare staff must treat the person in what is assessed as being their best interests, having consulted with the relevant persons under the MCA.

N.B. a court deputy does not have the authority to consent to or refuse consent to life saving treatment, even in an emergency.

6.4.3 If the individual's views are not known and cannot reasonably be ascertained, then a life-saving transfusion should be provided pending further investigations. If the knowledge of the healthcare staff in relation to the individual's wishes changes at any time (e.g. a valid and applicable Advance Decision comes to light), then the situation must be immediately re-assessed and treatment may need to be stopped.

6.5 Use of haemostatic agents

6.5.1 Some of these haemostatic agents may be used prophylactically to prevent bleeding whilst others may be used to manage haemorrhage. Please refer to contraindications for use. Systemic agents such as tranexamic acid may be used for both prophylactic management and treatment of haemorrhage. Consider using a combination of haemostatic methods such as tourniquet and tranexamic acid (which is unlicensed in this capacity) in knee replacement surgery.

6.5.2 Topical haemostatic agents:

- Collagen haemostat
- Oxidised cellulose
- Gelatine foam or sponges
- Tissue adhesives
- Local infiltration of tissues with adrenaline, Argipressin etc
- Packing of cavities e.g. uterine, abdominal and pelvic

6.5.3 Systemic haemostatic agents:

- Phytomenadione
- Tranexamic acid
- Desmopressin
- Recombinant Factor V11a (should only be used following consultation with the On Call Haematologist)

7.0 Management of Obstetric patients refusing blood products

7.1 Antenatal:

- Give iron and folic acid supplements
- Document patient's wishes in the patient health records
- A special consent form is available for operative treatment on patients who refuse to have blood products; this should be completed by the patient, doctor and a witness in the Pregnancy Assessment Centre/Antenatal clinics

N.B. Jehovah's Witnesses believe that life begins at conception and so do not agree with termination of pregnancy. If a termination is the only way of saving the mother's life and the mother has capacity, it will be up to the mother as to whether she consents or refuses consent to the termination.

N.B. However, once the baby is born, it has a separate legal identity to that of the mother, and there is a duty to treat the baby in what is assessed as being its best interests, taking in to the mother's wishes. If for example the baby requires a blood transfusion at birth, healthcare professionals must act in the baby's best interests. Such a situation will be the same as any situation where the views of the parent(s) differs from that of the clinical team about what treatment would be in the best interests of the child and a Court application is likely to be needed.

7.2 Labour

7.2.1 List:

- Inform Consultant Obstetrician, Anaesthetist and Haematologist, and if necessary the neonatal unit and paediatrician
- Have a low threshold for intervention
- Use Crystalloid solutions
- Consider Phytomenadione
- If the patient maintains her refusal to accept blood or blood products, and has capacity, her wishes must be respected
- Timely hysterectomy may save the patient's life
- Clamp uterine arteries early in procedure
- Sub-total as effective as total hysterectomy
- Consider transfer to intensive care unit after acute episode
- If in spite of all care, the woman dies, her relatives require support like any other bereaved family

7.2.2 If after employing all transfusion alternatives the woman dies, support should be promptly available for staff in these circumstances.

7.2.3 If the patient is under 16 years of age, it will be necessary to follow the legal guidelines for children (see section 5.2 above).

7.2.4 In the event that legal advice/intervention is required, during office hours, the Assistant Director - Risk Management, or in her absence the Complaints & Legal Services Manager should be contacted in the first instance, who will in turn seek advice from the Trust's Solicitors. Out of hours, the treating Consultant can seek legal advice via the Site/On-call Manager or directly.

7.3 Postpartum Haemorrhage

7.3.1 If a patient has any of the risk factors below, an infusion of oxytocin (Syntocin) should be considered after the delivery of the baby:

- Previous history of bleeding or postpartum haemorrhage
- Prolonged labour (especially when augmented with oxytocin)
- Abnormal placentation
- Large baby (>4.5kg) and or polyhydramnios
- Increased maternal age (>40 years)
- Fibroids/myomectomy scars
- Multiparity
- Maternal obesity
- Multiple pregnancy

7.3.2 Management of Postpartum haemorrhage – Keep patient fully informed:

- Consult with relevant specialists - Obstetrics, Anaesthetics, Haematology
- Establish IV colloid infusion
- Give oxytocic drugs, and exclude retained products of conception or trauma
- Proceed with bimanual uterine compression
- Give oxygen
- Catheterise and monitor urine output
- Consider CVP line
- Aortic compression against the spine using a fist just above the umbilicus
- Anticipate coagulation problems
- Proceed with following strategies (see Jehovah Witness guidelines):
  - Ergometrine with Oxytocin, unless patient is hypertensive, then use oxytocin alone
  - Carboprost (Hemabate) can repeated after 15 minutes
  - Oral misoprostol or rectal misoprostol
  - Recombinant factor VIIa (Novoseven- see separate guidelines for this unlicensed use)
  - Tranexamic acid
  - Consider Phytomenadione

- Interuterine balloon tamponade
- B-Lynch brace suture
- Interventional radiotherapy for embolisation (litigation of iliac arteries or bilateral ligation of uterine vessels as a last resort)
- Cell salvage
- Hysterectomy

7.3.3 Management of Postpartum Anaemia:

- Consider recombinant human erythropoietin with Iron to accelerate haemoglobin recovery
- Consider elective ventilation in ICU
- Use microsampling techniques to prevent unnecessary blood loss
- Hyperbaric oxygen therapy is an option in life threatening anaemia

8.0 Management of Medical patients refusing blood products

8.1 Since the presentation of medical patients can be so varied, the management of medical patients refusing blood products will be dependent of the symptoms and diagnosis of each medical problem.

8.2 Doctors should be aware that all patients have a right to treatment, and in some cases, if patient refuse blood products this can pose challenging situations. All doctors are advised to contact the Consultant Haematologist at the earliest opportunity to clarify what treatments may be available for each individual patient dependent on their individual problems and requirements.

9.0 Additional information – Jehovah's Witness position on Medical treatment:

- Will accept all kinds of medical treatment except blood
- Are not exercising a right to die
- Are keen to co-operate with medical professionals
- Do not stop others having blood
- Respect individual Jehovah's witnesses' decisions of blood fractions etc

9.1 What Jehovah's Witnesses will not accept:

- Transfusion of Whole blood
- Packed red cells
- Plasma
- Platelets or other major blood components
- White cells

9.2 What Jehovah's Witnesses will accept:

- Crystalloid:
  - Normal Saline
  - Hartmann's solution
  - 1.8% Hypertonic Saline
- Colloids:
  - Voluplex
  - Voluven
- Haemostatic Agents:
  - Oxycell
  - Kalostat
  - Tranexamic acid
  - Vitamin K
- Therapeutic agents:
  - Folic Acid
  - Vitamin B12 (Hydroxocobalamin)
  - Ferrous Sulphate
  - Iron Sucrose (Venofer)
- Erythropoetin

9.3 Matters of personal choice:

- Vaccines containing albumin or immunoglobulins
- Immunoglobulins
- Use of plasma derivatives
- Dialysis
- Intra-operative cell salvage
- Haemodilution
- Organ transplant

9.4 The role of the Hospital Liaison Committee (HLC)

9.4.1 HLC's were formed by the governing body of Jehovah's Witnesses to clarify their specific medical requirements. The role of this Committee is to assist in avoiding confrontation between doctors and patients, providing advice and assistance to both parties. They have an extensive worldwide network of professional opinion and up to date research at their disposal.

9.4.2 The Hospital Liaison Committee can:

- Provide medical articles and information about the latest developments in both bloodless surgery, and medical management
- Provide a contact list of consultants and physicians willing to work with Jehovah witnesses without the use of blood products
- Liaise between clinicians in order to share the benefit of experience and good practice
- Act as a resource for information regarding the beliefs and practices of Jehovah witnesses:

Alan Stark	Trevor Dew	Gary Holmes	Philip Thomas
Tel. 01482 842312 Mob. 07703 581415	01482 562168 Mob. 07870 301616	01482 858371 Mob. 07931 288243	01482 472064 Mob. 07905 434922

N.B. Staff should not give information to the HLC about individual patients without obtaining the patient's prior consent to disclosure.

10.0 Legal and Consent Issues

10.1 Capacity

10.1.1 Capacity – this refers to the ability of a patient to make a particular decision for them. If those treating a patient have any doubt about the patient's capacity, this should be investigated further and if necessary a formal capacity assessment carried out. For further information on assessing capacity, please see the 'Definitions' section of this Policy, the Trust's Policy for Consent to Examination or Treatment, and Chapter 4 of the MCA Code of Practice.

10.1.2 Please see below for issues of capacity in relation to adults (aged 18 years and over), young persons aged 16 and 17 years, and children under the age of 16 years.

10.2 Adults

An adult of 18 years and over is always presumed to have capacity unless proven otherwise.

10.2.1 Adults with capacity

An adult with capacity can consent to or refuse any medical treatment or intervention, however irrational their decision may seem to others.

10.2.2 Adults lacking capacity:

- If an adult is assessed as lacking capacity to give or withhold consent to medical treatment, healthcare professionals must ensure that they take all reasonably practicable steps to ascertain if there is a valid and applicable Advance Decision Document in existence. An Advance Decision Document enables someone aged 18 and over, while still capable, to refuse specified medical treatment for a time in the future when they may lack the capacity to consent to or refuse that treatment. If there is any doubt as to the validity and/or applicability of the Advance Decision, legal advice should be sought, and it may be necessary to make an application to the Court for a declaration as to what is lawful. If a Court application is to be made then a person may provide life sustaining treatment or perform an act which the person reasonably believes will prevent a serious deterioration in the patient's condition whilst guidance is sought form the court or until any dispute is resolved. Please contact the Trust Risk Management team for further information and/or advice

- If there is no valid or applicable Advance Decision Document healthcare professionals should ascertain whether there is a substitute decision maker authorised to make healthcare decisions on behalf of the patient in these circumstances. This will either be an Attorney appointed by the patient under a registered Lasting Power of Attorney (LPA), or a Deputy appointed by the Court. In both situations, the Attorney or Deputy will only be able to make healthcare decisions if specifically authorised to do so and must always act in the person's best interests. Providing that the necessary legal formalities are complied with (see Definitions section) a person may authorise an Attorney appointed under a personal welfare LPA to make decisions regarding life sustaining treatment. However, a Deputy will never have this power as part of their authority

- If healthcare professionals are satisfied that there is no valid and applicable Advance Decision Document in existence, and no Attorney appointed under an LPA by the patient or Court Appointed Deputy with the requisite authority, then treatment may be given if assessed as being in the person's best interests

- 'Best interests' is not defined in the MCA, but it is clear that the 'decision maker' must take into account more than just the best medical interests of the patient lacking capacity. Section 4 of the MCA contains a checklist of common factors which must always be considered by the decision maker when assessing best interests. Further information on best interests can be found in Chapter 5 of the Code of Practice, the Definitions section of this policy, and the Trust's policy on Consent to Examination or Treatment

- If a decision is to be taken in the patient's best interests, the 'decision maker' will have a duty to consult with all relevant persons as provided for in the MCA 2005 (see 'Definitions' section of this policy and Chapter 5 of the MCA Code of Practice for further information). If there is no-one to consult with other than paid or professional carers, **AND** if the decision concerns 'serious medical treatment', then an Independent Mental Capacity Advocate (IMCA) must be appointed as an advocate to represent the person and support them in their best interests. For further information on what constitutes 'serious medical treatment' and on IMCAs please refer to the 'Definitions' Section of this Policy and Chapter 10 of the MCA Code of Practice

10.3 Children

10.3.1 Parental Responsibility

This term refers to all the rights, duties, powers, responsibilities and authority which, by law, a parent has in relation to a child. People with parental responsibility (PR) include:

- the mother;

- the father if he was married to the child's mother at the time of the child's birth (even if the parents have since separated or divorced);

- the father if he was not married to the child's mother when the child was born but:

  – the parents jointly register or re-register the birth together and put the father's name on the birth certificate. **N.B. this provision will ONLY apply to registrations from 1/12/2003, and is not retrospective**

  – he now has a Residence Order in respect of the child

  – he now has a Court Order which gives him parental responsibility

  – he now has a formal 'Parental Responsibility Agreement' with the mother – this is only valid if it is in the prescribed form as required by the Court

  – he has since married the mother

- a guardian of the child appointed either by the court or appointed by a parent with PR or another guardian (but only takes effect after the parent's death)
- someone who holds a Residence Order
- a Local Authority which has a care order (**N.B.** if the child is placed in care voluntarily, parental responsibility remains with the mother/parents/guardian)
- someone who holds an emergency protection order
- any man or woman who has adopted the child. (Step-parents and/or civil partners do not have automatic parental responsibility – this must be gained by court order or adoption, or by entering into a formal Parental Responsibility Agreement with the parent(s))
- anyone granted a Special Guardianship Order by the court has parental responsibility whilst it is in force

10.3.2 Young persons aged 16 and 17 years of age:

- A young person (16-17 years of age) is presumed to have capacity in law to consent to medical procedures/interventions. If they have capacity, they can sign the consent form themselves, and their decision to consent to medical treatment cannot be overridden by a person with PR. It is however still best practice to try and encourage a competent young person to involve their parents/those with PR in their decision making, unless the healthcare professional believes it is not in their best interests to do so
- If a young person of 16-17 years of age with capacity refuses to give consent to a life-saving medical treatment/procedure, their refusal can legally be overridden by those with PR who are acting in their best interests. However, if this situation arises, healthcare professionals should seek immediate legal advice from Risk Management as there will be potential human rights issues in overriding a young person's valid refusal of treatment, as well implications for the family relationship, and it may prove necessary to make an application to the court for an order specifying the treatment which can lawfully be provided. For more detailed information on when/how to seek a court declaration, please refer to Appendix D of the Trust's Policy for Consent to Examination or Treatment
- In some circumstances the young person may not be able to make the specific healthcare decision at the time it needs to be made, and their capacity should be assessed using the 2 stage test laid down in the MCA 2005 (see the Definitions section of this Policy). If the young person is assessed as lacking the capacity to consent they will be treated in the same way as an adult, and the decision maker will have a duty to act in the young person's best interests, having consulted with all the relevant persons. It is important to note that a person under 18 years cannot make a legally binding LPA or Advance Decision. If the young person is assessed as lacking capacity, then under common law provisions a person with PR can consent on their behalf if acting in the young person's best interests

- In certain circumstances it may be necessary to seek the guidance of the Court and a declaration as to what treatment can lawfully be provided. Such circumstances may arise in the cases of young persons if:

  - The competent patient refuses to consent to treatment and the consequences are potentially serious. Practically, whether the parents would be prepared to consent or not in these situations is unlikely to remove the need to seek the guidance of the Court

  - The patient lacks the capacity to consent and there is a dispute between the clinical team and the parents about what treatment is in the best interests of the young person. Where the parents refuse to consent on the patient's behalf and the consequences for the patient are potentially serious it may be necessary to approach the Court

10.3.3 Children under the age of 16 years:

- Children under 16 years of age are not automatically presumed in law to have capacity to make decisions regarding their healthcare and medical treatment. However, if a child is assessed as having 'sufficient understanding and intelligence to enable him or her to understand fully what is proposed' (i.e. is Gillick competent), they will be competent to give consent to medical treatment. There is no specific age when a child becomes competent to consent to treatment and it will depend on the individual circumstances of the case. For further information on assessing Gillick competence, please refer to the 'Definitions' section of this Policy, and the Trust's Policy for Consent to Examination or Treatment

- Even if a child is assessed as being Gillick competent, their refusal to consent to life saving treatment can be overridden by those with PR who are acting in their best interests. Should such a situation arise where those with PR wish to override the refusal of treatment of a Gillick competent child, healthcare professionals should immediately seek legal advice from Risk Management as it may be necessary to seek a Court declaration as to what is lawful (see above)

- The treatment of a child who lacks capacity will be lawful if carried out pursuant to the consent of someone with PR. If the parents will not consent to the treatment, but it is considered by healthcare professionals to be in the child's best interests, and the consequences of a refusal of treatment are potentially very serious, it may be necessary to make an application to the court for a declaration as to what is lawful (for more detailed information on when/how to seek a court declaration, please refer to Appendix D of the Trust's Policy for Consent to Examination or Treatment)

10.4 Confidentiality & Disclosure to Third Parties

10.4.1 Patient confidentiality must be respected at all times, and balanced with the desire for the support of the patients. It is therefore of paramount importance that a Jehovah's Witness patient is asked in private as to what, if any, information may be disclosed to their family/friends and Jehovah Witness Liaison.

10.4.2 Any request from a Gillick competent child/young person for confidentiality must be respected by healthcare professionals, unless such disclosure can be justified on the grounds there is reasonable cause to suspect the child is suffering/is likely to suffer, significant harm, and the disclosure is necessary and proportionate to avoid this harm.

10.4.3 Advice may be sort from the safeguarding team in relation to any matter whereby the professional believes a child/young person may be at risk of harm.

10.4.4 Under the Mental Capacity Act 2005 an Attorney under an LPA or a Court Appointed Deputy may be authorised to consent to or refuse medical treatment where a patient is unable to make the decision for them, and they will require necessary information to make the decision.

10.4.5 If the healthcare professional is making a decision in the patient's best interests then they have a duty to consult person(s) engaged in the care/interested in the welfare of the patient, and this will require the sharing of necessary information. Chapter 16 of the Code of Practice to the Mental Capacity Act 2005 provides guidance to professionals on the sharing of information.

11.0 Useful telephone numbers

11.1 Assistant Director - Risk Management (ext. 7603 – DPOWH or ext. 2941 – SGH).

11.2 Complaints & Legal Services Manager (ext. 2333).

11.3 Safeguarding team (ext. 7821 – DPOW or ext. 5443 – SGH).

12.0 Monitoring Compliance and Effectiveness

12.1 As soon as any patients who refuse blood products presents to the Trust for treatment, section 5.1.2 of this policy states the Transfusion team should be made aware. The Consultant haematologist responsible for the patient (site specific or on call) will advise the referring team of any appropriate treatment. This action plan will include monitoring and additional advice as necessary.

12.2 Following the treatment of all patients who refuse blood products, the transfusion team will discuss and review the action plan, assessing the effectiveness, and making comparisons with the policy. Any changes to the policy will be made as appropriate and communicated to all Trust staff.

13.0 Associated Documents

13.1 Patient Agreement to Investigation or Treatment (Consent form 1).

13.2 NLAG Policy for Consent to Examination or Treatment.

13.3 NLAG Policy for Advance Decisions (Living Wills).

13.4 Procedure for the administration of blood and blood components & clinical guidelines for the management of Transfusion reactions 2006.

14.0 References

14.1 Mental Capacity Act 2005.

14.2 Mental Capacity Act Code of Practice.

14.3 NLAG Policy on consent.

14.4 NLAG Policy for Advance Decisions (Living Wills).

14.5 Management of anaesthesia for Jehovah's Witnesses; 2nd Edition 2005.

14.6 Association of Anaesthetists of Great Britain and Ireland.

14.7 Code of Practice for the Surgical Management of Jehovah's Witnesses 2002.

14.8 Clinical strategies for managing haemorrhage and anaemia without blood transfusions; 2003, Hospital Information Services.

14.9 Video – Transfusion Alternative Strategies -Simple, Safe, Effective.

14.10 Hospital Information Services.

14.11 Clinical strategies for managing haemorrhage and anaemia without blood transfusion in information services obstetrics and gynaecology; 2004, Hospital Information Services.

14.12 Care plan for women in labour refusing a blood transfusion; 2010, Hospital Information Services.

15.0 Definitions

15.1 Advance Decision (also known as Advance Directive/Living Will)

15.1.1 This is a decision made by a person after he has reached the age of 18 years and when he has capacity to do so, that if:

- At a later time and in such circumstances as he may specify, a specified treatment is proposed to be carried out or continued by a person providing healthcare for him; and
- At that time he lacks capacity to consent to the carrying out or continuation of the treatment

15.1.2 The specified treatment is not to be carried out or continued.

15.1.3 An AD can be withdrawn at any time, and generally may be oral or written.

15.1.4 If the AD relates to the refusal of life-sustaining treatment then in order to be valid it **must** be:

- in writing
- signed by the patient or someone else at their direction
- signed by person who has witnessed the signature and
- specifically state that it is to apply 'even if life is at risk'

15.1.5 For further information on Advance Decisions, please refer to the Trust's policy for Advance Decisions (Living Wills), and Chapter 9 of the MCA 2005 Code of Practice.

15.2 Best Interests:

15.2.1 Healthcare professionals have an ethical obligation to make their patients' best interests their first concern. The Mental Capacity Act does not actually define 'best interests' but is clear that in deciding what is in the best interests of a person lacking capacity, decision makers must take into account all relevant factors it would be reasonable to consider. As a starting point the Mental Capacity Act sets out a checklist of common factors that must always be considered, and these include:

- Considering all relevant circumstances, and making every effort to encourage and enable the person lacking capacity to take part in making the decision
- Taking into account any evidence of the patient's current and previously expressed preferences and wishes, including an advance decision
- Considering the beliefs and values that would be likely to influence the individual's decision if he had capacity, and any other factors he would be likely to consider if able to do so
- If practical and appropriate, taking into consideration the views of anyone named by the individual as someone to be consulted on matters of this kind, any carers or other people interested in the individual's welfare, any donee of a LPA appointed by the individual or any Deputy appointed by the Court, as to what would be in the individual's best interests
- What is in a person's best interests may change over time and a proper and objective assessment must always be carried out, even in an emergency situation

15.2.2 Chapter 5 of the Code of Practice provides guidance on best interests.

15.3 Mental Capacity

15.3.1 This is the ability to make a decision, and the starting point must always be to assume that an adult and young person (aged 16 & 17) has capacity unless it is established that he lacks capacity.

15.3.2 The test for capacity has been codified by the Mental Capacity Act, and is a 2 stage test which is decision specific. The test is:

- Does the patient have an impairment of, or a disturbance in the functioning of, their mind or brain?
- If yes, does this mean that the patient is unable to make a specific decision when they need to?

15.3.3 A person is unable to make a decision if they are unable:

a) To understand the information relevant to the decision

b) To retain that information

c) To use or weigh that information as part of the process of making the decision balancing risks and benefits, or

d) To communicate the decision

15.3.4 If a person is assessed as unable to take any one of the steps (a) to (d) above, they will not have capacity to make the particular decision in question.

15.4 Children - Gillick Competence

15.4.1 If a child of under 16 years of age has ''sufficient understanding and intelligence to enable him or her to understand fully what is proposed'' in relation to a particular intervention or procedure, they are said to be Gillick competent in relation to that procedure and are able to give consent. The child should have an understanding and appreciation of the consequences of having the treatment, not having the treatment, any alternative courses of action, and inaction. There is no specific age when a child becomes competent to consent to treatment; it will depend on the individual child, and the treatment or procedure being proposed. Although extra caution should always be taken when a child is below the age of 13 years of age.

15.4.2 Even if a child is assessed as being Gillick competent, it is still good practice to involve their family in decision making, unless the child specifically asks you not to. A request from a competent child under 16 to keep information confidential must be respected, unless disclosure can be justified on the grounds that there is reasonable cause to suspect the child is suffering/is likely to suffer, significant harm and the disclosure would be necessary and proportionate to reduce the risk of that harm.

15.4.3 Advice may be sort from the safeguarding team in relation to any matter whereby the professional believes a child/young person may be at risk of harm.

15.5 Lasting Power of Attorney (LPA)

15.5.1 Where an adult patient does not have the capacity to give or withhold consent to treatment, clinicians should consider whether the patient had appointed an attorney under a Lasting Power of Attorney (LPA) to consent or refuse the proposed treatment on their behalf (or whether anyone else is appointed to make treatment decisions on their behalf such as a court deputy).

15.5.2 The Attorney has a duty to act in the best interests of the patient, to follow the best interest's requirements of the Act and to have regard to the Code of Practice. The LPA applies only when a person cannot make the particular decision for themselves. To be effective the LPA must be registered with the Office of the Public Guardian.

15.5.3 Since 1 October 2007, a person with capacity has been able to appoint another person(s) to make healthcare decisions for them when they are unable to do so through a personal welfare LPA. Providing there are no limits on the attorney's authority (which will be evident from the Form) the attorney can consent to and refuse medical treatment. Any authority to consent to or refuse life sustaining treatment must be expressly granted. You should check any limits on the attorney's authority by asking for a copy of the relevant form. Also there may be more than one attorney who may be jointly and severally appointed to make decisions. The Code of Practice gives guidance on LPAs in Chapter 7. Where an LPA is made after an Advance Decision is made then the authority of the attorney will "trump" any previous advance decision unless the attorney's powers are limited to exclude decision making in circumstances where the Advance Decision is valid and applicable.

15.6 Independent Mental Capacity Advocates (IMCA's)

15.6.1 In most situations, people who lack capacity will have a network of support from family members or friends who are engaged in their care or interested in their welfare, or there may be a court appointed deputy or an attorney appointed under a Lasting Power of Attorney who can be consulted about best interests. Some people who lack capacity however may have no one who can be consulted so the Mental Capacity Act 2005 provides for an Independent Mental Capacity Advocate (IMCA) to represent and support them in their best interests. An IMCA is a specific type of advocate that will only have to be involved if there is no-one other than a person engaged in care or treatment in a professional capacity. An IMCA will not make the decision in question but the person who will make that decision must take into account any the information given or submissions made by the IMCA.

15.6.2 The Trust is be under a legal duty to involve an IMCA if the decision relates to:

- Serious medical treatment provided by the NHS; or
- The provision of, or any change in, accommodation in hospital or care home which is likely to last more than 28 days in a hospital or 8 weeks in a care home

15.6.3 "Serious medical treatment" is defined as:

- Providing, withdrawing or withholding treatment, in circumstances where:
  - in a case where a single treatment is being proposed there is a fine balance between its benefits to the patient and the burdens and risks it is likely to entail for him
  - in a case where there is a choice of treatments, a decision as to which one is to use is finely balanced; or
  - what is proposed would be likely to involve serious consequences for the patient

15.6.4 The duties of an IMCA are to:

- support the person who lacks capacity and represent their views and interests to the decision-maker
- obtain and evaluate information
- as far as possible, ascertain the person's wishes and feelings, beliefs and values
- ascertain alternative courses of action
- obtain a further medical opinion, if necessary
- act in the person's best interests

15.6.5 The decision maker also has the power to instruct an IMCA for a person who lacks capacity in relation to decisions concerning care reviews and adult protection cases if the decision maker considers that it would of particular benefit to the person who lacks capacity to have an IMCA to support them.

15.6.6 If you think a patient without capacity requires the services of an IMCA please see: Section 6 of the Mental Capacity Act on the intranet.

16.0 Dissemination / Implementation

Copies of this policy will be posted on the Intranet. Any amendments to the policy will be communicated as and when they occur.

The electronic master copy of this document is held by Document Control, Office of the Medical Director, NL&G NHS Foundation Trust.