

Guideline For Patients Who Refuse Blood

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Approval Group:	GGC Overarching Transfusion Committee

Important Note: The Intranet version of this document is the only version that is maintained. Any printed copies should therefore be viewed as 'Uncontrolled' and as such, may not necessarily contain the latest updates and amendments.

This protocol is adapted from the NHS Lanarkshire, NHS Ayrshire and Arran and Forth Valley Protocols for refusal of blood.

Acknowledgements to GG&C Chaplaincy Department and the Hospital Liaison Committee of Jehovah's Witnesses

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June 2016	Updated page 12, section 17, help and advice
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NHS GG&C aims to respect the wishes of all patients, adults, children and their families, and to provide high quality health care acceptable to them. All patients have the right to be treated fairly, with respect and acknowledgement of their individual needs, values and beliefs. The Equality Act 2010 lays obligations upon all public sector bodies to deliver their services without discrimination.

This document will be available via the <u>NHS GGC Sharepoint blood transfusion page.</u>

Copies will also be available on request from the Hospital Liaison Committee of Jehovah's Witnesses (contact details - <u>see section 17</u>).

1. AIM OF THE GUIDELINE

1.1 To protect the rights of patients, adults and children, in respect of their refusal to be treated with blood or blood products.

1.2 To enable clinicians to feel confident in their approach to treating patients as is clinically necessary, unless there is a specific and clear refusal of consent.

1.3 To protect clinical practitioners and the organisation from unnecessary confrontation and perhaps costly litigation by outlining the procedure to be followed.

2. ETHICAL CONSIDERATIONS

2.1 Many patients may decide to refuse to be treated with blood or blood products however, the most prominent group which falls into this category are The Jehovah's Witnesses. This religious movement was founded in the Unites States of America in the 19th Century; there are approximately 8,000,000 Jehovah's Witnesses worldwide and 10,000 in Scotland. Jehovah's Witnesses have absolutely refused the transfusion of allogenic blood and the primary components (red cells, white cells, platelets and plasma/FFP) ever since they have become universally available. For Jehovah's Witnesses this is a deeply held core value and they regard a non-consensual transfusion as a gross physical violation.

2.2 It is not the clinician's responsibility to question these principles, but they should discuss with each patient the medical consequences of non-transfusion in the management of their specific condition. It is important to bear in mind that other individuals for whatever reason, which may not be explicit, may refuse transfusion of blood or blood components/ products.

3. LEGAL AND CONSENT ISSUES

3.1 To administer blood in the face of refusal by a patient is unlawful and could lead to criminal and/or civil proceedings.

3.2 In the management of trauma, the transfusion status of the patient may be unknown. Nevertheless, the majority of Jehovah's Witnesses carry on their person a signed and witnessed 'Advance Decision to Refuse Specified Medical Treatment' document (<u>Appendix D</u>), absolutely refusing blood and releasing clinicians from liability arising from this refusal. This document is renewed regularly. A copy of this document will have been lodged with their GP as well as with friends and fellow worshipers.

3.3 If the patient is able to give an informed, rational opinion, or if an advance directive exists (example can be seen in appendix D), this should be acted upon. If the patient is unable to give their opinion and there is no advance directive, the clinical judgement of the doctor should take precedence over the opinion of relatives or associates. Such friends and relatives may be invited to produce evidence of the patient's Jehovah's Witnesses status in the form of an applicable 'Advance Decision' document.

3.4 Patients who refuse blood products may do so for a number of reasons, including reservations about the medical use of blood. The refusal may be a matter of patient choice or, in the case of Jehovah's Witnesses, a sincerely held religious belief, adhered to as part of commitment to faith. The clinician must establish what is acceptable or not acceptable to each individual. The second page of the GG&C General consent form excluding blood transfusion should be completed for each patient, a copy is to be filed in the patient's case notes. This details which products/procedures are acceptable for that individual patient.

Treating children of parents who refuse blood products which includes Jehovah's Witnesses – see <u>section 13</u>.

The doctor must be satisfied that the patient is not being subjected to pressure from others. Therefore they should explain to the patient that it is important to be sure that this important decision has been made without pressure from someone else. To this end, the doctor may request that they interview the patient on their own. The patient, of course, has the right to accept or reject such a request, preferring that the accompanying person remain as a support at this time. In practice most patients prefer the support of a companion at this stage. No other person is legally able to consent to treatment for a competent adult or refuse treatment on that person's behalf.

A competent adult is legally and ethically entitled to accept or refuse any specific treatment or procedure even though this decision may endanger their life. To administer blood in the face of refusal by a competent adult is unlawful, ethically unacceptable and may lead to criminal +/- civil proceedings.

Any patient is entitled to change their mind about a previously agreed treatment plan. The patient does not need to give an explanation for any change of mind. Should a patient decide to accept blood transfusion, it should be clearly documented that the previous refusal of blood has been revoked.

If, at this stage, the doctor feels that they cannot accommodate the wishes of the patient in relation to refusal of blood, and there is time, they should consider passing the patient to a colleague or even to another facility where there may be more experience in treating patients with such limitations to consent.

4. TREATMENT NOT ACCEPTABLE TO JEHOVAH'S WITNESSES

4.1 Jehovah's Witnesses usually refuse the transfusion of the four primary blood components;
red cells, white cells, platelets and plasma (FFP) and will carry documentation stating this.
4.2 Pre-deposited autologous blood (PAD) is not acceptable

5. TREATMENT ACCEPTABLE TO JEHOVAH'S WITNESSES

Jehovah's Witnesses will accept medical management to build up or conserve their own blood, to avoid or minimise blood loss and to replace lost circulatory volume. This would include sodium chloride (saline) solution, Hartmann's (Ringer-Lactate) solution, dextrans, modified gelatins, (e.g. gelofusin, haemacel) and starches (e.g. hemohes, voluven, tetraspan), human recombinant products such as erythropoietin (r-HuEPO) and clotting factors, VIII and IX.

6. TREATMENT THAT JEHOVAH'S WITNESSES CONSIDER TO BE A MATTER OF PATIENT CHOICE

6.1 Blood products derived from plasma including factor VIIa, albuminfibrinogen concentrate, intravenous immunoglobulins, cryoprecipitate, anti-D immunoglobulin, other specific immunoglobulins e.g. anti-tetanus, etc.

6.2 Treatment and procedures involving their own (autologous) blood. This would include normovolaemic haemodilution, cell salvage (both intra-operative and post-operative), renal dialysis, plasmapheresis, blood radio-labelling, etc.

7. MANAGEMENT OF PATIENT WHO HAS REFUSED BLOOD TRANSFUSION UNDERGOING ELECTIVE SURGERY

7.1 General Peri-operative Non-blood Management Principles

- These guidelines are drawn from general principles of peri-operative management applicable to all patients.
- Discuss with the patient/family the risks (short and long-term), benefits and alternatives to proposed interventions
- Jehovah Witness patients may contact Hospital Liaison committee (see section 17) for advice if necessary
- Employ a multi-speciality team approach
- Thoroughly plan the management of the patient to avoid allogeneic blood transfusion by using an appropriate combination of blood conservation strategies
- Maintain frequent, close observation for haemorrhage
- Anticipate potential risks of blood loss and be prepared to address them.
- Early recognition and prompt intervention to prevent/control abnormal bleeding
- Consult promptly with senior specialists experienced in non-blood management if complications arise

7.2 <u>General Therapeutic Principles</u>

- Control or avoid haemorrhagic and iatrogenic blood loss
- Optimise cardiac and respiratory support by maximising oxygen delivery (volume replacement, oxygenation, vasoactive agents) and minimising oxygen consumption (analgesia, mechanical ventilation)
- Restore/improve blood count by stimulating haematopoiesis

8 PRE-OPERATIVE PLANNING

A comprehensive care plan should be drawn up taking into consideration the risk factors and then employing an optimal combination of available alternative strategies.

Plan elective surgical procedures carefully

The surgery should be undertaken by a team sensitive to the beliefs of Jehovah's Witnesses If blood loss is anticipated, schedule a meeting for the patient with the Consultant Surgeon, and Consultant Anaesthetist **at least three weeks before the procedure.** The patient may wish to be accompanied by a relative or a representative of the Hospital Liaison Committee for Jehovah's Witnesses. There should be an independent witness present.

8.1 <u>At time of referral</u>

Medical history and physical examination

Full clinical history and examination including personal or family history of bleeding disorders and medication including non-prescription medication.

Laboratory Assessment/screening

- Establish baseline parameters:
- Full blood count
- Serum ferritin
- Serum folate
- Serum vitamin B12
- PT, PTT, fibrinogen
- Liver function
- Renal function (urea & creatinine)
- Additional investigation as indicated by the history of the patient and the degree of haemostatic challenge
- Further coagulation tests if personal or family history of bleeding contact Haematology department for advice.
- Note: Minimise iatrogenic blood loss consider using paediatric blood tubes.

Blood sparing options

If the procedure and the patient's condition is such that the clinician would normally request 2 or more units of cross matched blood, discuss with the patient which of the blood sparing options and alternatives would be acceptable, if available (Refer to the local Maximum Surgical Blood Ordering Schedule (MSBOS) for cross match details).

- Cell salvage both intra-operative and post-operative.
- Acute normovolaemic haemodilution.
- Human recombinant blood products (e.g. r-HuEPO).
- Blood products derived from plasma e.g. albumin, fibrin sealants, cryoprecipitate, clotting factors, etc.

This should be clearly documented on the 'GG&C Consent Form for the Refusal of Blood Transfusion' (<u>Appendix A</u>) (if appropriate).

8.2 From 6 weeks pre operatively

- Check FBC. Coagulation screening and serum ferritin, folate and B₁₂. If the patient is iron deficient, prescribe oral iron or IV iron of oral not tolerated.
- Consider stopping aspirin, NSAIDs and other anti-platelet agents, at least 7 days preoperatively
- Consider stopping warfarin and other anticoagulants if possible
- If the expected blood loss is high 15-20% of blood volume- consider recombinant Erythropoietin
- Ensure acceptability with patients and discuss further with Haematologists if appropriate
- Try to guarantee the date of surgery, since if surgery is postponed then pre-operative treatment will need to be continued until the new date to avoid a fall in haemoglobin level pre-operatively

A Flow chart is available in <u>(Appendix b)</u> - Care Pathway for Adult Patients Refusing Blood/ Blood Component Support requiring Surgery Emergency or Elective.

9. INTRAOPERATIVE MANAGEMENT

9.1 Anaesthetic Management

- Consider controlled hypotension to reduce intra-operative bleeding.
- Consider acute normovolaemic haemodilution. This may be acceptable to the patient.
- Cell salvage can be a valuable technique.
- Consider giving Tranexamic acid, *1gram* over 10 minutes intravenously, or other antifibrinolytic as appropriate.
- If the patient has received sedation, their competency to vary the consent which they have previously given will depend on the facts of the case.
- Broadly speaking, the law holds that a patient has capacity to consent to treatment if they are capable of receiving advice from a doctor, of understanding that advice, of balancing their issues in their mind and uttering their wishes.
- Surgical procedure(s) to specifically avoid and prevent blood loss:
- A senior surgeon should be operating
- Pay meticulous attention to haemostasis
- Procedures should be performed in stages to minimise loss of a large volume of blood. For example, a bilateral mastectomy could be performed in two stages
- Consider the use of interventional radiology early where appropriate for example, iliac artery balloons pre hysterectomy or caesarean section
- Minimally invasive techniques (endoscopic/laparoscopic surgery)

There are a range of measures which may or may not be available:

- Mechanical occlusion of blood vessels
- Electrocautery
- Ultrasonic scalpel
- Argon beam coagulator
- Tissue adhesives
- Arterial embolisation
- Medical antishock trousers (MAST)

Post-operative Care

- Optimise post-operative analgesia. Epidural analgesia may reduce post-operative respiratory complications.
- Serious blood loss may necessitate that the patient remains sedated and ventilated in ICU.
- In the event of significant blood loss give recombinant erythropoietin (300 units/kg) three times per week for two weeks, then 100 units/kg three times per week. Simultaneously replenish iron stores using intravenous iron. Also, nutritional support along with supplementary folate and Vitamin B12.
- Minimise phlebotomy for example, paediatric sample tubes
- Consider cell salvage via wound drainage, collection and re-infusion, if available.
- Tranexamic acid

An algorithm in <u>(Appendix C)</u> shows the Care Pathway for Post-operative Management of *Adult* Patients Refusing Blood Transfusion.

10 EMERGENCY OR TRAUMA SITUATIONS

In the management of trauma or emergency situations, the wishes of the patient may be unknown. Nevertheless, the majority of Jehovah's Witnesses carry on their person a signed and witnessed 'Advanced Decision' document absolutely refusing blood and releasing clinicians from any liability arising from this refusal. The following situations may arise:

A conscious and competent patient states that they wish to refuse blood products or identifies themselves as one of Jehovah's Witnesses and states that they are unwilling to accept the transfusion of allogeneic blood. The patient may or may not have on their person their 'Advance Decision' document. This document will clearly indicate their refusal to accept blood. It will also indicate what plasma derivatives they will accept and what autologous procedures are acceptable to them. If their 'Advance Decision' document is not to hand, the treating clinician will need to ascertain such details by interviewing the patient. Details should be fully documented and included in the patient's notes.

The treating team should respect the decisions of the patient. It is not the responsibility of clinicians to question these decisions, but they should discuss the medical consequences of non-transfusion in the management of the patient's specific condition.

The patient is unconscious or incompetent. Accompanying relatives or associates state that the patient would want to refuse blood or that they are a Jehovah's Witness and would not accept the transfusion of allogeneic blood. Such relatives or associates should be invited to produce evidence in the form of a valid 'Advance Decision' document. If they can produce such a document, the patient should be treated in accordance with the decisions indicated therein. If documentary evidence cannot be produced, the clinical judgement of the treating team should take precedence over the opinion of relatives or associates.

Even though clinicians may have dealt with a patient refusing blood or Jehovah's Witness patients on previous occasions, it is important not to presume to know what they will or will not accept. Although all Jehovah's Witness patients will refuse allogeneic whole blood, the use of plasma derivatives and autologous procedures is considered to be a matter of individual conscience or patient choice.

A Flow chart is available in <u>(Appendix C)</u> - Care Pathway for Adult Patients Refusing Blood/ Blood Component Support requiring Surgery Emergency or Elective shows this in algorithm format.

10.1 General Therapeutic Principles

- Use intra-operative blood conservation techniques where acceptable to the patient
- Prevent or treat coagulation disorders promptly.
- Minimise the volume of blood drawn for laboratory analysis during the perinatal/ perioperative period e.g. paediatric sample tubes
- When hysterectomy is performed the uterine arteries should be clamped as early as possible during the procedure. Subtotal hysterectomy can be as effective as total hysterectomy, as well as being quicker and safer.

If the patient survives the acute episode and is transferred to the ICU, the management there should include erythropoietin (R-HuEPO), parenteral iron and adequate protein for haemoglobin synthesis.

If, in spite of all care, the patient dies, the relatives require support like all other bereaved families. <u>The Spiritual Care Service - NHSGGC</u>

11 THE MANAGEMENT OF WOMEN IN LABOUR REFUSING TRANSFUSION

The detailed management of women in the ante-natal and peri-partum periods is covered in a separate guideline which is available via this link: <u>Women who refuse Blood Products, guideline for management (Obstetrics).</u>

The linked document <u>Care Plan For Women In Labour Refusing A Blood Transfusion</u> is available as an aid for medical staff and midwives managing a Jehovah's Witness (JW) or other patient who declines blood.

12 THE MANAGEMENT OF WOMEN WHO REFUSE TRANSFUSION WITHIN GYNAECOLOGY

The detailed management of women in the Gynaecology setting is covered in a separate guideline which is available via this link: <u>Women Who Refuse Blood Products, Guideline for Management</u> (Gynaecology).

13 TREATING CHILDREN OF ADULTS REFUSING BLOOD OR JEHOVAH'S WITNESSES

13.1 The position in Scots law as regards the capacity of children under the age of **16 years** to consent to medical treatment was clarified by s2(4) of the Age of Legal Capacity (Scotland) Act 1991 which stated that: "A person under the age of 16 years shall have legal capacity to consent on his or her own behalf to any surgical, medical or dental procedure or treatment where, in the opinion of a qualified medical practitioner attending him, he is capable of understanding the nature and possible consequences of the procedure or treatment"

13.2 Children below the age of sixteen may cause some difficult situations for the patient, parents and clinicians. Jehovah's Witnesses are usually well informed about the legal situation. They are generally aware of the provisions of the Children (Scotland) Act 1995 and the possibility of a Specific Issue Order under section 11. Such a Specific Issue Order should rarely be necessary but if this serious step is considered it is of the utmost importance to keep parents fully informed and given the opportunity to be represented at any hearing. Parents need to be assured that every possible step is being taken to avoid the use of allogeneic blood.

13.3 Children younger than sixteen may be competent to make their own decisions if they demonstrate a clear grasp of the proposed treatment and the issues involved. This is referred to as 'Gillick Competence'.

13.4 If the clinician is persuaded that a child's refusal to accept blood transfusion is a genuinely held personal belief, and not just a reflection of their parents' belief, then a clinician should give very serious consideration to the child's feeling. The 'Gillick' principle is unlikely to apply to a child below the age of twelve.

13.5 Trauma situations involving young children and unexpected neonatal emergencies can be particularly difficult. In such a situation where the parents feel unable to give permission to transfuse blood it may be felt that application for a Specific Issue Order would be too time consuming. If two doctors of Consultant status make a clear, unambiguous, signed entry into the clinical record that a blood transfusion is essential, or is likely to become so, to save life or prevent serious harm, then they should act upon the basis of their own clinical judgement. The courts are likely to uphold the decision of the doctors who administered the transfusion in such circumstances.

14 TREATMENT OF HAEMATOLOGICAL MALIGNANCIES

It is increasingly possible to treat haematological malignancies without primary blood component support. This will require a multidisciplinary team and the design of a specific care plan.

- Keep blood sampling to a minimum, but careful monitoring of the patient's haematological status must not be neglected.
- Correction of anaemia should be commenced promptly with special consideration being given to the use of erythropoietin and intravenous iron.
- Consider the early use of novel therapies which may have a reduced myelosuppressive effect.

For more detailed suggestions see 'Developing a Blood Conservation Care Plan for Jehovah's Witnesses with Malignant Disease' presented at the BSH Annual Scientific Meeting, April 2007. ⁽¹²⁾

Developing A Blood Conservation Care Plan For Jehovah's Witness Patients With Malignant Disease

15 DEATH

If, in spite of all care, the patient dies, the relatives will require support like all other bereaved families. The support of representatives of their religious faith should be offered and, where appropriate facilitated. The GG&C Healthcare Chaplaincy Service can be contacted to give pastoral care.⁽¹³⁾ <u>The Spiritual Care Service - NHSGGC.</u>

It is very distressing for staff to have to watch a patient bleed to death while refusing effective treatment.

Staff affected by this situation may find it helpful to have someone to speak to about their experience. Staff can self-refer or be referred by their line manager to the Employee Counselling Service or Occupational Health. The GG&C Healthcare Chaplaincy Service provides confidential, person-centred pastoral care; staff may self-refer or be referred by their manager. <u>The Spiritual Care Service - NHSGGC</u>.

16 GUIDNACE ON THE LAW OF CONSENT

See the Department of Health publication 'Reference guide to consent for examination or treatment' and 'Seeking consent: working with children' for a comprehensive summary of the law on consent.

Link to GMC guidance on consent: <u>About Decision making and consent - GMC (gmc-uk.org)</u>

17 HELP AND ADVICE

Further help and advice on the non-blood management of Jehovah's Witnesses may be obtained from the Hospital Liaison Committee of Jehovah's Witnesses. They operate a 24/7 assistance arrangement.

Name	Mobile Number	Landline	Email address
Mr Peter Warden	07974 578897	0141 641 6206	pwarden@jw-hlc.org.uk
Mr David Butler	07722475834	01236 601095	dbutler@jw-hlc.org.uk
Mr Paul Cura	07702 849965	01236 614121	pcura@jw-hlc.org.uk
Michael Mckay	07548 883088		mmckay@jw-hlc.org.uk

Contacts as of May 2024 are as shown below:

Anthony Chali	07877 312028		achali@jw-hlc.org.uk
Daniel Caillaud	07527 709574	0141 629 2777	dcaillaud@jw-hlc.org.uk
Simon Train	07798 504680		strain@jw-hlc.org.uk
Lewis Gover	07375 666813		GoverL@jwpub.org
David Hunter	07740987795		dhunter@jw-hlc.org.uk

Further advice is also available from the following document, these are available on the <u>NHS GGC</u> <u>Transfusion Sharepoint page</u>.

18 APPENDICES

APPENDIX A: GG&C CONSENT FORM FOR THE REFUSAL OF BLOOD TRANSFUSION

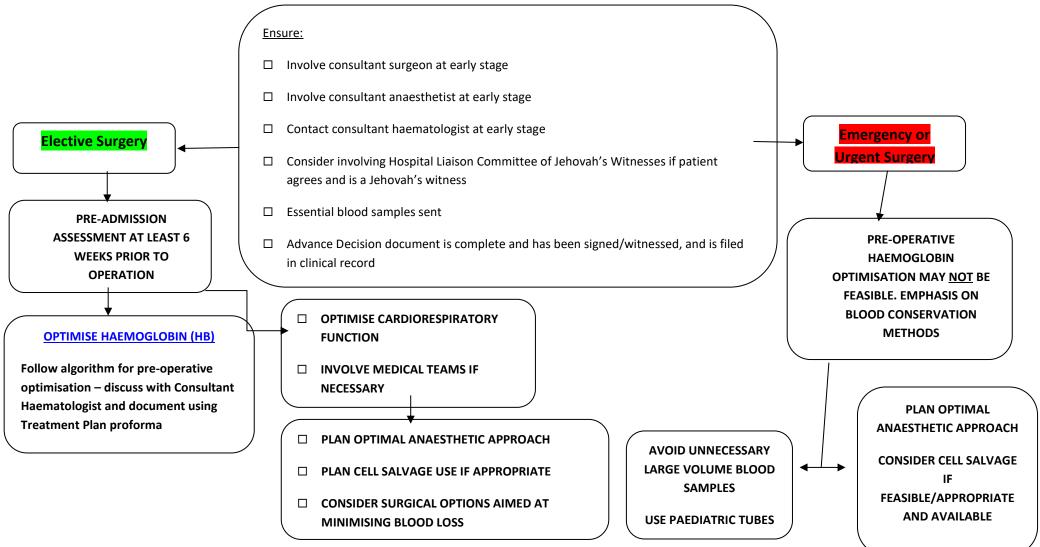
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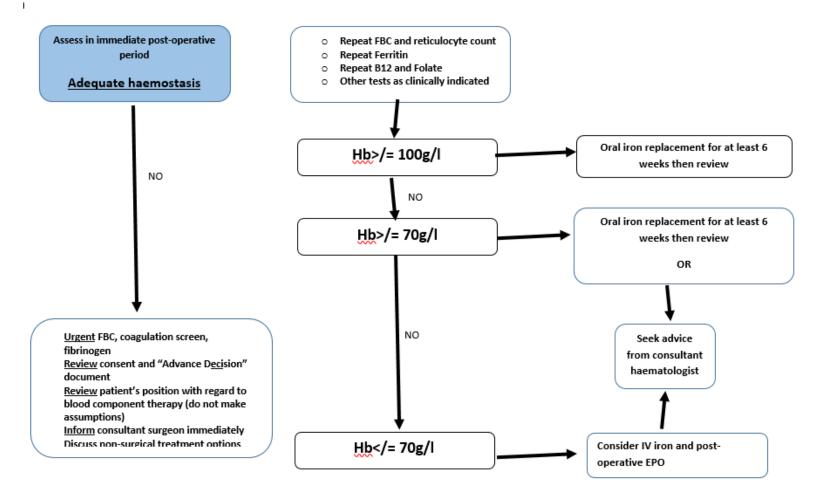
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APPENDIX B : CARE PATHWAY FOR ADULT PATIENTS REFUSING BLOOD/ BLOOD COMPONENT SUPPORT REQUIRING SURGERY EMERGENCY OR ELECTIVE



APPENDIX C: CARE PATHWAY FOR POST-OPERATIVE MANAGEMENT OF ADULT PATIENTS REFUSING BLOOD TRANSFUSION



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APPENDIX D: EXAMPLE OF AN ADVANCE DECISION DOCUMENT

Advance Decision to Refuse Specified Medical Treatment

- 1. I, (print or type full name), (date) complete this document to set born forth my treatment instructions in case of my incapacity. The refusal of specified treatment(s) contained herein continues to apply even if those medically responsible for my welfare and/or any other persons believe that such treatments are necessary to sustain my life.
- 2. I am one of Jehovah's Witnesses with firm religious convictions. With full realization of the implications of this position I direct that NO TRANSFUSIONS OF BLOOD or primary blood components (red cells, white cells, plasma or platelets) be administered to me in any circumstances. I also refuse to predonate my blood for later infusion.
- 3. Regarding minor fractions of blood (for example: albumin, coagulation factors, immunoglobulins): [Initial one of the three choices below.]
- (a) _____ I refuse all
- (b) _____ I accept all
- (c) I want to qualify either (3a) or (3b) above and my treatment choices are as follows:
- 4. Regarding autologous procedures (involving my own blood, for example: haemodilution, heart bypass, dialysis, intra-operative and post-operative blood salvage): [Initial one of the three choices below.]
- (a) _____ I refuse all such procedures or therapies
- (b) _____ I am prepared to accept any such procedure
- (c) _____ I accept only the following procedures:

I am prepared to accept diagnostic procedures, such as blood samples for testing.

5. Regarding other welfare instructions (such as current medications, allergies, and medical problems):

Page 1 of 2

- dpa-EBi 12/05

6. I consent to my medical records and the details of my condition being shared with the Emergency Contact below and/or with member(s) of the Hospital Liaison Committee for Jehovah's Witnesses.

7.			
	Signature	Date	

Address

Telephone Number(s

Printed in Britain

8. STATEMENT OF WITNESSES: The person who signed this document did so in my presence. He or she appears to be of sound mind and free from duress, fraud, or undue influence. I am 18 years of age or older.

Signature of witness	Signature of witness
Name Occupation	Name Occupation
Address	Address
Telephone	Telephone
Mobile	Mobile
9. EMERGENCY CONTACT:	
Name Address	NOBLOOD
Telephone Mobile 10. GENERAL PRACTITIONER CONTACT DETAILS: A copy of this document is	Advance Decision to Refuse Specifical Treatment bignadocumaniae
lodged with the Registered General Medical Practitioner whose details appear below.	Advance Decision to Refuse Specified Medical Treatment (signed document inside)
Name	NO BLOOD
Address	

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19 REFERENCES

"Code of Practice for the Surgical Management of Jehovah Witnesses" Royal College of Surgeons of England (2002)

Caring for patients who refuse blood - a guide to good practice (2016)

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Anaesthesia and peri-operative care for Jehovah's Witnesses and patients who refuse blood (July 2018)

Anaesthesia and peri-operative care for Jehovah's Witnesses and patients who refuse blood Association of Anaesthetists