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Hereditary Haemochromatosis Nurse Led Venesection Protocol

Target Patient Population: Patients with Hereditary Haemochromatosis requiring venesection

Target Staff Population: CIU nursing staff in NHS Fife

Scope

This is a protocol for nurse led venesection in patients with hereditary haemochromatosis (HH).

Introduction

HH is a genetically inherited condition in which patients inherit two abnormal genes, one from each parent. It causes excess iron absorption from the gastrointestinal tract despite adequate levels within the body. This excess iron can cause organ damage, such as cirrhosis of the liver, cardiac failure and diabetes. Not all patients with HH develop organ damage; however, it is not possible to predict who will be affected and as a result, all patients are managed in the same way. The mainstay of treatment is to lower iron levels, into the normal range, by venesection (i.e. the removal of a quantity of blood from a vein).

Red blood cells require iron to make haemoglobin. Most of the iron within the body is in haemoglobin although there is also storage iron called ferritin. As most of the body's iron is in red blood cells, blood loss results in iron loss, for every 500mls lost around 250mcg of iron is lost. In response to blood loss, the body synthesises new red blood cells. This requires iron and gradually depletes iron stores. Therefore, in HH venesection is used to normalise iron levels.

There are two stages to the venesection process: initially a frequent (usually weekly) programme until ferritin (stored iron) levels are <50 (this may take up to a year or more); and then a maintenance programme aiming to keep ferritin levels between 30 - 100 (usually every 3 - 4 months). If venesection is initiated before cirrhosis, cardiac failure and diabetes develop then life expectancy is normal.

To replace the volume of blood removed fluid replacement is given at each venesection. For the majority of patients' oral fluid replacement is sufficient. In those who have had a previous fainting episode intravenous (IV) fluids may be required. IV fluid can be administered in two ways; as intravenous fluid return (i.e. 0.9% NaCl 500mls via the same cannula after the venesection is complete); or, isovolaemically (i.e. 0.9% NaCl 500mls via a separate cannula as patient is being venesected).

Patients in maintenance phase are eligible to be blood donors.

Referral Pathway

Consultants should refer patients to CIU by clinic letter which should be copied to the GP.

The clinic letter should include the following information

Name:
Address:
CHI/Hospital No:
DoB:
Telephone No:
Consultant:
Diagnosis:
Date of diagnosis:
Current ferritin:
Past Medical History:
Medications:
Whether further medical review is planned:
If already on a venesection programme include venesection interval and fluid replacement i.e. oral/IV/isovolaemic

The referring secretarial team contacts CIU to arrange first appointment by phone on 01383 627011.

The secretarial team will contact the patient by letter notifying them of the appointment and a venesection patient information leaflet should be included.

Any subsequent medical clinic review letters should be CC to CIU.

Management of venesection programme in patients with HH

There are two phases to venesection management. These are described below:

Phase 1 - Initial venesection

Aim: Achieve ferritin <50

1. Initiate weekly venesection using venesection SOP
2. Haemoglobin (Hb) to be checked prior to each venesection
    i. If Hb >105g/l proceed with venesection
    ii. If Hb <105g/l delay for 1 week and repeat Hb at next visit
3. The patient's hand held record must be completed at each visit
4. Check ferritin every 8 weeks until ferritin <300
5. Once ferritin <300 check every 4 weeks until ferritin <50
6. Switch to maintenance programme when ferritin <50

Phase 2 – Maintenance venesection

Aim: Maintain ferritin <100

1. Once ferritin <50 patients should be venesected every 3 - 4 months (N.B. patients already established on a programme may be on a different venesection interval)
2. Hb and ferritin to be checked at each visit
    i. Hb result MUST be available prior to proceeding with Venesection using Hemocue machine
    ii. Ferritin results are used retrospectively to adjust the interval between venesections.
    iii. Ferritin should be checked 1 week prior to venesection to ensure there is not a more current level available that may affect treatment
3. If Hb>115 (males) or > 110 (females) proceed with venesection using the appropriate venesection SOP
4. The patient's hand held record must be completed at each visit
5. Adjust venesection interval once ferritin available
    i. 30 - 100 - continue current venesection interval
    ii. >100 on 2 occasions - reduce interval by 1 month, reverting back to original interval if ferritin remains stable
    iii. <30 on 2 consecutive visits - adjust interval to 6 monthly, reverting back to 4 months if ferritin >100
6. Patient followed up in Haemotology Clinic until stable and on maintenace then reviewed annually.
7. Patient discharged into CIU care. Haemotology consultant available via generic email for any queries.

Follow up of ferritin results

- Paper copies of ferritin results should be returned to CIU (CIU should be used as the requesting source).
- Nursing staff will use ferritin levels to guide venesection intervals (see phase 2– Maintenance venesection page 3).
- Paper copies do not need to be returned to the consultant in charge and can be filled directly in notes.
- Nursing staff should seek advice from original referring consultant if the ferritin results fall out with phase 2– Maintenance venesection guidance or if they have clinical concerns about the patient.
- Contact with medical staff can be made by telephone or email.

Patient Follow Up

- Once assessment of liver disease, and other end organ disease is complete, patients will be discharged from routine follow up.
- Nursing staff will arrange subsequent venesections (as per phase 2– Maintenance venesection).
- Advice can be sought from referring consultant as required.
- If a patient repeated fails to attend CIU staff should contact the relevant consultant team.
- Venesection will be continued until 80 years of age then discharged.

Haematology Consultant Team can be contacted using the generic Haematology email address. Fife-UHB.FifeHaematologyTransplant@nhs.net
Gastroenterology Consultant Team can be contacted using individual Consultant email addressed.

Management of venesection programme in patients with iron overload secondary to blood transfusion

These patients generally have had chemotherapy for haematological malignancy and do not tolerate weekly venesection. They require the initial phase of venesection but not maintenance venesection

Aim: Achieve ferritin <400

1. Initiate 4 weekly venesection using venesection SOP
2. Haemoglobin (Hb) to be checked prior to each venesection
    i. If Hb >105g/l proceed with venesection
    ii. If Hb <105g/l delay for 2 week and repeat Hb at next visit
3. The patient's hand held record must be completed at each visit
4. Check ferritin every 12 weeks until ferritin 400
5. Once ferritin is under 400 patients can be discharged from venesection/CIU
6. Patients will have ongoing haematology outpatient follow up

Hereditary Haemochromatosis Venesection SOPs

There are 3 different venesection SOPs depending on the type of fluid replacement required. This information is available from the referral form or the nursing notes.
New patients will be commenced on protocol 1 unless otherwise directed by the medical team.

1. Hereditary Haemochromotosis Venesection SOP – oral fluid replacement
2. Hereditary Haemochromatosis Venesection SOP – intravenous fluid return
3. Hereditary Haemochromatosis Venesection SOP – isovolaemic fluid replacement

Hereditary Haemochromotosis Venesection SOP - oral fluid replacement

1. Determine whether patient is on initial or maintenance programme (see referral form or nursing notes).
2. If on initial programme check full blood count (FBC) using Hemocue machine, prior to venesection. Take ferritin (clotted/yellow tube) post venesection if required on this visit (see phase 1).
3. If on maintenance programme check full blood (FBC) using Hemocue machine, prior to venesection. Take ferritin (clotted/yellow tube) post venesection if required on this visit (see phase 2).
4. Check Haemoglobin (Hb) meets criteria for venesection (see phase 1/2).
5. Determine type of fluid replacement (see referral form or nursing notes). If for fluid return or isovolaemic venesection, please refer to the appropriate SOP.
6. Explain the procedure and reason for venesection to the patient. Give patient information booklets and venesection diary.
7. Check vital signs, blood pressure and pulse.
8. Apply tourniquet and cannulate with a size 20GA (pink) cannula.
9. Connect a Baxter Interlink Injection Site (bung) to cannula.
10. Insert needle from the venesection pack into bung.
11. Give 500mls of oral fluid replacement.
12. Leave tourniquet in place for the duration of the venesection.
13. Remove 1 unit of blood (500mls) Obtain ferritin, from line if required, post venesection.
14. Remove tourniquet.
15. Disconnect pack and dispose of in sharps bin.
16. After 15 minutes observation period, re-check blood pressure and pulse, if satisfactory remove cannula and discard in sharps bin.
17. Ensure that patient has return appointment.
18. Once ferritin available check if alteration of the venesection interval is required.
19. If alteration required contact patient and make new appointment.

Hereditary Haemochromotosis Venesection SOP – intravenous fluid return

1. Determine whether patient is on initial or maintenance programme (see referral form or nursing notes).
2. If on initial programme check (FBC) using Hemocue machine prior to venesection. Take ferritin (clotted/yellow tube), post venesection, if required on this visit (see phase 1).
3. If on maintenance programme check (FBC) using Hemocue machine prior to venesection. Take ferritin (clotted/yellow tube), post venesection, if required on this visit (see phase 2).
4. Check Haemoglobin (Hb) meets criteria for venesection (see phase 1/2).
5. Determine type of fluid replacement (see referral form or nursing notes). If for oral or isovolaemic venesection, please refer to the appropriate SOP.
6. Explain the procedure and reason for venesection to the patient. Give patient information booklets and venesection diary.
7. Check vital signs, blood pressure and pulse.
8. Apply tourniquet and cannulate with a 20GA (pink) cannula.
9. Connect a Baxter Interlink Injection Site (bung) to cannula.
10. Insert needle from the venesection pack into bung.
11. Leave tourniquet in place for the duration of the venesection.
12. Remove 1 unit (500mls) of blood.
13. Remove tourniquet.
14. Disconnect pack and dispose of in sharps bin.
15. Prime a fluid administration set with 500mls 0.9% NaCl then attach to cannula. Administer over 30 minutes (prescribed by consultant prior to attendance. Valid for 6 months only)
16. Re-check blood pressure and pulse, if satisfactory remove cannula and discard in sharps bin.
17. Ensure that patient has return appointment.
18. Once ferritin available check if alteration of the venesection interval is required.
19. If alteration required contact patient and make new appointment.

Hereditary Haemochromatosis Venesection SOP – isovolaemic fluid replacement

1. Determine whether patient is on initial or maintenance programme (see referral form or nursing notes).
2. If on initial programme check full blood count (FBC) using Hemocue machine, prior to venesection. Take ferritin (clotted/yellow tube) post venesection, if required on this visit (see phase 1).
3. If on maintenance programme check full blood count (FBC) using Hemocue machine prior to venesection. Take ferritin (clotted/yellow tube) post venesection, if required on this visit (see phase 2).
4. Check Haemoglobin (Hb) meets criteria for venesection (see phase 1/2).
5. Determine type of fluid replacement (see referral form or nursing notes). If for oral or intravenous fluid return, please refer to the appropriate SOP.
6. Explain the procedure and reason for venesection to the patient. Give information booklets and venesection diary.
7. Check vital signs, blood pressure and pulse.
8. Apply tourniquet and cannulate with a 22GA (blue) cannula.
9. Prime a fluid administration set with 500mls 0.9% NaCl then attach to cannula. Administer over 30 minutes (prescribed by consultant prior to attendance. Valid for 6 months only
10. Remove tourniquet.
11. Apply tourniquet and cannulate the opposite arm with a size 20GA (pink) cannula.
12. Connect a Baxter Interlink Injection Site (bung) to cannula.
13. Insert needle from the venesection pack into bung.
14. Leave tourniquet in place for the duration of the venesection.
15. Remove 1 unit (500mls) of blood.
16. Remove tourniquet.
17. Disconnect pack and dispose of in sharps bin.
18. Re-check blood pressure and pulse 15mins post venesection, if satisfactory remove both cannulae and discard in sharps bin.
19. Ensure that patient has return appointment.
20. Once ferritin available check if alteration of the venesection interval is required.
21. If alteration required contact patient and make new appointment.

Venesection for Haemochromatosis or Iron Overload due to Blood Transfusion
Patient Information Leaflet

The usual, relatively simple, and highly effective treatment for genetic haemochromatosis or iron overload consists of regular removal of blood. Known as venesection, venesection therapy or phlebotomy, the procedure is the same as for blood donors; every pint (450-500mls) of blood removed contains about a quarter of a gram of iron.

After venesection, the body then uses some of the excess stored iron to make new red blood cells.

Initially, venesection will usually be performed once a week (or every 4 weeks for iron overload secondary to blood transfusion), depending on the degree of iron overload. Treatment may need to be continued at this frequency for up to two years, occasionally longer. During the course of treatment, serum ferritin levels are monitored, indicating the size of the remaining iron stores. Treatment will usually continue until the serum ferritin level indicates minimal iron stores.

In genetic haemochromatosis, this is not the end of the story however; excess iron will continue to be absorbed, so the individual will need occasional venesections, referred to as maintenance therapy. Typically, this means every 3 to 4 months, for the rest of his or her life. Monitoring serum ferritin is used to assess whether venesection is required more or less often.

Your haemoglobin, a measure of red blood cells, will be checked before every venesection. If the haemoglobin falls too low (called anaemia) venesection therapy may be paused.

Preparation for the procedure at home
Please eat as normal and drink plenty of non-caffeinated fluids prior to your venesection, as it will make it easier to insert the needle into one of your veins and you are less likely to feel faint following the procedure.

Please do not take your high blood pressure medication on the morning of the day you attend for venesection. High blood pressure medication can be started the following morning. If you are unwell on the day you are due to attend for venesection please contact the Clinical Intervention Unit on 01383 627011 for advice.

Preparation for the procedure at the Clinical Intervention Unit

Venesection is carried out by a Heath Care Support Worker (HCSW) within the Clinical Intervention Unit (CIU) at Queen Margaret Hospital, Dunfermline.

Before the venesection is carried out your HCSW will explain the procedure to you and ask you a few questions regarding your medical history. Some patients experience a fainting episode during this procedure. Please notify your nurse if you have ever experienced fainting when giving blood or having blood tests.

Please notify the HCSW if you are on aspirin, clopidogrel or blood thinning agents such as warfarin or rivaroxaban.

A finger prick blood test is taken to measure your haemoglobin. Your blood pressure and other observations will be taken. If you are feeling well, the haemoglobin finger prick and your blood pressure and other observations are satisfactory, venesection can proceed.

How is the venesection procedure carried out?

- A tourniquet will be placed on the upper part of your arm and tightened slightly.
- A needle is used to insert a cannula into your vein.
- The cannula is secured into position with tape.
- A bag is connected to the cannula for the purpose of collecting the blood.
- Bloodletting (withdrawing of blood) is not a painful process. The pain that may be felt during this procedure is when the needle initially punctures the skin but that does subside.

It generally takes approximately 15 minutes to drain 450-500mls of blood.
Sometimes, depending on your requirements, your doctor may order fluids to be given via another cannula, inserted into your opposite arm. During your procedure you will be given water to help prevent dehydration.
Once enough blood is taken, the tourniquet is removed.
The cannula is left in place and you will continue to drink water for 10-20 minutes.
Your blood pressure and other observations will be repeated. If these are satisfactory and you feel well the cannula will be removed and a gauze pad will be placed over the area where the needle went in and held in place with medical tape.
You will be asked to apply pressure for a few minutes to prevent bleeding or bruising.
You will be allowed home.

Are there any side-effects?
The procedure is safe and in most people without side effects.
Most people can lose around a pint of blood without experiencing any unwanted side effects, however, occasionally people may experience the following.

- **Bruising or Bleeding:**
  You may get a bruise at the cannula site.

Inform the nurse if you are taking blood thinning medications prior to the procedure eg warfarin or aspirin, as pressure will need to be applied for longer after removing the needle. The nurse will check your needle site before you leave. You should keep your gauze dressing on for 24 hours.
If bleeding occurs later at the cannula site, press on it firmly with a clean tissue for a few minutes. Avoid strenuous exercise and lifting heavy objects with that arm for the rest of the day. Any bruising should disappear after a few days.

- **Feeling Faint:**
  Occasionally people can feel faint during or following venesection. If this happens we will lay you down flat and give you a drink. This will make you feel better quite quickly. Drinking plenty of fluids before you come in for your procedure and afterwards, will help avoid this. It is advisable to avoid drinking alcohol and vigorous exercise for the rest of the day.
  If you feel faint we may give you fluid through a vein in your other arm during the next procedure.

- You may feel a little lethargic for a couple of days.

You can resume all your normal activities after the procedure.
Keep hydrated and drink two litres of fluid daily for 48 to 72 hours following your procedure.

Can I drive afterwards?
It is advisable to have someone drive you home after your first venesection.

What happens next?
Another appointment will be made for your next venesection prior to leaving the CIU. If you are unable to attend this appointment it is important to let CIU know and another appointment can be arranged, as missing appointments may be detrimental for your medical condition.
The CIU team can be contacted on 01383 627011, where possible please phone between 3-4pm.

Further information on genetic haemochromatosis can be found at https://haemochromatosis.org.uk/

NHS
Fife

QUEEN MARGARET HOSPITAL
ADMINISTRATION CHART

Affix Patient Label Name: CHI: Date of Birth:	**QMH Clinical Intervention Unit**	**Consultant:**

Isovolaemic Fluid replacement during venesection

DATE	IV FLUID DRUG	VOL	Rate ml/hr	Start Time	Batch no. / Expiry	Given by /Checked by
	Sodium Chloride 0.9% infusion	**500ml**	**1000**			
	Sodium Chloride 0.9% infusion	**500ml**	**1000**			
	Sodium Chloride 0.9% infusion	**500ml**	**1000**			
	Sodium Chloride 0.9% infusion	**500ml**	**1000**			
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	Sodium Chloride 0.9% infusion	**500ml**	**1000**			
	Sodium Chloride 0.9% infusion	**500ml**	**1000**			

Prescibed by: (Sign and Print) ………………………………………………………………… **Date:**………………………

Prescriptions are valid for a maximum of 6 months

V 1 Sep 2015

Summary of references:

Diagnosis and therapy of genetic haemochromatosis (review and 2017 update). British Society of Haematology.

Diagnosis and Management of Hemochromatosis. American Association for Study of Liver Diseases Practice Guidelines. Anothony S. Tavill. Hepatology May 2001 p 1321 -1328.