

Reviewing a Patient Receiving Home Parenteral Support

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Patients receiving home parenteral support (HPS) require regular review by the multidisciplinary nutrition support team (NST) either face-to-face in a clinic or remotely by a telephone or a video link (virtual appointment). After discharge from hospital a review follow-up clinic appointment is ideally given within the first 4-6 weeks and thereafter at regular intervals dependent on clinical stability (usually every 3-6 months lasting 20-30 minutes). The healthcare professionals will monitor the patient's underlying illness (if gastrointestinal), hydration, nutritional, psychological and social status and any complications. It is the forum for detecting problems, planning for the long-term, checking the goals of treatment and for providing support. During the consultation different team members may take the lead in the discussions (e.g. the doctor on underlying condition, the specialist nutrition nurse on catheter care/problems, the dietitian on hydration/nutritional status and the pharmacist on medications). However, there will be much overlap. In children transition from paediatric to adult care needs to be carefully planned with both teams meeting together with the patient and parents/carers.

Key points

1. The follow up should be by a multidisciplinary NST (doctor, nurse, dietitian and pharmacist) and may be face-to-face or virtual.
2. Before seeing the NST, the patient is weighed and body mass index (BMI) and percentage weight loss (%WL)/gain are calculated. Heart rate, postural blood pressure and temperature may be recorded. The NST will review these, along with the current blood results and any recent communications.
3. When the patient is seen, current symptoms are assessed. (e.g. diarrhoea, vomiting, abdominal pain, stomal/stool output, etc.).
4. Hydration/electrolyte status is assessed by asking about thirst, cramps, urine output and oedema. Ideally, the patient will have measured their 24-hour urine volume on 1-2 occasions.
5. Nutrition status is assessed by asking about feeling cold and the fitting of clothes/rings. In addition to BMI and %WL, mid-arm muscle circumference (MAC) and triceps skinfold thickness are measured to determine the mid-arm muscle circumference (MAMC) or are measured with bioelectrical impedance analysis (BIA). Grip strength is also determined.
6. Problems of a wound/stoma, or any symptoms suggesting complications of the HPS (e.g. catheter-related blood stream infection (CRBSI), occlusion, fracture or central vein thrombosis, intestinal failure associated liver disease (IFALD), renal disease or metabolic bone problems) are identified.
7. The patient is examined (if appropriate). Note is made of hydration (dry or oedematous) and nutritional status. The vascular/enteral access and catheters/enteral tubes (including for distal feeding) are inspected, the abdomen is palpated and wound/stomas are inspected (including colour/consistency of any stomal/stool output).
8. The underlying diagnosis, any complications, catheter care regimen, medication and the HPS prescription are discussed. Consideration is given to stopping/changing the HPS regimen or its composition. The risks of complications are minimised as far as is possible (e.g. sepsis, thrombosis, liver, bone and renal disease). The underlying diagnosis treatment plan is reviewed. The goals of the fluid/nutritional support are reassessed.
9. All the medicines (oral, enteral tube, sub cutaneous, intramuscular, intravenous or topical) are reviewed including glucagon like peptide-2 (GLP-2) agonists. The absorption of any oral drugs is considered based on the time till maximum concentration (Tmax) and the biopharmaceutical classification. High doses of oral medicines may be needed (e.g. loperamide).

10. The frequency of blood tests (including blood counts, renal, liver, bone, C-reactive protein, minerals (includes magnesium) and vitamins), urine sodium concentration and bone density measurement needs to be determined.
 11. The psychological state, any worries, coping mechanisms, and ways of improving the quality of life are discussed. An anxiety and depression and/or a quality-of-life questionnaire may be used. The NST will give as much support as possible in this setting (a separate follow up discussion may be needed with one or more of the NST on another occasion).
 12. Surgical plans (if any) including transplantation/links to other centres/units or services are reviewed. Appropriate bowel mapping may need to be arranged. Ideally, these discussions occur in a joint clinic with the surgeons.
 13. The home care service is reviewed:
 - This includes the deliveries, storage of equipment, ancillaries, parenteral support bag and home nursing (if required).
 - The individual's potential ability to learn to take care of their central venous catheter and parenteral support administration should be explored with the patient.
 - The nursing Blueteq number should be reviewed and renewed accordingly (the initial allocation of a Blueteq number for nurse training is 28 hours).
 - The parenteral support Blueteq number should be reviewed and renewed accordingly (initial allocation of Blueteq number is for 12 months).
 - The Blueteq number should be suspended if a patient has been weaned off parenteral support.
 - The red/amber/green (RAG) rating and contingency prescription should be assessed.
 14. All information is recorded on a local and/or national register (e.g. Intestinal Failure Registry in England). The GP/referring hospital should be sent a letter summing up the outcomes of the visit.
 15. Patient should know about voluntary patient support and advocacy groups such as PINNT and groups relevant to their underlying disease (e.g. Crohn's and Colitis UK).
 16. An agreed timeframe for the next appointment should be agreed. Reasons for a patient not wanting to attend a clinic appointment need to be gently explored.
- alter the HPS regime to reduce these symptoms, all prescriptions should be looked at critically.
4. Hydration/nutritional status is more difficult to assess at virtual appointments, but the degree of thirst should always be asked. A postural drop of blood pressure is an important indicator of chronic dehydration. Renal function and a random urine sodium concentration measurement are helpful, but note that very underweight patients have a low baseline creatinine.
 5. Nutritional status, in some centres, is additionally assessed by BIA or in some centres computerised tomography (CT) at the third lumbar vertebra (only if a CT scan has been performed for another reason). An assessment of body composition should be made at least annually.
 6. Patients should be given plenty of time and space to describe any problems they may be having with the HPS, equipment (e.g. pump, fridge) and with their underlying disease. Patients will tend to describe different problems to different health professionals.
 7. The entry site of the central venous catheter should always be inspected. The integrity and function of the catheter should also be determined. Often at this point swabs for culture and, if deemed appropriate, central and peripheral blood cultures may be taken.
- If patients have unhealed wounds, it may be useful to inspect them, though it is often not appropriate to take down complex dressings and stoma bags in the clinic. Patients can always be asked to provide photographs and send these to the team. An ideal arrangement is for a stoma nurse to be available for the HPS clinic.
8. A patient's whole illness (e.g. Crohn's disease) may not be reviewed in all HPS clinics and some centres may only review the HPS. Diagnoses may change with time (e.g. possible dysmotility to enteric neuropathy). Consideration is given to the possibility of utilising the enteral route and reducing the HPS requirements (e.g. nights off, or a change to a multi-chamber bag if having a compounded bag). There needs to be separate consideration for hydration optimisation, and for nutritional optimisation.
 9. Drugs mainly include anti-diarrhoeal (loperamide and codeine phosphate) and anti-secretory (omeprazole or pantoprazole) drugs and, increasingly, GLP-2 agonists. There should be a plan to reduce/stop opioids and cyclizine (especially intravenously). Drugs taken orally may need to be given in a higher than licensed dose to be absorbed or consideration given to a topical route. The use of an intravenous proton pump inhibitor (PPI) should be limited to patients who have not responded to an oral PPI.
 10. Renal, liver and bone function tests should be performed regularly as well as checking magnesium, zinc, selenium, copper, haematinics (vitamin B12, folate, ferritin/iron studies), international normalised ratio (INR), and vitamins (A, D and E are most easily measured). A lipid profile is valuable occasionally to ensure that triglycerides are adequately cleared from the circulation, though most patients are not infusing lipid every day. C-reactive protein should also be checked at the same time, as a raised level can be an indicator of occult infection, but also because a raised level can invalidate certain measurements, such as of the micronutrients. A baseline bone density scan, and also liver ultrasound (to determine the presence or absence of gallbladder stones, liver texture and degree of steatosis) should be arranged at appropriate times. Many HPS centres are now undertaking regular FibroScans in long-term HPS patients to help detect intestinal failure associated liver disease (IFALD), although its validity in detecting fibrosis in IFALD, has not been conclusively demonstrated.

Explanations

1. The core team should include a nurse, dietitian, pharmacist and doctor. In most centres, it would be unusual for every patient to be seen by every team member at every clinic visit. It may also be possible and useful for patients to be seen by surgical, psychological and stoma care colleagues, if necessary. There needs to be appropriate space for the NST and confidential discussions.
2. A preliminary discussion with the NST about the current observations, blood tests (done by the HPS centre and/or GP) and any communications from other healthcare professions, carers, relatives or the patient should occur. This will make it clear which team members are most important to the visit. Other information may need to be found such as outcomes from other clinics or other hospital attendances. The NST needs to be aware of new issues that are of major concern to the patient (may include new activities, sports and conception/pregnancy/adoption).
3. Symptoms can be from the underlying disease process or from the HPS. The latter could include excess nocturnal micturition and non-specific effects of infusions. While it may not be possible to

11. Quality of life can be assessed by general questioning, or by formal questionnaires (e.g. the Parenteral Nutrition Impact Questionnaire (PNIQ)), which can be sent to the patient in advance of a clinic. While the outcome of formal assessment will not change the basic nutritional requirement, it can be useful in making balanced judgements between what is thought to be required nutritionally, and with what the patient can cope. Anxiety and depression may need a referral to mental health services.
12. Establishing current anatomy and planning the timing of surgery (if required) will need to be assessed in close liaison with surgical colleagues, often best done separately from the HPS clinic, such as at a joint medical/surgical MDT meeting. There will also need to be close liaison with gastrointestinal radiologists who will use various imaging modalities to assess bowel anatomy, quality and length, and the abdominal wall. For patients referred in from other hospitals, it will be essential to obtain detailed histories and operation notes leading up to the first assessment visit.
13. All HPS centres should have quarterly review meetings with the homecare companies (HCCs) both to flag up generic problems and those with individual patients. Patients will also have access to the MDT to flag up problems as soon as they occur.
14. The exact method of data recording will vary from hospital to hospital, but most will be using computerised medical records. Many hospitals will have an internal database of patients either linked to the hospital computerised medical records or managed separately within the MDT. HPS centres will also need to upload data to the IF Registry, as required by NHS England. Ideally, all blood results should be held within the hospital computerised medical record, so that serial measurements can be easily tracked and plotted.
15. Voluntary patient advocacy groups, for example PINNT, can provide shared experiences and open routes of communications for new patients on HPS to talk to others with experience of living with the treatment, as well as useful practical advice and tips on aspects such as holidays, travelling, insurance and energy supply/bills.
16. Clinic appointments may be missed for good reasons but sometimes it is due to fear/anxiety and ways to alleviate this are needed.

Important information

1. Blueteq number

A Blueteq® number must be obtained by a member of the NST at the HPS centre before the patient is discharged. The Blueteq® number is attached to the HPS centre, so a new number must be obtained if a patient changes HPS centre. Numbers are valid for 12 months, so yearly update is required. All HPS patients should be registered on the IF Registry (formerly known as e-BANS). The registry needs to be maintained for all patients, including details of any admissions, surgery, outpatient clinic outcomes and any HPS-related complications.

2. RAG rating

Homecare companies (HCCs) are vital in supplying HPS to patients. Due to the complexity of this service, there may be occasions during which a HCC's capacity may be compromised (e.g. Covid-19 pandemic, workforce shortages or product shortages). Clinical teams must have robust contingency regimens in place for every patient, and compounding priority categories must be agreed. This (RAG rating) will enable those patients at highest clinical risk to continue to receive compounded HPS (RED rated), whilst those able to be managed on hybrid, multi-chamber bags or IV fluids and electrolytes are supplied with an alternative regimen (AMBER or GREEN rated).

Suggested reading

- BIFA guidelines and recommendations, position statements, and top tips: www.bapen.org.uk/about-bapen/bapen-special-interest-groups/bifa (especially on monitoring)
- Royal College of Physicians (2023). Modern outpatient care. Principles and practice for patient-centred outpatient care. Available online: https://medicalcare.rcp.ac.uk/media/bemfa4cv/cqid_qi_modern-outpatient-care_0.pdf

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