

Home Parenteral Nutrition Services in England Patients Charter (Version 2)



Introduction

The national HPN framework is commissioned by NHS England to improve standards and access to home parenteral nutrition services for adults and children in England. Only companies who have formally applied to be on the framework and have demonstrated they meet the specified standards are authorised to provide homecare.

A framework lasts for 2 years with the option to extend for a further 2 years. The current framework commenced on 1 April 2020.

The purpose of this charter (Version 2) is to provide you with information on home parenteral nutrition services outlined within the framework. It replaces the original charter issued in 2016. It includes what you can expect from the service and also explains your rights and responsibilities, in line with the NHS constitution principles.

The constitution can be found at

<http://www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Documents/2013/the-nhs-constitution-for-england-2013.pdf>

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The framework explained

Home parenteral nutrition (HPN) care is the process through which feeds and fluids are provided directly to patients at home, along with the equipment and any care that may be clinically needed to administer these safely. HPN care is funded by the NHS who contract commercial homecare companies to provide the service as outlined within a detailed set of standards. These standards form The *National Framework Agreement for the Supply of Home Parenteral Nutrition for England* (or framework for short) and cover all aspects of home parenteral nutrition, including the making and delivery of the feed and ancillaries, and the provision of specialist nursing for those not able to administer the feed themselves. The framework was developed as part of a national tender process commissioned via NHS England and the Commercial Medicines Unit. It contains over 500 individual specification points which companies have to demonstrate they are able to comply with.

The tender process



This is a structured process involving experienced healthcare professionals, commissioners and patient representation. The specification points of the existing framework which ran from 1 April 2016 were reviewed point by point to check that they were still appropriate. The wording on some points was changed to remove ambiguity, and some new points were added.

A number of standard documents accompany the framework which all homecare companies and HPN centres must use. Examples of these include patient and nurse training competencies, patient needs assessment form, and a standard ancillary list. These were also reviewed and updated to make sure they reflect current practice.

While the drive behind the framework is quality and equity of access to services, inevitably there is a need to consider the cost of these services – which is considerable. In addition, the number of individuals requiring home parenteral nutrition and/or fluids continues to increase. In order to secure the on-going provision of homecare for *anyone* needing it, NHS England require cost efficiencies to be demonstrated. The tender process and development of the new framework set out to reduce unnecessary waste of product and services, and while this may result in some minor changes to what you can expect from the service, everything you/your child need to administer HPN will continue to be provided.

Patient rights from the tender process

- You will have all the necessary equipment to safely administer HPN and or fluids.
- The homecare company allocated to you will have been assessed during the tender process to meet all of the standards required to provide a safe and effective home parenteral nutrition service.
- If there are to be changes to your homecare service, your HPN centre will discuss them with you before they are implemented.
- If your HPN centre decides to change your homecare company, the reasons behind this change will be discussed with you.
- Transfer of personal data will not occur without prior permission from yourself.
- Any transfer of care between homecare companies should be seamless.
- You can request a transfer of homecare company if you are not happy with the service you are being provided with, however this is dependent on one of the other companies having the capacity to take on your care, and there is no guarantee that the service will be any different from another company.

How this will affect me/family member

Most existing patients will not notice any changes to their HPN service. If you experience any changes to the service and are unhappy with them, please talk to your HPN centre. Information on how to make a formal complaint can be found on page 11. The national tender exercise aims to ensure that all key aspects of good quality HPN care remain, and to make that care available for **all** patients across England. However, we have to be mindful that there are limited resources available, and so we need to use them responsibly.

Equipment



You should be offered an ambulatory pump, drip stand, dressing trolley or tray, and a fridge (if your bags need to be refrigerated). The equipment provided to you is on loan from the homecare company and needs to be returned to them on request. Any changes to the make of pump you are provided must be approved by your HPN centre and only ones evaluated by LITRE can be offered. You will only be supplied with a second pump if there is a clear clinical reason why this is necessary. Adults can be provided with a supply of gravity giving sets for emergency use in case of pump failure. Second pumps can be temporarily provided for any holidays abroad.

Ancillaries



The ancillary items included in the framework are based on current evidence and best practice guidelines. If there is no clinical evidence to support the choice behind products, for example make of glove or dressing towel, the homecare company can select which product to supply. This permits significant cost savings to the NHS, and is standard practice in hospitals. This may mean you are sometimes sent products [brands] you don't like, however, you will always be sent products that comply to the framework description. If there is clinical evidence to support the choice behind an item, for example needle free connector, make of dressing, then your HPN centre in conjunction with you can choose which specific products to request. Note: NHS England will only reimburse your HPN centre for items which appear on the standard ancillary list.

Medication



There are a small number of intravenous drugs which can be supplied via the framework. These are antacid medication (for example Pantoprazole), anti sickness medication (for example Cyclizine, Ondansetron) and antimicrobial locks (for example Taurolock/Taurolidine, Ethanol). If you have nursing, these can be administered by the homecare nurses *as long as it* coincides with a connection or disconnection visit. Note: Concerns have been raised about the use of IV Cyclizine in HPN patients and consequently some HPN centres do not prescribe it.

<https://www.bapen.org.uk/pdfs/bifa/position-statements/position-statement-on-the-use-of-cyclizine-in-patients-receiving-pn.pdf>

Nursing



The NHS funds HPN nursing, **not** the homecare company. Nursing visits are for patients and/or carers receiving training, or patients *unable* to administer parenteral nutrition themselves. The framework only covers nursing for the provision of HPN and necessary central venous catheter care. Other duties, for example the administration of drugs not on the framework, are included *if* they coincide with an HPN related visit. An initial nursing allowance of up to 28 hours is given for patients/carers undergoing training, and NHS England need to be informed if patients require more than 28 hours, plus the reason for the ongoing nursing support. There must be a clinical indication for nursing.

Travel



The travel service that is funded under this framework is for the following:

Delivery of product & ancillaries to a UK mainland destination, including port or airports

- Packaging to ensure that the cold chain is maintained where required
- Nursing (UK) *if* there is nursing available at the holiday destination
- Letters explaining medication and equipment

The service does not cover:

- Transport of feed/ancillaries abroad
- Compounding abroad
- Delivery & collection of a fridge to a holiday destination



The homecare company delivers your care on behalf of your HPN centre. The prescribed parenteral nutrition and/or fluids will be delivered directly to your home. This service is funded by the NHS. Your HPN centre is billed directly by the homecare company, who then review the invoices for each patient, and then submit an invoice to NHS England for reimbursement.

Support and advice:

- You will have access to help and support. Before you leave hospital, you will receive information from your homecare company giving details of the service that will be provided to you.
- You will meet with a homecare representative before initial discharge who will be able to provide you with all the information you need about the homecare service.
- You will be given a free phone number for an out-of-hours telephone advice service by the homecare company.
- A named co-ordinator will be your central point of contact at the homecare company. The co-ordinator will be courteous and fully conversant with the HPN service.

You can expect to be treated with courtesy and respect at all times from all staff:

- All communications (written, face-to-face, telephone, email or web based) will be timely, appropriate and effective.
- Any information transferred between you (or your guardian/parent), HPN centre and homecare company will be kept confidential at all times. All healthcare providers must comply with Information Governance requirements set down in law.
- You should have a group of named drivers who will be smart in appearance, courteous, fully conversant with the delivery system, and will deliver the products to your room of choice. They will wear visible company identification.
- Deliveries will be made in unmarked vans, or if there is a company livery this will not be identifiable as a medical supplier.
- All personnel involved in your treatment will have undergone a satisfactory Disclosure and Barring Service (DBS) check.

Deliveries and equipment:

- Your deliveries will be in an allocated two-hour window. You will be notified of any changes outside of this. It is not possible for you to request a specific two-hour window, or the company to be able to guarantee a slot.
- All your stock items will arrive fit for use and in line with your stock list. You should be notified before the delivery if any items have been substituted or are out of stock.
- If you request alternative equipment (e.g. fridge/pump) this may be provided, but only if there is a clinical reason to support the change.
- The homecare company is responsible for maintaining and servicing all equipment on loan to you. If equipment (e.g. pumps, fridges) break down these will be replaced within six hours.



What your homecare company expects from you (patient/carer/guardian/parent)

Before you start receiving home parenteral nutrition you will need to fill out a registration form . This shows you have understood the information provided to you, and that you are happy to start home parenteral nutrition.

Communication with the homecare company

- Please be courteous at all times when dealing with personnel from your homecare company. There is a zero tolerance policy to violent, racist, sexual or aggressive behaviour.
- Routine communication with your homecare company should be carried out during their normal working hours. A 24-hour advice line is available for urgent queries/enquires.
- Please ensure that you or your nominated representative are present at the agreed delivery time. If you are unable to be there please inform your homecare company as early as possible.
- Please inform your homecare company if you are admitted to hospital. Any feed already made can be delivered to home or to the hospital, but if you are going to be in hospital for an extended period, the hospital will need to make their own arrangements for providing you with a suitable feed.
- Please give your homecare company a minimum of six weeks' notice if you have any travel plans and need your feeds to be delivered to another UK mainland location. If less notice is given the company may not be able to meet your request.
- Please inform your homecare company if you plan to move home, so that they can co-ordinate delivery to your new address.
- In order for your homecare company to develop their service your contribution to any patient satisfaction surveys is encouraged.

Stock and equipment

- As a partner in the provision of your homecare service, the homecare company rely on you to keep adequate stock levels, including a 2 week safety stock, of all non-prescribable items on your list and report any problems. Please do not over stock your ancillaries: they may expire, or you may change to a different item, so they may be wasted. Once delivered to you, stock cannot be returned for use by another patient.
- If you are no longer using a particular ancillary please inform your homecare company and HPN centre so that it can be removed from your stock list.
- The equipment provided for you to administer your HPN, and the nursing notes, belong to the homecare company and must be returned at the end of your treatment. You have a responsibility to ensure they do not get damaged or lost, and are stored and used according to the instructions your homecare company provides. The pump is for home use only and should not be taken into hospital with you. It is recommended that you check with your home insurance company if the medical equipment on loan to you can be covered by your existing policy, or with an amendment to it.
- The items supplied to you by the homecare company are for your use only. Do not share, or give medicines, medical fluids or ancillaries supplied to you, with or to anyone else. You could be liable for any negative outcomes as a result of someone using items originally supplied to you.
- To keep your feeds safe and stable, always ensure that your fridge is closed securely and kept within the required temperature (2- 8°C).

Nursing service

What can you expect from your nursing service?



The nursing service will deliver aspects of your homecare specified by your HPN centre. Nursing visits are for patients and/or carers receiving training, or for patients unable to undertake the procedures themselves. There must be a clinical reason for nursing.

You can expect to be treated with courtesy and respect at all times from the nursing staff:

- You should be offered a named nurse as a primary point of contact. All nurses attending your home will have company issued identification.
- All communications (written, face-to-face, telephone, email or web based) will be timely, appropriate and effective.
- The visiting nurse will be smart in appearance, courteous and respectful, and will be fully aware of the HPN service that you are receiving, and perform the procedures in the room of your choice.
- Any nursing staff attending your home will be fully competent in the procedures and protocols outlined in the framework competencies, national unified PN procedure and your HPN centre's instructions.
- The nursing staff will respect your home and will wear shoe covers if requested.
- All nursing staff will have undergone a satisfactory Disclosure and Barring Service (DBS) check.
- Any information transferred between you (or your guardian/parent), HPN centre and homecare company will be kept confidential at all times. All healthcare providers must comply with Information Governance requirements set down in law.
- All nurses have a responsibility to safeguard patients in their care and to share any concerns they may have with you, and if deemed necessary, formally report their concerns to your local safeguarding team.

What the service covers:

- The nurses may administer parenteral nutrition, intravenous fluids and any other IV medications on your home prescription. They are not able to administer other medication unless your HPN centre has made a request and sent a prescription to the homecare company. They will also provide necessary central venous catheter care, for example changing the dressing.
- Although you may request that certain nurses visit you, there is no guarantee that your requests can be honoured as there are a limited number of nurses available in each area. This includes requests for male or female nurses.
- A maximum of 2 visits (maximum 1 hour per visit) can be made in a 24 hour period.
- Your nursing visits will be in an allocated two-hour window. You will be notified of any changes outside of this. Note: Visit times for training are scheduled for 'off peak' times, as priority for the popular time slots is given to those needing long-term nursing.
- The nursing service can continue for as long as it is clinically indicated, however if you have been signed off as being able to undertake the procedures yourself, you will no longer receive nursing unless there is a valid clinical reason why you are unable to undertake the care yourself.
- If there has been a break within the service, for example if you have been in hospital, 48 hours' notice is required before the nursing service can start again.
- In the unlikely event that the nursing service feel they are unable to continue supplying nurses, unless there are concerns surrounding the safety of the nurses visiting your home, the nursing service cannot be withdrawn until a satisfactory alternative service can be secured.



Visits to your home

- Please be courteous at all times when dealing with nursing staff.
- The nurses have a right to care for you in a smoke free environment. If you smoke, please do not smoke for at least 1 hour in the room in which the nurse will be treating you.
- If you have pets, please consider keeping them in a separate room during the course of the visit.
- Nurses visiting your home need to feel safe, so other family members or visitors to your home also need to treat the nurses with courtesy and respect. Please remember that some behaviour may make the nurses feel unsafe (for example, intoxication, use of illicit drugs, being inappropriately dressed, using obscene or sexual language, watching pornography in the nurse's presence).
- There is a zero tolerance policy to racist, violent, sexual or aggressive behaviour. Racist, violent, sexual or aggressive behaviour may result in the immediate withdrawal of the nursing service.
- While the nursing visit will try to have as little impact on your daily routine as possible, it cannot be guaranteed that you will not have to make some concessions to the nursing visits, for example changing the time you and your family eat.
- Unless there is a valid reason for not allowing entry to a nurse that arrives early for a scheduled visit please do not make them wait outside until the start of your 2 hour window.

Communication with the homecare nurses

- As a partner in the provision of your nursing service please give as much notice as possible if you are not going to be in for a scheduled nursing visit. Your HPN centre will still be charged for the visit if the nurse was not informed not to attend. If there are repeated incidents where you are not available at the time of your scheduled visit then the nursing service may not be able to continue.
- Please inform your nursing service if you are admitted to hospital.
- Please inform your nursing service and HPN centre if you have any plans to travel. They will then let you know if there are nursing staff available at your travel destination (UK only).
- Please inform your homecare company if you plan to move home, so that they can co-ordinate nursing visits to your new address.
- In order for your nursing service to develop their service your contribution to any patient satisfaction surveys is encouraged.



Your HPN centre will have experience in caring for patients requiring HPN. The HPN centre is responsible for appointing one of the approved homecare companies to provide you with homecare, and for specifying all aspects of your homecare service that the homecare company must deliver.

Support and advice

- You will have access to help and support. Before you leave hospital, you will receive information from your HPN centre detailing contact numbers for who to contact during working hours and out of working hours.
- Your HPN centre will regularly review you in out-patient clinics with regard to your clinical health and homecare service. This will give you time with your clinical team to discuss any concerns. You need to be seen at least once a year in order for your HPN centre to continue prescribing your home parenteral nutrition.
- The HPN centre will work with you to decide the most appropriate equipment and ancillaries, and you should be offered alternatives if there is a clinical reason to support this.
- You will be able to request changes in relation to certain aspects to your homecare service after consultation with your HPN centre. Your homecare company will then be instructed of any agreed changes.

You can expect to be treated with courtesy and respect at all times from all staff:

- All communications (written, face-to-face, telephone, email or web based) will be timely, appropriate and effective.
- You have a right to confidentiality at all times.
- Any information transferred between you (or your guardian/parent), HPN centre and homecare company will be kept confidential at all times. All healthcare providers must comply with Information Governance requirements set down in law.
- All staff at your HPN centre will have undergone a satisfactory Disclosure and Barring Service (DBS) check.



Communication

- As a partner in the provision of your homecare service the HPN centre relies upon you to inform them of any changes to your condition or circumstances that may impact on your homecare.
- Please be courteous at all times when dealing with your HPN centre.
- If you are unable to attend a clinic appointment, please notify your HPN centre as soon as you are aware of this so that your clinic slot can be given to someone else who needs it. If you do not attend an appointment your slot will have been wasted. You need to be seen at least once per year in order for your HPN centre to continue prescribing your infusions. If you repeatedly do not attend for review your prescription may be stopped.
- Please make sure that you tell your homecare company if you are not going to be available for a scheduled delivery or nursing visit. If you do not do so, the HPN centre will still be charged for the delivery.
- Please remember to inform your homecare company if you are admitted to hospital.
- In order for your HPN centre to develop their service your contribution to any patient satisfaction surveys is encouraged.

Your feeds and equipment:

- If you have a scheduled delivery from the homecare company, which necessitates you being there; you have an obligation to notify the homecare company if unforeseen circumstances mean that you can no longer be present. Where possible this should be in advance of your delivery time as the HPN centre will still be charged if the delivery is unable to take place, and will incur an additional delivery charge for the re delivery of the feed.
- If you are admitted to hospital, you may bring the feeds that you already have at home, but please do not bring your pump, as this is the property of the homecare company and is for your use at home only.
- The equipment provided for you to administer your HPN is on loan from the homecare company. It remains the property of the homecare company. You have a responsibility to ensure that it does not get damaged or lost, and is stored in appropriate conditions as specified by your homecare company.
- The items supplied to you by the homecare company are for your use only. At no time should you share them with or give them to, anyone else. You may be considered legally responsible if someone is harmed by medical items that you have given to them.

Social media

Social media has become a daily part of life for many of us. There are some wonderful groups on line which can provide invaluable information and advice, but there can be a negative side as well, as some people chose to use social media to air their concerns and opinions regarding the quality of care they receive.



Hospital trusts and homecare companies have policies for staff using social media either professionally or personally, and each site also has terms and conditions regarding what can and cannot be posted. There are some closed patient sites which also have terms of reference regarding suitable content, however, anything posted on a general site is open to anyone to read.

Frequently asked questions



1. Can I request a change of homecare company?

If you are unhappy with the service from your homecare company you *can* request to change to another, however there is no guarantee that another company would be able to take on your care. It is best to discuss your concerns first with your HPN centre and homecare company to see if the issues can be resolved. It may be that the concerns you have would be present with another company too.

2. Do I have to learn to take care of my line and parenteral nutrition?

The nursing service is for training of patients and/or carers, and for patients unable to undertake the procedures themselves. It is not there to provide regular check up visits. Most people will be able to be trained for some, if not all, of the procedures. Training and promoting independence should form a part of all transition pathways for children and young people. As long as there is a valid clinical reason why you need nursing support it will be provided.

4. Why can't my home parenteral nutrition be sent to hospital if I am an inpatient?

If your parenteral nutrition has already been made then it can be sent to a hospital if you are an inpatient there. Any parenteral nutrition needed after this will need to be made by the hospital where you are an inpatient. If the hospital does not have the facilities to make your prescription then they can purchase it directly from your homecare company.

5. Can I specify which nurses visit me?

Although the companies employ a large number of nurses, they provide a service to the whole of England. Therefore the number of nurses available to you may be quite limited. You will not be asked to accept a nurse if there are concerns about their competency or behaviour, however, it is not possible for a company to grant specific requests regarding which nurses you like or do not like. This includes being able to guarantee nurses of a particular sex. 10

Making a complaint about your homecare service



Homecare company

Should you need to make a complaint about the service offered by your homecare company this can either be directly to the company or via your HPN centre.

Homecare nursing

Complaints about a particular nurse, or the nursing service in general, can be made directly to the company or via your HPN centre.

HPN centre

Please contact your HPN centre directly, or if you do not feel able to speak to them directly, via the Patient and Advisory Liaison Service (PALS) of the hospital. Details of this service will be available on the Internet.

Any complaints should be acknowledged within 48 hours either verbally or in writing and a full report sent to you within 14 days. If you feel that any formal complaints are not resolved to your satisfaction you should contact the Health Ombudsman. Details are given below.

Useful contacts

Health Ombudsman

Customer helpline 0345 015 4033

8:30am - 5:30pm Monday – Friday

www.ombudsman.org.uk

NHS Constitution

<http://www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Document/2013/the-nhs-constitution-for-england-2013.pdf>





HPN Patients Charter

This charter has been authored by the HPN Stakeholders Group - a multidisciplinary panel of experts commissioned by NHS England

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