Immunoglobulin Home Therapy Booklet for GPs
INTRODUCTION

A booklet to give GPs an outline of the home therapy programme and the role of the general practitioner.

WHEN TO USE THIS BOOKLET

To be given /sent to GP prior to patient commencing home therapy training.

HOW TO USE THIS BOOKLET

GPs should read this information prior to their patients starting home therapy with intravenous or subcutaneous (normal) immunoglobulin. This will aid effective communication between GP and CIAU staff to optimise the care of the patient.

RISK MANAGEMENT

To reduce the risk of complications and help patient maintain independence in giving their own treatment safely.
Information on Home Therapy for General Practitioners

Aims
To outline the Home Therapy programme and the role of the General Practitioner (GP) in this programme

Objectives

➢ To ensure GPs are aware that their patient (s) have been prescribed immunoglobulin

➢ To inform the GP about the process of Home therapy and the training involved for his/her patient

➢ To enable the GP to highlight any potential problems or concerns regarding the patient’s or infusion partners suitability for the Home therapy programme

➢ To inform the GP about potential adverse reactions and information given to the patient on the action to take with:
  - Mild
  - Moderate
  - Severe reactions

➢ To provide the GP with contact details for further support and advice as required:

Contact numbers

Sister Fran Ashworth  Senior Immunology and Allergy Nurse Specialist  Daytime 0114 2434343      Bleep 2918 at the NGH or by Long range pager via Northern General Hospital switchboard

Sister Tracy Brown  Immunology and Allergy Nurse Specialist  0114 2266964  8.30 – 16.30 hrs only

Consultant Immunologists Dr Egner, Dr Sargur or Dr Shrimpton  can be contacted during normal working hours on 0114 2269020 0r 0114 2269052 or LRP via switchboard.

There is no routine out of hours cover, but the consultants will be happy to be contacted in the unlikely event that advice is required in an emergency.
National Guidelines for Home Immunoglobulin Treatment

It is a requirement that patients receive formal competency based training at a recognised centre before infusing intravenous or subcutaneous immunoglobulin at home.

Guidelines for Home Immunoglobulin therapy have been approved by the professional medical and nursing bodies and by the Department of Health.
http://www.ukpin.org/home/standards

“The low incidence of adverse reactions with current intravenous and subcutaneous immunoglobulin preparations and the ability to take measures to prevent such reactions has enabled self infusion at home to be undertaken safely”

The Sheffield Teaching Hospitals NHS Foundation Trust offers an approved Intravenous / Subcutaneous Immunoglobulin Home Therapy Programme for patients and infusion partner.

Conditions treated with Immunoglobulin

Immunoglobulin replacement therapy is indicated for primary antibody deficiency disorders and for patients with combined immunodeficiencies of lymphocyte function which also involve deficient antibody production. These diseases include Common Variable Immunodeficiency, X linked Agammaglobulinaemia, Specific Antibody Deficiency, IgG Subclass Deficiency, IgA Deficiency, X linked Hyper IgM Syndrome, Duncan’s syndrome, Wiscott-Aldrich Syndrome and Severe Combined Immunodeficiency (SCID) and its variants.

Immunoglobulin is globally in short supply and concern over its availability has led to the National demand management programme for Immunoglobulin to be set up. This provides a guide on the appropriate use of immunoglobulin products. It is overseen by a local committee.

The link below provides information on this demand management plan, a list of immunoglobulin preparations available and a summary of indications for the use of Immunoglobulin.


Adverse Effects – identification, management, importance and incidence

Adverse reactions occurring during or immediately after intravenous or subcutaneous immunoglobulin administration are extremely rare. Studies have shown the rate to be less than 0.5% with no severe reactions (J Clin.Immunol. 1995, 15, 116-119, Lancet 1995, 345, 365-369). Patients receive training in the prevention, recognition and management of adverse reactions.
Adverse reactions are rare, but more likely to occur in patients receiving normal immunoglobulin for the first time; following a prolonged period between treatments; when switching to a different normal immunoglobulin product; using higher than recommended infusion rates or in patients with an untreated bacterial infection. Infusions should therefore be delayed until such infections have been controlled with antibiotics (at least 48hrs) and the patient is apyrexial and shows signs of improvement.

**Local reactions** such as redness and swelling are common at the site of subcutaneous infusions and generally resolve over a few hours without any specific treatment.

**Minor reactions** such as headache, flushing, shivering may occur. These symptoms are managed by stopping the infusion and the administration of Paracetamol. Once symptoms subside, the infusion can be restated at the initial rate and can usually be increased gradually and completed.

**Moderate reactions** such as chest tightness and wheezing may occur. The infusion should be stopped and medical advice sought.

**Severe reactions** such as chest pain, severe breathlessness or collapse require urgent medical help. Patients are taught to self-treat severe reactions with intra-muscular epinephrine (adrenaline) pending medical assistance.

All adverse reactions should be reported by the patient to the immunology team. In the event of moderate or severe reactions, the subsequent infusion should be carried out in hospital.

**Selection of Suitable Patients for Intravenous or Subcutaneous Immunoglobulin infusions at Home**

1. Patients must have expressed a wish to infuse at home, and have suitable venous access for intravenous therapy only.

2. All patients and infusion partners must be committed and motivated to learn.

3. Patients must have 3 months of hospital infusions of the same preparation of intravenous / subcutaneous immunoglobulin product without adverse effect, and demonstrate competence in its administration and in the recognition and management of adverse effects.

4. The General Practitioner should agree to the administration of therapy at home in his/her practice area. The GP will be approached by the Immunology Nurse Specialist.

5. Availability of a Telephone service while infusing is vital.

6. For IVIG administration there must be an agreed infusion partner (relative or friend) trained to carry out venepuncture present at all infusions. Patients infusing via the subcutaneous route may not require an infusion partner.

7. Refer to Appendix Home Treatment Agreement Form
Training

Training is co-ordinated by the Immunology Nurse Specialist and local hospital (if applicable). Training is structured to meet individual patient needs and with the aid of the competency based home therapy training programme. Community nurses are welcome, but not required, to attend.

Initially, patients and infusion partners are encouraged to participate in preparing and monitoring the infusions and venepuncture under the guidance of a named doctor/nurse in hospital.

Patients and infusion partners attend the CIAU for treatment and undertake home therapy training during their scheduled infusion appointments. The patients and partners (if applicable) are instructed in all aspects of storage, preparation and maintenance of the Immunoglobulin infusion and aseptic technique. Venepuncture (if applicable) and adverse reactions are covered in some detail as per CIAU Competency Based training programme.

Following this, further infusions should be carried out in hospital with minimum supervision. The Immunology Nurse Specialist will make a further assessment before the first infusion is carried out at home and ensure adequate competency has been achieved.

A test paper must be completed with 100% pass rate before the next stage of the home therapy programme continues.

No one is allowed to infuse at home until both they and their infusion partner are judged competent and safe.

Adrenaline is not supplied to every patient on home therapy; a risk assessment is undertaken on an individual basis.

Adrenaline may be prescribed to patients on IVIG, depending on the patients’ wishes and their proximity to local hospital, to use in the extremely unlikely event of a severe reaction. The hospital will provide an initial Epipen when patient is ready to go home on IVIG therapy and thereafter the GP will be responsible for the continuing prescription. Adrenaline in the form of an Epipen is not normally supplied to patients on subcutaneous infusions. Patients are advised to have antihistamines and paracetamol at hand during the infusion.

Equipment

The following equipment is provided free of charge to all patients. There is no cost to the GP.

Drip stand, sharp bins, infusion sets, tourniquet, blue butterfly needles, gauze, tape, sterile sheet, alcohol surface and skin wipes, vacutainer system blood sampling bottles, any special equipment needs i.e. dressing packs etc., are provided free but only on an individual basis.

Infusion pumps are not required for intravenous therapy but are supplied for patients on subcutaneous therapy.
These items are delivered by a home care company who also collect the clinical waste including sharps bins.

The Role of the General Practitioner

Agreement from the GP is always sought and is vital to successful home therapy, but the ultimate responsibility for the patient’s treatment remains with the Consultant Immunologist.

Aspects of care for which the GP is responsible

- Monitoring the general health of the patient at routine practice appointments and alerting hospital if cause for concern
- Responding quickly to the need to prescribe a minimum of 10 days high dose oral antibiotics for infections. In most circumstances Sheffield formulary antibiotics should be effective as first line treatment.
- Responding to emergency calls from infusion partners in the unlikely event of a serious adverse reaction
- Ensure that immunoglobulin is entered onto GP computer system in such a way as to alert interactions and monitoring requirements, whilst minimising risk of an FP10 prescription being issued by the GP surgery
- GPs may be requested to take 3 monthly blood samples for CRP, LFTs and trough immunoglobulin levels immediately prior to a patient’s infusion. It is the responsibility of the patient to make arrangements for this with their GP if required. Results are monitored by the hospital team.
- Prescribing subsequent Epipens, if necessary
The Role of the Immunology Nurse Specialist

The CIAU Immunology Nurse Specialist acts as a co-ordinator for the training of patients, infusion partners and health care professionals and the long-term management of the Home Therapy Programme. She / He liaises between other members of the health care team and acts as a resource for specialist advice and information regarding Immunoglobulin infusions and complications of immunodeficiency. She / He provides information and support to patients and partners.

The Immunology Nurse Specialist may visit local hospitals (if appropriate) or patients’ homes for training and monitoring purposes if necessary.

Patients should submit their infusion logs which will be monitored at least three monthly to ensure early action if problems arise.

The Role of the Immunologist

Regular follow-up by the Clinical Immunologist is essential and in patients with specific complications, shared care with appropriate organ-based specialists is necessary. In order to provide optimum service, it is important that patients on Home therapy continue to be monitored by the Clinical Immunologist at 3-6 monthly intervals or at the discretion of the medical team. If the patient fails to comply with the agreement they may be removed from the home therapy programme.

Support and Follow-up

The patient keeps an infusion log which is sent to the Immunology Nurse Specialist three monthly.

Telephone advice from the Clinical Immunologist or Immunology Nurse Specialist is available at all times during working hours. Out of hours advice for General Practitioners and patients is available via the Northern General Hospital switchboard in an emergency (see Contact No’s on Page 3).

Blood results are monitored regularly and annual assessments of patients are undertaken by medical and nursing staff.
Appendix. HOME THERAPY AGREEMENT FORM

I .................................................. confirm that I wish to be trained by the Immunology Nurse Specialist in the administration of immunoglobulin’s in my home environment and have read the information sheets provided.

1) I am fully aware that immunoglobulin’s are a blood product.

2) The side effects of immunoglobulin’s have been discussed in detail with me by the Consultant and Specialist Nurse.

3) I am fully aware of the potential risks of immunoglobulins.

I have the agreement/support of my General Practitioner
(Name) Dr ............................................. and an infusion partner

(Name) ........................................................

I confirm that the risks of undertaking the home therapy have been explained to my infusion partner and me.

Signed