#### Non-attendance at clinic

If you do not attend your scheduled six-month review, another appointment will be arranged within a month of the initial appointment.

If you do not attend the second appointment, TCP will be notified and requested to discontinue home delivery within one month until further notice.

A nurse will contact you by telephone and letter and you will be required to attend your nearest Treatment Centre for a clinic review.

The nurse will ensure that you will have two treatment doses or a 100% factor rise in case of emergency. No further supplies will be delivered to the patient's home without the authorisation of the patients Haematology Consultant who will meet with you to reaffirm your commitment to your home treatment programme.

The Home scan app is called mpro5Hx and this can be downloaded free of charge to your mobile phone device. The mpro5Hx app is a safer & more convenient method of recording your treatment. Real time data capture allows both you and your clinical team to review your treatment together and plan you care safely and effectively. You clinical team will provide you with a user guide and details on how

National Coagulation Centre (NCC), St James's Hospital, Dublin 8.

Phone: 01 2162141

**Galway University Hospital** 

Phone: 091 542348

Cork Coagulation Centre Cork University Hospital Phone: 021 492 2278

# Home Treatment

### Patient Information leaflet









#### What is Home Treatment?

Home Treatment is an effective way for persons with haemophilia to manage their condition. Home Treatment means <u>you</u> can treat bleeds quickly by injecting yourself with an agreed amount of clotting factor concentrate (CFC). This means you don't have to come to the hospital for every bleeding episode and you can prevent bleeds if you are taking regular treatment (prophylaxis).

#### **Treatment Options**

- On demand treatment
- Prophylaxis

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#### What is 'On demand' treatment?

'On demand' treatment is where you treat yourself with clotting factor concentrate as soon as a bleed or injury occurs.

#### What is Prophylaxis?

Prophylaxis involves taking regular treatment of clotting factor concentrate which will:

- reduce the frequency of all bleeds
- prevent bleeds at certain times e.g. when playing sport
- reduce the frequency of bleeding in "target joints" e.g. if one joint has regular bleeds

All prophylaxis doses will be decided according to the individual needs and bleeding pattern of the individual.

# Commitment to the Home Treatment Programme:

Choosing on demand treatment or prophylaxis involves **partnership** between the patient and your team at the Haemophilia Centre.

Once you have started on the Home Treatment programme you will be required to link in with your nearest TreatmentCentre at regular intervals.

#### Commitment from you will involve:

- Attending a review Clinic in the Haemophilia Centre every 6 months.
- Recording and reporting your bleeding episodes and recording your CFC usage is vital. This information is vital as it will help you and your Haemophilia Team to choose the right dose and frequency of clotting factor concentrate (CFC) for you.

Your Treatment Centre will provide you with education on how to manage the Homescan application (mpro5Hx) on your mobile phone or withwritten documentation (pink sheet) to record the treatment you are infusing.

This information will be held electronically to ensure all relevant Haemophilia centres can plan your care safely and effectively

# Home Delivery of your Clotting Factor Concentrate

- Your Treatment Centre will send a prescription to TCP who will liaise directly with you to arrange a time and date of delivery.
- Deliveries are scheduled weekly, monthly or two monthly depending on the individual patient requirements
- TCP will liaise with your treatment centre with regard to delivery issues, extra orders or other issues as they arise.
- For repeat prescriptions of CFC you will have to attend the clinic in your treatment centre every six months or according to your clinical needs.

Appointments for the review clinic will be sentto you. If the proposed appointment date is not suitable, you have a responsibility to contactthe centre and agree an alternative date and time. Text message reminders are also sent to those whose mobile numbers are on file.