

**Meeting with Mr & Mrs M [REDACTED]
Monday 24 March 2003**

A further meeting was arranged and this time Staff Nurse Shea from the centre was present with Professor Ludlam and Mrs McKigen. Mr & Mrs M [REDACTED] brought along Caroline Pretty from Lothian Health Council.

It was agreed that Mr & Mrs M [REDACTED] would continue their care under Professor Ludlam meantime. Mr M [REDACTED] explained that he could not sit down in the waiting room because of the pain in his joints. Mrs McKigen again suggested referral to the pain clinic and this time Mr & Mrs M [REDACTED] agreed to take this offer. Professor Ludlam will refer.

It was also discussed that following the move to NRIE Mr M [REDACTED] walking around will not be such an issue because there are corridors where can walk without upsetting others in the waiting room.

Professor Ludlam agreed that Mr M [REDACTED] could be seen early on a Thursday afternoon for routine appointments because Mr M [REDACTED] has difficulty in the mornings and it was further agreed that arrangements would be made so that the appointments for NRIE were in a different week to the WGH appointments and also WGH would be asked to give Mr M [REDACTED] appointments at 12.30 on a Friday as Mrs M [REDACTED] was concerned for her safety at the other clinic at the WGH.

It was also agreed that Mrs M [REDACTED] would come to the hospital herself to pick up factor VIII and Mr M [REDACTED] would only attend if he required examination or formal clinic appointments.

Mrs M [REDACTED] explained that they just wanted someone to listen and Professor Ludlam explained Staff would listen carefully to what Mrs M [REDACTED] had to say and to try and ensure he got appropriate treatment. Professor Ludlam explained that much effort was put in to communication with the Infectious Diseases Unit to try and ensure good co-ordination of treatment. Professor Ludlam asked Mr M [REDACTED] to take enough factor VIII to prevent bleeding in order that he could have some quality of life. Mrs M [REDACTED] explained that they both felt that if they did this they would be made to feel that they had used too much but did not see that this could be over use in a clinical sense only cost. Staff Nurse explained that the basis for clinical use did not include cost and regretted Mr & Mrs M [REDACTED] had felt that cost was an issue.

Mr M [REDACTED] does not feel that there can be any other cause for his pain in knee and ankle other than bleeding and therefore to mobilise would require greater amounts of factor VIII.

At the end of this meeting Mrs McKigen asked Mrs M [REDACTED] if she wanted anything further done at the moment or did she want to arrange another meeting. Mr & Mrs M [REDACTED] declined both offers and said that she would come back if there were any further concerns at a later date.