

Minutes of the formal complaint meeting held on Friday 2 May at the Royal Free Hospital to discuss the care of Mark Ward.

Present :

- Mr Mark Ward and his partner**
- Mr Chris James,**
 - Chief Executive, Haemophilia Society**
- Professor [redacted] GRO-D**
 - Director of Haemophilia Centre**
- Dr Sanjay Bhagani,**
 - Consultant, infectious diseases**
- Andrea Gascoigne,**
 - Complaints officer, medicine directorate**

AG thanked all those present for attending and outlined that the purpose of the meeting would be to assist MW in resolving his outstanding issues relating to his formal complaint. She asked MW if he would tell the attendees what he would like to achieve from the meeting.

MW stated that he wanted to discuss the history of his care, in particular relating to the breakdown of communication that had occurred in the management of his care. He also wished to talk about what the plans were for his future care. He advised that his trust had been destroyed by the series of events outlined in his complaint. He confirmed that he had built up his experience in the field of haematology through being a patient and also by his associations with the committee and trustees of the Tainted Blood project and with the Haemophilia Society.

MW began by explaining that Professor Lee, of the haemophilia department, had formerly been responsible for his care and that he had been very satisfied with the way she had managed his care. However, Professor Lee took early retirement and no longer works for the Royal Free Hampstead NHS Trust.

MW outlined the history of his care, as follows. In 2004, MW was told he needed a knee replacement.

MW raised with Dr Yee the issue of the spontaneous bleeds he had been experiencing consistently over a period of several months. He informed Dr Yee that he felt this problem was related to his anti-retroviral medication. Once Dr Yee had agreed, MW was told to come in for the knee replacement procedure and she confirmed that she would review his anti-retroviral medication at that stage. However, the anti-retrovirals had to be stopped at that time but were later reinstated. MW questioned this issue at the time and told the medical team that as soon as he started taking the anti-retroviral drugs, his leg swelled up. MW found he was still susceptible to bleeding – this was while he was still an inpatient. MW was discharged in February and returned to the hospital to have a joint review with Professor Margaret Johnson and Dr Yee. However, Dr Yee informed MW that Professor Johnson had been called away on an emergency and the consultation went underway without her. It was decided that MW would stay on the Anti-retroviral drugs for three months.

MW pointed out that he actually saw Professor Johnson following the consultation and he felt she had looked embarrassed at seeing him.

The following day, MW had a huge bleed into his leg and was consequently seen by Mr Goddard's registrar.

MW advised that he had had a further meeting with Professor Johnson and Dr Yee but had subsequently gone under the care of Dr Sanjay Bhagani (SB). MW stated that he had been questioned repeatedly as to why he would not have the drug Interferon. MW always maintained that he had his reasons for this decision and he continued to decline the offer to prescribe him with Interferon. MW felt there was real pressure put on him to be prescribed with Interferon.

MW outlined the management of his care in 2005, when he had been admitted on two occasions with severe abdominal pain, which was not looked into. He had been given a CT scan and was referred to the gastroenterology department. However, MW had stated at the time that the problem was not with his stomach, but with his kidneys. MW had been told he was suffering from irritable bowel syndrome – however, it later transpired, while he was under SB's care, that he had severe kidney damage. MW recalled clearly that during his consultation with Dr [GRO-D] he had been asked abruptly why he did not want to have Interferon. Dr [GRO-D] had emphasized that Dr Yee had had very good results with patients who had taken Interferon. MW again declined this offer of treatment with Interferon. MW distinctly recalled that Dr [GRO-D] had told him, "You don't want treatment; I don't want to see you". MW stated that, again, no thanks to the Haemophilia Centre, he found out that his Hepatitis C status was negative.

The Hepatitis C status was disclosed to MW by Dr Gaby Slapak. The negative status had been reported in May 2005, but had not been communicated to MW. MW advised that he had felt let down by Dr Yee and Dr [GRO-D] who had been responsible for the management of his liver and Hepatitis C care.

MW informed those present that two weeks earlier, he had undergone a fibroscan of the liver at the Royal Free, the result of which was 5.2, an extremely good result. MW confirmed that he has done everything possible to improve his health – he does not drink and gave up smoking. He also highlighted that his love for his partner had given him a yearning to live out what were proving to be the best years of his life, against all the odds and having fought through years of ill-health, after being diagnosed as haemophiliac while a teenager.

AG invited [GRO-D] to respond to MW's account of the management of his care. [GRO-D] advised that he had returned to the Haemophilia Centre at the Royal Free after an absence of 20 years. He confirmed that he felt it was unacceptable that there had been such a long period before MW had been advised that his Hepatitis C had spontaneously cleared. He regretted that this issue had not been followed up according to good practice.

[GRO-D] confirmed that he and SB had discussed MW's care and advised that they have never seen this very late spontaneous clearing of Hepatitis C. [GRO-D] advised that he felt it was partly due to SB having formulated the optimum combination of treatments for MW. [GRO-D] confirmed that the current view on Hepatitis C treatment is that if the liver enzymes are not raised, then the clinician should not pursue treatment. [GRO-D] advised that there had been a reason to ask MW to have treatment when his liver enzymes were raised. [GRO-D] stated that they do have outpatients who need this treatment and end up having a transplant. However, [GRO-D] felt that his team should acknowledge that they had missed this issue in MW's treatment.

[GRO-D] stated that he appreciated that trust had broken down between MW and Dr Yee and confirmed that Dr Yee was not now in charge of MW's management.

With regard to the problem with HIV patients and the spontaneous bleeding experienced by MW, [GRO-D] confirmed that the teams are very much aware of this and that the HIV medications do cause the bleeding. He added that MW had been very sensitive to the medications and that he was prone to this complication. [GRO-D] concluded by advising that MW had a problematic interaction with the haemophilia.

[GRO-D] confirmed that, with regard to MW's other organ problems, this depended on the different specialties working together to communicate well and he acknowledged that this had not always been successful.

With regard to MW's future care [GRO-D] advised that the Haemophilia Centre are responsible for co-ordinating his care, with SB as a specialist advising on HIV care. [GRO-D] confirmed that Hepatitis C is a considerable problem for haemophiliacs and that the Haemophilia Centre works very closely with the liver unit on this aspect of care. He advised that he hoped they could now offer MW a good level of service. The Renal Unit at the Royal Free is a centre of expertise that can be drawn on. With regard to the side effects of medications, [GRO-D] stated that it is important to monitor the condition of all the organs.

[GRO-D] advised that, in his opinion, where an organ system seems to be giving a problem, the team should send the patient to the relevant specialist. He stated that this is an ongoing situation where the teams are not able to predict what the next complication might be. He advised that doctors do differ in their practice but that patients have choice and, hopefully, the team can find someone MW will be happy with.

[GRO-D] acknowledged that the therapeutic relationship is very important. With regard to the services that can be provided by a general practitioner [GRO-D] appreciated that the Haemophilia Centre does provide some of these services but, as MW is based in Brighton, it may often be more appropriate for him to contact his GP. [GRO-D] confirmed that communication with patients' GPs is by letter and by telephone. He advised that his team would try to keep this at an optimal level. In the future, patients' GPs will have access to investigative results electronically.

[GRO-D] highlighted that, in the management of MW's future care, good co-ordination between specialties is of primary importance. [GRO-D] stated that he believed that using the specialists available within the Royal Free is the best way forward. He acknowledged that communication and co-ordination can sometimes fail, as highlighted by MW's personal experience.

[GRO-D] confirmed that MW's concerns had been considered in depth and that he had been heard and his fears acknowledged. [GRO-D] stated that he appreciated that his team had to be 'on the ball' and keep working well with the other specialists responsible for MW's care, including the GP.

MW highlighted that when he had been under Professor Lee's care, all of the other clinicians had reported back to her and this had seemed to work very well.

[GRO-D] confirmed that all of the specialists involved in MW's care are copied into the letters concerning his care. All of the correspondence and investigation results are filed into MW's medical records file. Laboratory and scanning results are now available very quickly within the hospital, as they are reported electronically. [GRO-D] cautioned that, where letters are concerned, there will always be a slight time lag.

CJ thanked GRO-D for his response and confirmed that he had been pleased to hear what GRO-D had confirmed in terms of MW's care in the future. He highlighted that the management of MW's future care had been the main driver for the complaint and for the request for the meeting today. MW had lost trust in the clinicians responsible for his care and the main concern had been how he was going to regain that trust. It was important that MW should feel he could attend the Haemophilia Centre with confidence and with the knowledge that similar oversights will not recur. CJ stated that he had appreciated the advice given by GRO-D regarding the importance of communication.

MW highlighted that his main concern was that the survivors are totally unique and that they are not always being treated as unique. He stated that he felt like he was being divided up. He outlined that he had always tried to work with all of the doctors. He confirmed that, if he had been approached, he would have given blood to see how it had happened. MW confirmed that he always takes care to give detailed information about his symptoms and GRO-D concurred that MW had always been a very co-operative patient and had helped the team with research in the past.

GRO-D concluded that, as MW had lost trust in a particular doctor, his care had been transferred to GRO-D care. GRO-D acknowledged that MW had experienced a difficult period regarding the management of his care – but he felt that the level of care had returned to a good standard. GRO-D advised that he hoped both clinicians and MW could move forward now to give MW the service he wants and deserves.

MW thanked GRO-D for these comments and stated that he felt the level of communication needed to be high. MW asked to be addressed and communicated with as an intelligent person.

GRO-D acknowledged that, following the episode of tainted blood being administered, MW had been exposed to many unknown pathogens. He confirmed that, although there had not been any cases arising from this episode, the teams would continue to be vigilant into the future.

MW's partner stated that he felt the ideal situation for the future provision of MW's care would be one where all of the clinicians involved reported to GRO-D with GRO-D taking overall responsibility.

GRO-D confirmed that he would endeavour to maintain this working practice.

MW thanked everyone present for attending and confirmed that, following the group's discussions, he was feeling positive about his future care and for his future good health.

AG thanked everyone for attending and for their positive contributions and the meeting was closed.

2 May 2008

Royal Free Hospital