

A perspective of an adult with haemophilia
~ Mike O'Reilly

To present a perspective of an adult haemophiliac on the importance of comprehensive care I thought it was relevant to first cover the various stages of progressive improvement in treating haemophilia over the past 60 years' I was diagnosed with severe haemophilia A at 9 months of age in early 1949.

As a child with Haemophilia in the 1950's care was predominantly from parents and treatment from the medical profession reactive and limited by lack of knowledge and available technology at that time. Most treatment for bruising and joint haemarthrosis was undertaken at home with ice packs and bed rest until the bleeding episodes had run their course. Hospitalisation was mainly confined to internal or life threatening bleeds with fresh blood transfusions being the only effective treatment and stays lasting several weeks. As visiting hours in those years were confined to Sundays only 2to 4pm as well as the physical aspects it was also emotionally traumatic for a child to face these periods of hospitalisation. Consequently, due to the lack of a fast acting coagulant product, haemophiliacs suffered severe damage to weight bearing joints by their early teens.

Treatment was uncoordinated between hospitals and practitioners due to the limited knowledge of haemophilia and it's small footprint on society. Basic knowledge was acquired and shared from small groups of parents and a few dedicated medical staff who used to meet irregularly at one of their residences which was the beginning of the Haemophilia Society (forerunner of the Haemophilia Foundation). Information was scarce, generally unscientific and prone to creating false leads and hope eg; in the early 1960's a theory emanated out of the USA that RAW PEANUTS produced a coagulating effect that delivered positive benefits for haemophilia. Many of us in my age group can remember consuming vast quantities of raw peanuts in the hope of developing coagulating properties in our blood. Alas the only outcomes were to be a high risk of developing Ape like qualities of "swinging from tress" (not good for haemophiliacs) and a life long abhorrence of raw peanuts.

In the mid 1960's a quantum leap in treatment occurred with the discovery of factor viii & ix and the availability of Cryo –Precipitate to treat haemophilia. However comprehensive care was still only a "dream" at that time, with the main source of any defined treatment plan appearing to come (from my perspective) the Blood Bank. They provided product and information on it's use to principal hospitals and doctors in most states. Fortunately each major hospital seemed to produce a small band of dedicated personnel who progressively acquired a broad based pool of knowledge on haemophilia but it was still lacking in coordination.

Each member of the haemophilia community had their own system of treatment depending upon which hospital and general practitioner looked after their needs. Personally I attended the Mater hospital here in Brisbane until my early twenties for infusions of cryo-precipitate. However response times could vary considerably, not due to a lack of dedication on the part of the medical staff, but rather a limitation in the knowledge of haemophilia and its needs. This resulted in delays in treatment times and the inevitable increase in damage, especially to joints. A visit to a hospital casualty department was viewed with trepidation and often caused the patient to delay the decision for treatment until the trauma episode was well advanced (far from the appropriate response).I know that this was a common feeling amongst haemophiliacs of my vintage.

In the late 70's I attended the Alfred hospital while working in Melbourne. Its casualty department was well established to handle the needs of haemophilia due mostly to the work of Dr. Sawers over a long period of time. Cryo –precipitate was kept on site at the Alfred rather than the blood bank. Response times from arrival at casualty until infusion were very quick. However in hindsight the focus of care for haemophilia was still on post trauma treatment. Upon my return to Brisbane I found that treatment options had expanded and I could receive factor viii infusions from a pathology company 24 hours a day by providing about one hours notice .To me this was a major improvement in my quality of care. Then a change to Health Regulations no longer allowed nurses to give intravenous injections. As doctors were not always available at this facility response times deteriorated rapidly and availability of treatment no longer guaranteed--it was back to the drawing board.

It was around this time that “home treatment “ began to be trialled due to the development of factor viii and ix in concentrated form and even if you could not give the infusion yourself factor viii concentrate could be kept at home and administered by your local GP. This was a vast improvement in shortening the time for treatment and also for me for travelling within and out of the country in relation to my work. However treatment was still focused on “reacting” to a trauma event. The growth of the Haemophilia Society in the 70's and 80's (propelled by the tragic emergence of HIV and Hep C virus's in the blood supply) began to pursue a more coordinated approach to treatment, both pre and post, from the health care community. In the 1980's the development of prophylaxis treatment for young haemophiliacs was a major advancement in the evolution of proactive care that will see positive results for the community into the future.

The haemophilia society progressed as part of this evolution into the Australian haemophilia foundation whose work has been instrumental in the 90's and into the 21st century in coordinating a more comprehensive care program to meet the needs of its patients. eg; haemophilia centres at major hospitals in each state. These centres have provided a quantum step forward in overall service by coordinating the provision of appropriate specialist services in addition to primary factor replacement care. Physiotherapy care specifically tailored to the treatment of haemophilia related injuries is one of these. For most of the lives of mature haemophiliacs we avoided physiotherapists as the usual treatment and exercise programmes that were so beneficial to the general population caused havoc to the muscles and joints of our community members. It has not been until the provision of physiotherapists with special training /knowledge of haemophilia via the haemophilia centres that we have benefited from these services. Now they are an avenue for proactive treatment for old as well as new muscle and joint injuries, previously “unavailable “to haemophiliacs. Physiotherapy is now a recommended and vital part of a comprehensive care program, eg. hydrotherapy and low load exercise programs coupled with prophylaxis treatment has enabled haemophiliacs to recover to a higher level of fitness at a much faster rate than in past years. This has significant benefits in both medical and social terms. Faster healing times and protection or improvement to joint and muscle performance yields a reduced demand on medical services and hence costs in the long term. There are also significant pluses in a social sense (eg quicker return to employment or studies) and an improvement in the personal quality of life.

The linking of specialist services to haemophilia centres has produced significant improvements in the management of haemophilia for all age groups.

Orthopaedics and rheumatology are areas where I have personally benefited significantly by their inclusion in the comprehensive care program. No longer do you

need to be referred to a specialist “outside the system” which is not a criticism of the specialist but more in the complications of post information coordination back to the patients treating doctor. Bringing these services under the one umbrella has diminished this. It also has enabled a much quicker build up and more expansive pool of specific haemophilia knowledge to be shared between state haemophilia centres and assisted in the training of medical personnel.

As the haemophilia community ages they require a more holistic approach to their total health care requirements especially for the 50+ band. This group of which I’m one puts us into a fairly unique situation as up until 30years ago few haemophiliacs had lived past 50. This holistic approach encompasses not just classic haemophilia related treatment but specialist medical services covering general health issues. These can sometimes be masked by the shadow of haemophilia eg cardiovascular problems, diabetes etc also recommended general health tests after a specific age which might involve procedures like a colonoscopy require special arrangements for a haemophiliac. I believe these would be best handled by a haemophilia centre. Also dental health care is one area which seems to have fallen outside the umbrella of these centres and which could be included in future development plans.

Overall these centres and their focus on providing a comprehensive care program have made a major improvement in the treatment of haemophilia and a positive impact on the quality of life of our community. I can only strongly urge members of government and medical administration to continue to support funding these centres and their development programs. Without them the long term outcome would be one of deteriorating health standards within our haemophilia community and progressive increase in costs financially and socially to government departments.