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THE LIMBLESS VETERANS

ROYAL MARINES
CHARITABLE TRUST FUND

Improving Clinical Care for Veteran Trans-Femoral Amputees

Author: J W White

13 June 2015

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The White Report

Since the aftermath of World War One, Blesma, The Limbless Veterans has acted as an advocate on behalf of Service and ex-Service personnel who have lost limbs or the use of limbs. Almost without exception, those who have suffered such traumatic injury in recent conflicts are counted amongst the membership and well known within the Association. Blesma is the lead Service charity upon living with limb loss.

For this reason, the Royal Marines Charitable Trust Fund approached Blesma seeking advice upon the prosthetics service for veterans no longer in the MoD provisioned Defence Recovery process. We therefore asked ex-Royal Marine Jon White to write a report on the performance of the NHS in looking after the many complex injuries that he and his peer group endure.

The NHS is trying hard and building momentum with those Limb Centres being invested in as a result of the Murrison initiative, and the successful Veterans Prosthetics Panel. However, these are injuries not seen before and there is new technology, too. We need a more flexible, realistic and practical approach, to continue building expertise for treatment in the UK, to benefit the nation.

Barry Le Grys
Chief Executive

British Limbless Ex-Service Men's Association
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The White Report

Jon White – Biography

Jon White is a former Royal Marines Captain who was injured by an IED while serving on Operation HERRICK 12 in Afghanistan in 2010. He lost both legs above the knee and his right arm at his elbow, but has refused to let the injuries define him in a negative way.

He has barely used a wheelchair since June 2011 and has become an inspirational speaker, leadership consultant and, along the way, he also designed and project managed the building of his new home.

Jon comes from a Marines family – his father John served 25 years – with a commitment to serve and he joined the Young Officer Training course at The Commando Training Centre Royal Marines, Lympstone in September 2002, aged 19. He became a Troop Commander and Company Second-in-Command before specialising as a Mountain Leader.

Inner strength, discipline, determination and corps camaraderie are in his DNA. They have aided his recovery and are now part of his campaign to improve clinical care for his fellow Service amputees.

Jon, now 32, received his first prosthetics at the Defence Medical Rehabilitation Centre Headley Court, but the level of his injuries and disability, combined with the lack of UK-based expertise at the time, meant he needed to be treated by a specialist Hanger Clinic in Oklahoma, USA.

He has witnessed the care and capabilities of health systems on both sides of the Atlantic and believes that fusing them together will improve the potential for Service veterans to pursue independent lives.

Jon, who lives in Devon with his wife Becks and two children, George, who is two-and-a-half years old and eight-month old Pippa, has used his healthcare knowledge to investigate clinical possibilities and has interviewed veterans to discover what works well and what needs improving.

He is uniquely placed to compile a status report with detailed recommendations and to drive it through to the benefit of the injured and NHS services.

Jon has barely stopped since leaving the wheelchair behind and is now a sought-after speaker at corporate events and has launched a leadership consultancy after creating his own made-to-measure home, which featured on Channel 4's *Grand Designs*.

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He constantly seeks new challenges and completed the gruelling Devizes to Westminster kayak race in 2012, with colleague Colour Sergeant Lee Waters, Royal Marines, in just over 28 hours. He was awarded the Gluckstein Trophy for endeavour.

“We have an opportunity to, at this moment in time, put a process in place that will benefit all; veteran amputees and the wider amputee community in the UK. We can improve services whilst making financial savings.”

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The White Report

Executive Summary

The rehabilitation pathway for Britain's Above Knee Amputee Veterans needs to change.

The NHS and its staff do their best for the cohort of 160 operationally-wounded men, but it was not set up to cope with such complex injuries and recovery profiles.

These are young, fit, determined former Forces personnel with huge potential for society, yet they can experience daily frustration, delay and complications on a needlessly lengthy medical journey.

The aim of The White Report is to help the government create the conditions to allow the potential of our injured Service personnel to shine. Its proposals will help build a Service that will deliver the first class care they need and deserve.

The Report, a result of extensive research into the experiences of Service veterans who were operationally wounded since 2003, is a positive contribution and offers the nation a great chance to establish a gold standard care system.

It signposts the route to better, more lasting therapy, freedom of choice and can even save funds for the NHS and the country.

I have spoken to veterans, clinicians and administrators to determine areas of the current system that can be improved. Their testimonies point us towards a new provision for prosthetics that creates a synergy between the Defence National Rehabilitation programme, the NHS and the Hangar Clinic in Oklahoma City, USA.

Together, we can:

- Create a four-tiered system to give veterans the level of care they want or need
- Share the best clinical and technological practices from around the world to improve UK care
- Establish an effective training system so that the UK can deliver better services

The White Report explains a cost-effective service that will help veterans return to independence as wage earners, tax payers and to raise families, released from the psychological and physical burden of sub-optimal care.

They deserve an efficient and effective clinical care system. It can be done.

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Aim

1. To identify the most effective (balance of quality, cost and expedience) way for the UK Government to provide short, medium and long term clinical care for the UK's modern cohort (injured 2003 onwards) of Above Knee (AK) Amputee Veterans.

Recommended Option

2. The following recommended option is proposed after investigating all of the potential options and recognising current legislation and the desire to improve the UK based service. The following option is a hybrid of the potential options designed to maximise the benefits and negate the risks as much as possible. There are no legislative barriers to this option.

a. A four-tiered system should be made available to the outlined cohort

(1) Tier 1 should be the local Limb Fitting Centre

(2) Tier 2 the nearest Murrison Centre

(3) Tier 3 The Defence National Rehabilitation Centre (DNRC) or DMRC Headley Court in the interim

(4) Tier 4 Hanger Clinic in Oklahoma City (OKC)

b. The patient cohort should be given the freedom to choose which tier they utilise indefinitely

c. The NHS should be responsible for the provision of Tiers 1 and 2, the MOD should be responsible for the provision of Tiers 3 and 4. The Treasury should transfer the appropriate Murrison funds from the NHS to the MOD on a case by case basis.

d. Patients receiving Tier 4 treatment should engage with the DNRC after each intervention in order to allow Research and Development

e. A training system should be put in place whereby clinicians and technicians from Tiers 1 and 2 can access the knowledge gained by DNRC regardless of their employing company. i.e. If Company A has the service provision contract at DNRC, employees from Companies B, C and D can still access DNRC for training.

f. The Third Sector should take on T&E responsibility for Tier 3 and 4 treatment

3. The rest of the paper develops why this recommendation has been made

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Situation

4. **The Patients** Young, fit and determined, with considerable potential to be contributors to society. That is the nature of many of the UK's Operationally Wounded (since 2003) Service Veterans. However, they can only start to fulfil that potential once they are in a position where they are no longer dependant on regular clinical care and can, therefore, live independent lives.

   Of those lucky enough to have kept their senses and faculties, Trans-Femoral Amputees have the most frustrating journey. They generally have the physical potential and there is definitely the technology to allow them to be independent walkers, but only when these two factors are glued together by good clinical care. The more limbs lost, the more important this care becomes. There are Service Veteran examples of Triple (Bi-lateral Trans-femoral and Unilateral Trans-humeral) Amputees who have achieved total independence, receiving minor clinical inputs just once or twice a year, and major clinical inputs as far apart as three years.

   They work full time in busy jobs earning good wages and therefore contributing taxes, raising families, and being paying consumers. To be clear, there are many for whom the current system appears to be working; whether this is due to the level of their personal ambitions or due to the relative condition of their residual limbs, making them relatively easy to fit, is not fully known. This modern cohort consists of 160 AK amputees, of which 116 are missing the second leg either above or below the knee.

5. **Current UK Provision** All but three (Plymouth, Isle of Wight and, most recently, Preston) of the UK Gov provided prosthetic centres are subcontracted to four main service providers: OpCare, Blatchford, RSL Steeper and Ottobock. The majority of amputations in the UK are due to Vascular Disease, Type 2 Diabetes and Cancer. This cohort presents different residual limbs and generally has lower aspirations in terms of prosthetic care outcomes. Difficulties emerge for prosthetists when they are presented with the patient cohort described in "The Patients" paragraph. The difficulties are threefold:

   a. **Expedience** These are young workers with families and the busy lives of 20-40 year olds. They cannot afford to be without their prosthetics for weeks at a time.

   b. **Functional Sockets** Traumatic amputations often lead to misshapen residual limbs with reduced fleshy protection, sensitive neuromas and radically high levels and amounts of amputations per patient.

c. Technology WIS Service members are being issued with some of the most advanced technology available. This technology takes understanding, skill and experience to optimise set-up for each patient. The prohibitive costs of these technologies has prevented that understanding, skill and experience being built within the NHS.

6. Under the "Military Covenant" the NHS has been forced to address these difficulties. As a result of Dr Murrison's report, 11 centres around the country have become "Murrison Centres". This means that they have successfully applied to become specialist centres for dealing with Veterans. This has been done to try and concentrate learning, knowledge and experience for dealing with traumatic amputations. These centres will also be given access to extra funding in order to provide the more expensive technology provided by the MOD.

The issue is that renaming a centre as "specialist" and making extra money available does not give the team the specific expertise required overnight. With the cohort being so small, it could be argued that the necessary expertise will take too long to gain for the benefit of the current cohort, especially when spread around 11 centres. The result of all this is that some of the patients will find themselves in a state of perpetual interventions (each costing money to deliver) as clinicians experiment unsuccessfully, again and again, in order to try and deliver the patients' needs. Not only is this expensive, but it is both physically and psychologically harmful for the patients; sub-optimal prosthetic care is tantamount to physical abuse, literally physically wounding patients.

This is a process which the author has both witnessed and experienced within Government provision. If patients so desire, they can apply for exceptional case funding to see a private clinician in the UK or EU. Legislation currently prevents treatment outside of the UK, however this has been overcome in other areas such as Proton Beam Therapy for cancer treatment.

7. The History of Hanger

There is a small cohort who have discovered a better standard of care than anything received in the UK and wish to continue receiving this level of care. The question is often asked: "Why can't we just copy what Hanger do?"

This paragraph aims to explain why Hanger are where they are, and why it is not a simple case of just copying them. The first thing to realise is that Hanger is a large company with more than 700 offices in the USA. However, when the UK patients talk about it, they are actually referring to a single office – The Oklahoma City office – with Mr C Simpson CPO.

It is this office which has a particular expertise that has come from its singular history. This office has its roots in a family-run prosthetic business set up by Lester Sabolich in 1947. His son, John Sabolich trained as a prosthetist, too, and took over the business. Kevin Carrol joined John in 1988. Kevin studied prosthetics in Dublin (1978-81) and did further training over the following years at the University of Strathclyde. In the mid-80s he won a place on an exchange programme and went to work with Dr Hans Richard Lehneis PhD CPO in New York.

It was whilst working for Sabolich that Carrol took his further studies to a new level, initially designing the CATCAM socket. His studies included experimental analysis of over 100 cadavers, blood flow analysis, MRIs, CAT scans and X-rays of patients with and without sockets. The Sabolich Socket was developed taking all the newly gained knowledge into consideration. Soon afterwards, in 1995, Sabolich was bought by Nova Care. Suddenly, Carrol was given national influence and not only did his reputation widen but so did his experience. He quickly became recognised as a leading expert in Lower Limb Prosthetics.

In 2001 Nova Care was bought by Hanger, resulting in an even wider net, more funding and further development. In 2002, he met Cameron Clapp, a 15-year-old triple amputee. His team worked with Cameron, utilising the latest lower limb technology to reset the bar on what was achievable. Manufacturers have since become interested in their work and, as a result, continually consult them in trials and development programmes. This means that when a new technology becomes available, they already have a deep understanding of it. Their continued success has led to patients travelling from all over the USA and the world to see the Oklahoma team. Kevin travels around the USA daily, giving clinics and training. He regularly sees 15 Trans-femoral patients in clinic a week. His understudy, Mr Chadwick Simpson, is now the Chief Prosthetist at Oklahoma City and treats circa 30 Bi-lateral TF patients a year, plus many more Uni-laterals.

Hypothesis

8. The hypothesis is that the cost, time and risk involved in trying to recreate the expertise of the Oklahoma City Hanger Clinic office for such a small number of patients will far outweigh the cost, time and risk of continuing to send them to Oklahoma for their treatment. This cost may appear large, but actually, when compared to the true costs (which are rarely revealed) of care in the UK, there will be little difference and the expedience and quality of care strongly suggests that this foreign treatment is the best available option. With this in mind, it seems logical that the Government funds this.

Potential Options

9. **Option 1** Change nothing. Veterans continue to attend Murrison Centres. Those who are dissatisfied with the level of care seek Third Sector funding for better care either in the UK or abroad.

10. **Option 2** Intensive up-skilling of one specialist centre. Find the Murrison Centre with the most relevant skill and experience, or the DNRC when it is operational. Approach the Hanger Clinic to provide six-month work placements to include Kevin Carrol's Trans-femoral Comfort Flex Socket Fitting course, for two prosthetists and two technicians.

11. **Option 3** Government takes on funding of Hanger and other private treatment for those who want it. If a commitment was to be made, and it became financially viable for Hanger, it may be helpful if this could be supported by requesting Hanger do a six monthly, one week clinic in the UK to provide ongoing support and possibly even training to UK based clinicians. This would probably depend on the numbers of patients requiring this type of care.

12. **Option 4** Utilise UK based private clinics. There are several private clinics in the UK. These tend to recruit more experienced prosthetists and, due to charging higher fees, are able to give more time to each patient than Government-funded clinics. Therefore, the standard of service is likely to be higher – they depend on their ability to provide higher quality services for their business survival.

Current Known Costs

13. Below are the costs of providing a pair of X3 legs, with feet, sockets and all other necessary components.

a. **NHS Supply Chain Charge** circa £120,000 for the major components. Clinician/socket time, socket materials and sundries are then charged on top of this. Sockets are expected to last six to 18 months, the NHS will be charged for any time involved with unsuccessful fittings. Multiple sockets will be made for multiple activities, each being charged for.

b. **UK Private Provider 1** £130,000. Sockets expected to last one to three years. Multiple sockets will be made for multiple activities, each being charged for.

c. **UK Private Provider 2** £133,500. Sockets expected to last one to three years. Multiple sockets will be made for multiple activities, each being charged for.

d. **Hanger Clinic in OKC** £89,000. (This is with the three-year warranty, the extended six-year warranty that the UK clinics provide is an extra £13,000). Sockets are expected to last two to 10 years. One set of sockets will be made and utilised for multiple activities.

14. The NHS costs are on top of the costs of the basic contract, identifying the cost of this per delivery to patient has not been done. The reason for this is that different clinics have different contracts, for instance some clinics are given a budget and have to share it between their patients, others charge the NHS a set rate per appointment, therefore their budget is directly linked to the amount of appointments they service each year.

15. It costs circa £20,000 to adapt the author's first car to allow him to drive. With his Hanger treatment, he is now able to drive any automatic vehicle with a portable, simple and cheap (less than £100) steering adaptation. Not only is this a huge financial saving (for the Government funds and Third Sector funds that pay this bill) but it also allows such normal activities as swapping cars with his wife, sharing the driving on long journeys and being able to hire a car at short notice. Other Hanger patients have also received these benefits.

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The Initial Comparison

Table 1

Option	Supporting Factors	Risks	Barriers
1	1 No Extra project work required 2 No change to spending/budget	1 Dissatisfied patients 2 Overburden on Third Sector 3 Continued sub-optimal care service	1 The will of determined patients and their advocates 2 Public pressure if the situation becomes widely known
2	1 Improved long term care quality 2 Convenience of high quality UK-based care for patients	1 Failure to retain personnel who have been invested in 2 Prohibitive outlay costs 3 Care quality outcome still not meeting the required standard despite investment	1 Hanger are unlikely to be willing to engage in this manner
3	1 Satisfied patients due to improved expedience and quality of care 2 Reduction in expenditure on care 3 Potential to transfer knowledge and up-skill UK-based care services 4 Reduced work load on NHS clinics allowing better care to be delivered to other patients	1 Exchange rate fluctuations affect the cost of treatment 2 Greater responsibility is placed on the patient for minor up-keep of limbs due to the travelling distances	1 Current Department of Health Legislation
4	1 Likely higher (than NHS) standard of care	1 Relatively uncontrollable 2 Comparably expensive 3 Care quality outcome still not meeting the required standard for all	

Recommended Option (repeated from para 2)

16. The following recommended option is proposed after investigating all of the potential options and recognising current legislation and the desire to improve the UK-based service. The following option is a hybrid of the potential options designed to maximise the benefits and negate the risks as much as possible. There are no legislative barriers to this option.

a. A four-tiered system should be made available to the outlined cohort:

(1) Tier 1 should be the local NHS Limb Fitting Centre

(2) Tier 2 should be the nearest NHS Murrison Centre

(3) Tier 3 should be the DNRC or DMRC in the interim

(4) Tier 4 should be The Hanger Clinic in Oklahoma City

b. The patient cohort should be given the freedom to choose which tier they utilise indefinitely

c. The NHS should be responsible for the provision of Tiers 1 and 2, the MOD should be responsible for the provision of Tiers 3 and 4. The Treasury should transfer the appropriate Murrison funds from the NHS to the MOD on a case by case basis

d. Patients receiving Tier 4 treatment should engage with the DNRC after each intervention in order to allow Research and Development (Parameters TBC)

e. A training system should be put in place whereby clinicians and technicians from Tiers 1 and 2 can access the knowledge gained by DNRC regardless of their employing company i.e. If Company A has the service provision at DNRC, clinicians from Companies B, C and D can still access DNRC for training

f. The Third Sector should take on T&E responsibility for Tier 3 and 4 treatment

16. Note: It is believed that Hanger would not provide any training for their Intellectual Property (IP). However they may, if invited, choose to tender for the service provision contract at the DNRC. This would allow a degree of their training and IP to be brought into the UK, however it needs to be recognised that if this happened, just because the staff have Hanger on their uniforms, they would not be instantly working to the OKC clinic standard. The clinicians would be recruited from the UK and would need time to gain experience and be trained by Hanger, therefore Tier 4 should remain open.

Predicted Outcomes

18. The following outcomes are predicted if the recommended option is implemented correctly:

a. There would be a proportion of patients who would choose to continue treatment with their current Tier due to the convenience of locality and current satisfaction

b. Many would utilise the Tier 3 option, again the balance of convenience and satisfaction making it viable for their individual needs

c. It is suspected that somewhere in the region of 10 to 20 patients would choose to utilise the Tier 4 option

d. Over time, as experience grows across the tiers, the majority of patients would probably step down a tier for the sake of convenience

Note: It is recommended that this step down should not be forced, it should be when the patient feels comfortable and the option to step up a tier should remain open.

Benefits

19. The following benefits are predicted if the recommended option is actioned correctly:

a. Improved patient satisfaction; the mere availability of choice as well as the availability of higher levels of care will hugely increase patient satisfaction

b. Financial savings; the more patients who choose Tier 4 the more money the UK Government will save. As appropriate experience and skill level is improved across the tiers, less time and fewer materials will be wasted, saving on what are already extremely tight budgets

c. Improved care for civilians and non-attributable veterans; the system should assist in up-skilling across the tiers. This increased skill, extra time created, plus the extra capital for more advanced technology created by the savings mentioned above will result in a better standard of care and living for all

d. No legislation needs to be changed, therefore minimising administrative work and time on the implementation of the plan

e. Over time, the DNRC may well become a European Centre of Excellence which may well then attract the attention of manufacturers and allow engagement in Trials and Development, giving them a similar advantage to the Hanger OKC clinic

Secondary Issues

20. Upper Limb Care. For Trans-femoral amputees with upper limb amputations, the prosthetic care for the upper limb becomes more complex than for a person who is purely an upper limb amputee. This is due to the fact that the limb will be used in different ways, mainly supporting the body when moving in a seated position or tackling obstacles such as stairs. The author's experience is that UK-based services have yet to fully understand this. The result was several inappropriate limbs being fitted in the UK until he was eventually fitted very successfully by the team in Oklahoma City. They have an upper limb specialist Prosthetist; Mr Charles Anderson CPO. Whilst fitting and treatment is carried out in Oklahoma City, the fabrication is done by a specialist team in California. They are Hanger's National Upper Limb Fabrication Specialists. It is therefore recommended that upper limb care be continued in Oklahoma City for those who are also receiving their lower limb care there, and efforts to improve the UK-based services are made in parallel to the above list of recommendations.

Next Steps

21. The following steps are recommended to help implement the recommended option:

a. Engage with the MOD to initiate support and ensure the DNRC has the necessary capacity

b. Engage with the Treasury to work out the system for appropriate transfer of funding

c. Engage with the NHS Commissioners to gain their support

d. Publicise the concept to the WIS community as a viable plan and ask for feedback

e. Make adjustments if necessary and appropriate

f. Engage with Hanger about the tender for the DNRC service provision contract

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STATEMENT

Mark Ormrod

So, my story started on the day I got injured, which was Christmas Eve 2007, but to try and keep things short I'll summarise where I can.

– I was injured Christmas Eve 2007 & became the UK's first triple amputee from Afghanistan

– Spent six weeks in Selly Oak Hospital (Birmingham)

– Spent the next two and a half years, on and off, in rehab (Headley Court)

– Travelled to Hanger Clinic (Oklahoma City) in 2009 to be mentored by another triple amputee

– Left the military July 1st 2010

During my recovery at Headley Court, although the facilities and treatment were great because I was the first casualty to lose three limbs, I found it difficult not having a role model or a mentor to look up to and learn from. Plus, because no one had dealt with my level of injury before, it made my recovery a lot slower and more difficult as I was effectively the guinea pig for people to trial things on. I didn't mind that because that was just the way it was, but after a while it started to get a bit repetitive and depressing.

During my recovery I decided to take to the internet to see if there was anyone anywhere in the world who had injuries similar to mine who I could learn from to try and take my independence as far as I could. One day, during my search, I came across a young man in California called Cameron Clapp who had become a triple amputee at 15 in 2002 when he was hit by a train. In short, what this guy was doing was incredible and far beyond what I was capable of back then, so I reached out to him for help and support. We became friends and he helped me with advice, via the internet, on how to become more independent. He also introduced me to his team of prosthetists and clinicians who had helped him gain the level of independence he had and we also became friends as they gave me help and advice to improve my walking and work towards becoming a full-time prosthetic user.

After a few months of communicating, I was invited to America to meet with Cameron and his team where I was to spend three weeks training in a completely immersed environment, pushing myself hard to achieve new things. To say these three weeks changed my life would be an understatement. I won't lie and say that it was easy but

I was introduced to a whole new world of mentoring, peer support and immersion training that I hadn't ever experienced before.

Whilst I was there, the clinicians were kind enough to make me some new temporary sockets (free of charge) using their advanced and patented Comfort Flex socket design. This was the piece of the puzzle that was missing for me. Anyone who knows anything about prosthetics will tell you that without a good socket, even the most advanced prosthetic leg in the world is useless as you will be unable to use it to its full capacity because you will always be dealing with the sores, rubbing, chafing and skin breakdown that come with a poor fitting socket – things I had experienced daily until this point. Although I was in a lot of pain from training in the sockets I had in the UK, once I was fitted with the Comfort Flex socket everything started to become easier; because the fit was so much better I wasn't constantly fighting to keep my leg on or readjusting it when my foot twisted around. Over the days, the pain also wore off because of the fact that these fitted so much better.

When I came back from America my life had changed forever, I was now a full-time prosthetic user, (I haven't used a wheelchair since June 2009, which, for someone with my injuries, was unheard of over here). As the days passed and I got stronger and more confident, I was achieving more and more.

When I had all of my affairs in order (housing, finances etc) I decided it was time for me to leave the military and start afresh as a civilian, the only thing I had to finalise was the funding to get my treatment in America. I went to see the Commanding Officer of Headley Court who was aware of my situation and I explained my plight. He told me that although the sockets I had were not funded by the military they were issued to me whilst in service and because of that I would get the necessary funding to continue my treatment as a civilian. Everything I now needed was sorted and I transitioned to become a civilian.

I was lied to! After leaving the military and, needing funding for some new and more permanent carbon fibre sockets, I went down every route that was available to me but to no avail. Everyone told me that there was no way I would be able to have my treatment funded in America, and that now I was a civilian the NHS was the best I could hope for. To say that they were unprepared and inexperienced is an understatement. It was like going back to Day One in my rehabilitation and starting again. To cut a long story short I had to beg, borrow and steal money from wherever I could until eventually, through a friend who was the personal helicopter pilot to a very wealthy and generous man, I was given more than £40,000 to get the permanent carbon fibre sockets that I needed as well as a set of running legs.

Later, in 2010, I was part of a team that ran more than 3,500 miles from New York to LA in aid of military charities (supported the entire route, free of charge, by Hanger Clinic) which obviously put my sockets under extreme stress. Towards the end I took a nasty fall and fractured one, meaning that I would soon need a replacement. Again, I went down every route I could think of to try and get the funding but was unsuccessful, and in the end it was The Royal Marines Association (A CHARITY!) that agreed to pay the $20,000+ I needed for my prosthetics upgrade.

Ever since leaving the military I have had to beg, borrow and steal what I could to get the treatment that I needed to live the high activity life that I enjoy. Help For Heroes have funded the provision of my prosthetic arm as there was nobody in the NHS capable of building the arm that I needed, and so I had to go back to America. In January 2014 The Royal Marines Charitable Trust Fund (ANOTHER CHARITY!) paid more than £90,000 to provide me with new sockets and the latest microprocessor knee as the NHS were refusing to buy it for me. Despite a pot with £11 million pounds sat there for the spending, I was told that the money made available by Dr Murrison could only be spent within the NHS, and private treatment was not an option meaning I would have to be the guinea pig again. I did manage to use some of that money to get a prosthetic upgrade but it wasn't the latest upgrade available, and whilst being treated by the NHS in Plymouth I was threatened and told that if I took the limbs that they provided me with (Geniums) to America to be properly configured and fitted with Hanger Clinic's sockets then they would take my legs off me and leave me with nothing! After that conversation I left the Plymouth Limb Fitting Centre and never went back.

Many people often ask me why I go all of the way to America to get treatment but the answer is simple:

– First of all, it showed me what was actually possible to achieve with three limbs missing. I was never limited and, because of that, I lead a very full, productive and fulfilled life

– If I take care of my health and prosthetics, I will usually only have to go back every four to five years to get new sockets, and the knees need replacing every five years anyway. Within the military/NHS system I would have to get new sockets made every couple of weeks/months because they were made so poorly and never fitted correctly

– I know when I go over there that I am getting the highest level of care in the world by people who live, eat and breathe prosthetics, and who have spent thousands of hours researching, testing and trialling the latest technology to ensure people like me can live the best possible life available. They do not have a 9-5 attitude like I have experienced in the UK

– The people at Hanger Clinic are four to five years ahead of anyone in the UK with regards to the technology available. They work hand in hand with the prosthetics manufacturers and have a level of skill and experience that is unparalleled

What the people at Hanger have given me is priceless; they have given me my life back. Because of them, I am able to be a productive husband. I am a fully interactive father to three children. I can hold down a full-time job, I travel the country and the world alone, with no need for wheelchairs, adaptive equipment or careers. I can partake in sports, challenges and adventures, and I am now in the privileged position where I can pass on the knowledge they bestowed to me to other amputees who think once you lose a limb (or several) that your life is over and that you are destined to a limited life using a wheelchair or extremely painful, ill-fitting prosthetics.

This is just a very quick overview of my situation and I would be happy to discuss this with anyone face to face should the need arise. As it stands, I still continue to beg, borrow and steal to get the care and equipment that I need, it is a source of extreme stress and anxiety for me, my wife and my children, who all depend on me. I have found a solution to my injuries that gives me the highest level of independence and enables me to live a life which I am very proud of and grateful for. Having to beg charities for money hurts my pride and makes me feel that my sacrifice for this county wasn't worthwhile, to have to go through this after having given so much is painful and is actually more a cause of distress then the actual injuries themselves.

Blesma
THE LIMBLESS VETERANS

ROYAL MARINES CHARITABLE TRUST FUND

STATEMENT

Neil Heritage

I was injured in November 2004 serving in Iraq. I lost both legs above the knee following a suicide bombing and was the first soldier of the conflict to receive multiple amputations. Being injured prior to April 2005 means I don't receive a pay out for my injuries and am therefore not in a position to fund my own prosthetics.

My first 18 months of prosthetic care was at the West Midlands rehabilitation centre, an NHS clinic. I was given some very basic components as that was all that the NHS could provide. This made learning to walk extremely difficult and I spent a great deal of time trying to get the MOD and the NHS to supply appropriate equipment for my level of injury.

In late 2005 my care was moved from the NHS to the new prosthetic service at Headley Court. I had new sockets made and some trial components (unfortunately not the C-leg that I had been asking to trial). The sockets made at Headley Court were so poorly fitting that I reverted back to the NHS sockets that were also in need of refitting. Over the next two years I had several pairs of sockets made at Headley Court by different prosthetists without ever finding the comfort of fit to be able to use the limbs for more than a short period.

In early 2007 I decided that I couldn't get a good enough socket produced at Headley Court to make progress and asked to be medically discharged with the idea that I could return to the NHS where the treatment had been far more successful. At this time I was using a wheelchair about 75% of the time and on discharge, in mid-2007, I was finally given the C-leg.

Post discharge, I returned to the West Midlands rehab centre and had a new set of sockets made. This was by far the best I had to date and enabled me to walk far more, however the legs would fall off after a few hours use each day. I was then informed I could no longer use this centre as it was not my local one. The reason I had used it was to see the Prosthetist there who was regarded as one of the best in the country working for the NHS.

I was then moved to Bournemouth and, as I was in need of new sockets as mine had become too loose, they made me a pair. These where very uncomfortable and I was unable to use them. At this time I wanted to start running but the NHS told me I could not be supplied with sports limbs on the NHS and suggested I use a private clinic and ask a military charity to help pay.

I went for a meeting at Dorset Orthopaedic which is generally recognised as the top prosthetic provider in the country. They made me a pair of running legs as part of a sponsorship deal and I started running. The legs were so much better than anything I had used before, I asked Help for Heroes if they would fund my walking legs to be made there, having explained the problems I was having and they agreed. The walking legs were made in January 2009 and for the first time since injury I was able to use them all day and walk longer distances. I no longer needed to use a wheelchair and had good mobility.

In the summer of 2011 I found out about the Hanger Clinic in Oklahoma and, having pretty much reached the celling of function and mobility on my current leg set-up, I went to the amputee conference in America to find out a bit more and to see if it was possible to make my life closer to normal.

Having spent five days with the Hanger team I was convinced that this clinic had the experience and knowledge to provide me with the optimum set-up and sockets to improve my function. They dealt with hundreds of people in my situation. In the UK, I have never been treated by somebody with any experience of a high activity Bi-lateral amputee.

The problem I had was to fund the trip to America. I was extremely fortunate that a supporter of a charity I was involved with heard about my situation and offered to fund the treatment.

I went to Hanger in January 2013 and have been extremely pleased with the results; the sockets are really comfy and I can use them for 18 hours a day without any problems. As well as this, the new set-up has improved my function and improved my quality of life. My biggest concern is what will happen when I need more treatment. I'm not in a position to fund private care and it currently looks likely that I will be treated by the NHS.

It has now been two and a half years since I received treatment at Hanger Clinic in the USA and I have been treated by my local NHS Centre since.

They have supplied me with X3 knees, which were fitted to my Hanger sockets. I was happy with the set up of these new knees.

In May 2014 I had to undergo revision surgery in both legs as I was suffering from pain. After the surgery and a recovery period I needed to be fitted with new sockets. My prosthetist made the sockets in the style that I had been used to. With the changes happening to my limbs post surgery it took around six months to get well fitting sockets. In addition, I have had prosthetic components supplied for scuba diving and rock climbing. In an ideal world, the speed of socket production would be significantly

faster, but on the whole I am very pleased with my current prosthetic provision. My opinion is still that Hanger is by far the best treatment available for Bi-lateral amputees, but I'm never likely to be in the financial situation where it is an option for me. I'm surprised at the improvements at my Centre (Bournemouth) which is not one of the nine Murrison Centres.

Blesma
THE LIMBLESS VETERANS

ROYAL MARINES CHARITABLE TRUST FUND

STATEMENT

Simon Harmer

What follows is some observations about my prosthetic treatment and rehabilitation, both in the Armed Forces and in the National Health Service.

My Injuries

I was injured in Afghanistan at the beginning of my tour, towards the end of October 2009. Amongst other injuries, I lost my right leg just below the knee and my left leg above the knee. I spent just over five weeks in Selly Oak Hospital.

Prosthetic Care in DMRC Headley Court

I started my rehabilitation in Headley Court (HC) in December 2009 and was walking on prosthetics two months after I was injured. However, I was still using the parallel bars and I was not permitted to take my new legs with me on Christmas leave.

I found my prosthetic treatment whilst at HC more than adequate. I did only require one set of legs and still only use one set. I do not have running blades or shower legs.

The advantages of a residential and full-time prosthetics department cannot be underestimated for a high frequency user of prosthetic limbs.

Any 'tweaks' could be managed after receiving a new set of legs or if any adjustments had been made. This was useful because problems might manifest or only become apparent after a period of settling in, which could be a few hours or a few days.

All the individuals who worked in the department enjoyed solving problems and exchanging ideas with their peers, with patients and also, probably more importantly, with other specialist clinicians. The one commodity which HC enjoyed the most was the time which could be allocated to a patient.

Prosthetic Care in the NHS

The treatment I have received whilst in the NHS has been the same since I have left the Armed Forces. The expertise is no different and the skill set seems to be no different. I do, currently, have issues with my prosthetics – they are not fitting as well as they should and they are rather uncomfortable. This means that although I use them throughout the day I'm not actually covering as much ground as I used to. I have to say this is a result of my time management to book and attend an appointment and no fault of my department. However, the thing that my NHS department can't offer me is a residential appointment where 'tweaks' can be sorted. Neither can they offer me the time which a high frequency user really needs.

I am not suggesting that I require different or better care than a non-veteran, but I am suggesting that we are a different demographic and have different needs and requirements based on our average age, daily prosthetic use and ability.

In a perfect world we would still have access to HC as veterans or have access to the new rehabilitation centre currently being conceived under the direction of the Duke of Westminster.

Blesma
THE LIMBLESS VETERANS

ROYAL MARINES CHARITABLE TRUST FUND

STATEMENT

Councillor Jonathan Lee

The prosthetic care I have had since being injured in October 2007 to date has been incomplacent.

Headley Court

The care here was superb but a long way to travel. Every time I needed an appointment it was a six-hour round trip for me to get to Headley and back to my home just for a 15-minute appointment. Also, my care from the beginning to the end at Headley Court was changeable. In the beginning, I was able to get an appointment at any time, but from the end 2009 onwards it became quite difficult to get appointments that suited me, and trying to fit appointments in with work and resettlement while leaving the Army was impossible due to the amount of travel it would take.

NHS (Nottingham Mobility Centre)

The care in the NHS is nothing like Headley Court. The staffing is poor, the facilities are disgraceful, there is a lack of privacy to even get changed – you are expected to take your trousers off in front of other patients with no privacy whatsoever. You turn up for your appointment on time and an hour later you're still waiting to be seen. It takes a lot longer to see someone in the NHS and procedures you have to go through to get your prosthetic legs approved are far too long. It took me six months to get my leg that had broken approved due to the NHS not being able to afford it and having to go through the Ministry of Defence to get approval. The worst thing is the other patients make you feel guilty as you have better prosthetics than them. Then the staff get annoyed because the patients start asking for your legs, and they know the patients will not get them.

The prosthetics themselves

Depending on the staff you get, the prosthetic is different one hundred per cent. There seems to be no communication between Headley Court and the NHS – it took me a year to get my first appointment with the NHS as they were waiting on paperwork and my Doctors' notes from the Army. I've started looking at private prosthetic care as I just feel the NHS is not up to par with the care we should be getting.

STATEMENT

Rory Douglas Mackenzie (Ret Army CMT)

AK Right leg

Current limb care centre: Roehampton

Finally, after 10 months of treatment, I have got a superb fitting socket (AK). I did, unfortunately, totally lose patience and hope, and asked Blesma for financial aid to assist me in private treatments by Ian Jones. Thankfully, this wasn't necessary this time around, BUT it would feel very comforting to know that financial aid would be available should I still have been battling with my Limb Centre. I believe this sort of aid is not available at the moment, however I may be wrong.

I would strongly suggest to offer all Limb Fitting Centres, including Roehampton, more Genium knee training (programming, setting, PC settings).

STATEMENT

Jon Bevan (pre-2003 injury)

My biggest bugbear with the NHS is trying to get prosthetists to listen to you; they usually operate under the "I'm the professional and I know best," credo.

They need to understand fit and comfort of socket must be their first and foremost consideration. After all, they don't have to wear it!

Personally, I'm fed up of the endless trips for adjustments to my socket because they don't get it right first time!

Blesma
THE LIMBLESS VETERANS

ROYAL MARINES CHARITABLE TRUST FUND

STATEMENT

Anonymous

My experience of NHS prosthetics since leaving Her Majesty's Armed Forces

I was medically discharged from the Army in January 2014 after sustaining injuries on operations in Afghanistan whilst serving with The Parachute Regiment. An IED blast resulted in the amputation of my left leg below the knee, right leg above the knee, right arm below the elbow and a few other injuries.

Since leaving the Services, I've realised how high the standard of care is at Headley Court, and how unsuitable the NHS is for military amputees.

At Headley Court you are told; 'You'll just transfer to the NHS and they'll provide the same level of care as DMRC'. The reality is that everything is much slower. Making appointments, ordering components, making the prosthesis; it's all painfully slow.

As a young, fit and motivated individual – like many of my former colleagues in the same situation – I find that the poor level of prosthetic provision from the NHS is actually holding me back instead of enabling me. Having to make many long journeys to my prosthetic centre only to be disappointed by parts not being in stock or not being ordered, having mistakes made whilst making sockets and a general lack of urgency is frustrating to say the least.

An appointment takes the whole day, including travel to and from a centre. Mine is two hours away. And having a new socket made can require one appointment each week for up to six or even eight weeks. Losing a whole day each week only to get a sub-standard socket at the end of it is ridiculous, and a waste of time and money.

Everyone knows what it's like to have their time wasted and having things take longer than they would like. But for an amputee, getting that socket right is the difference between living your life how you want or being stuck at home, or in pain for every step you take or, heaven forbid, using that wheelchair. That's why the current situation is so infuriating; because you have to use the NHS, you have to put your life on hold and you're not getting the best result at the end of the day.

If I could afford to fund my own private prosthetic provision, I would. As would many other veterans. But it is exceedingly expensive. Men and women who have been wounded whilst serving their country should be receiving the best care available and should not be forced to pay vast amounts of money for what they need. Unfortunately, this is not the case, far from it.

I hope this changes in the future.

Blesma
THE LIMBLESS VETERANS

Blesma, The Limbless Veterans – Factsheet

Blesma, The Limbless Veterans exists to assist limbless veterans to lead independent and fulfilling lives. Today, it is one of only a few charities that remain from the 18,000 that were born out of the First World War.

Blesma is dedicated to assisting serving and ex-Service people who have suffered life-changing limb loss or the loss of use of a limb, an eye or loss of sight. We support them in their communities throughout the UK and overseas.

Blesma provides networks where Members enjoy support from our professional Welfare Team and the opportunity to engage with others who have similar injuries and backgrounds, bonding to overcome everyday battles through our Activities programme. Members can take part in a range of activities from skiing and skydiving to photography and fishing, for free, all over the UK and abroad.

We work tirelessly for our Members when the conflicts that have affected them are no longer in the news. Since 1932, we have been the only national Service charity that supports limbless veterans for the duration of their lives. Our Members range from the youngest military amputees to those who fought in WWII, some having lived with limb loss for more than half a century. Whilst modern medicine transforms the physical injury, it is a complicated process to treat the emotional trauma and related lifelong health problems. We currently support more than 3,500 people, 340 of those as a result of action in Iraq and Afghanistan, with 97 double amputees and 19 triple amputees.

Our team of Regional Support Officers provides local welfare assistance to Members' and their families with home visits, support with the filling in of paperwork and representation in tribunals and on panels. They represent the interests of the individual Members they support by ensuring local statutory services are delivered, dealing with local authorities on behalf of Members and, where necessary, liaising with other charities and agencies.

Blesma runs a residential home providing 24-hour nursing and residential care for those unable to live in their own homes. It offers exciting adventure breaks, quiet holidays, and first-class residential care. Packed full of life, love, and barely-believable stories, nothing embodies Blesma's spirit more than our Blesma Home in Blackpool.

We receive no government funding and rely completely on generous public donations. Thankfully, our fantastic base of supporters and fundraisers help us to continue delivering care to our Members.

For more on what we do go to www.blesma.org or call 020 8590 1124.

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THE LIMBLESS VETERANS

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