Airing Pain Programme 81: Life after limb loss

Supporting amputee veterans to rebuild their lives, and psychological techniques beyond words.

Hundreds of veterans of the conflicts in Iraq and Afghanistan sustained injuries leading to the loss of one or more limbs. In the second of this ***Airing Pain*** *miniseries on pain management for ex-service men and women we look at the support available to help amputees rebuild their lives.*

At the Specialist Mobility Rehabilitation Centre (SMRC) in Preston Gregg Stevenson tells Producer Paul Evans about his two-year journey towards regaining mobility and adjusting to civilian life after losing his lower legs in an explosion. Thanks to prosthetic legs, a dedicated team of healthcare professionals and his own determination, Gregg is now a personal trainer helping others in similar situations.

Dr Fergus Jepson, who oversees the medical care at SMRC, explains why getting a prosthetic limb is just the first step on the road to recovery. Candy Bamford, the Centre's Counselling Psychotherapist, describes how she helps veterans to control their pain and confront traumatic memories by using psychological techniques better suited to the military background of her patients than the more typical 'talking therapies'.

Paul Evans: This is ***Airing Pain***, a programme brought to you by Pain Concern, the UK charity providing information and support for those of us living with pain and for healthcare professionals. I'm Paul Evans, and this is the second of a series of programmes to support military veterans living with chronic pain. It's funded by the MacRobert Trust and Forces in Mind Trust.

In the last programme we talked to Dr Dominic Aldington, a pain doctor now with the NHS and, formerly, as an army doctor in the Defence Medical Rehabilitation Centre at Headley Court in Surrey. You'll hear it referred to as the 'DMRC'.

In this programme we'll be looking at what happens when veterans, in particular, amputees, leave Headley Court and the army and continue their rehabilitation treatment as civilians, for the most part, within the NHS.

In England, there are nine enhanced centres for war veterans with regards to prosthetics. Dr Fergus Jepson is a consultant in amputee rehabilitation in the Preston centre.

Fergus Jepson: The services that we offer are prosthetics – predominantly – orthotics and wheelchair services, and this is for veterans, but the majority of what we do is with regards to prosthetics. What we would then anticipate doing is maintaining the high standard of prosthetic care that they've had in Headley Court and maintaining that into civilian life.

I think initially, there was an awful lot of concern by a lot of the ex-servicemen as to what sort of standard they would get in the NHS and we try to allay those fears initially by holding meetings here and inviting servicemen who we are going to discharge in conjunction with our local personal recovery unit here in Preston – in Fulwood, in Preston. And we held joint meetings here to show them around, to meet the team, so that they would feel confident that they knew *where* they were going, the sort of people they were going to see and we gave them an idea of how we intended to treat ex-servicemen and how we'd *already* treated ex-servicemen.

So I think that allayed a lot of those fears for patients coming up to Preston, who were about to be discharged [from Headley Court].

Over the years we've changed how we manage war veterans because they have an increased demand – not just amputations, but a lot of the other complex injuries that occur with the amputation [such as] blast injuries.

So being able to engage with them prior to coming here, so when they do come here as a patient, they know where they're coming. I think it's also important to mention that a lot of patients have been within the community for many months, if not a year or so, prior to being discharged from DMRC. So a lot of the patients were still undergoing rehab and discharge protocols for quite a long time, but living either at home or wherever they were making their home and back in very much civilian life for several months prior to being officially discharged from the army.

Evans: You were saying that there are more complex injuries – or obviously different injuries to civilian people – what sort of things are we talking about here?

Jepson: We're talking about multiple limb loss; we're talking about very complex associated injuries to other limbs or even to the same limb, so we're talking a great deal more scar tissue than you would anticipate finding in, say, for example, a diabetic or dysvascular patient. Where you have blast injuries, you've often had infection being present and then the sequelae of the

treatment for that infection. And also, don't forget the impact of the blast can often lead to fractures in *other* areas of the body as well, so this all leads to quite a complex patient caseload.

Evans: I would think an important thing is stopping that initial injury becoming a chronic pain condition.

Jepson: My experience of that with the ex-servicemen is probably quite limited. And I say that because most of the patients who come here have been through DMRC and thus their pain has been managed down there, usually extremely well. I would say that the cohort of patients that I see who are ex-servicemen, where they have been discharged from the army with painful conditions, then have struggled to live with the disability associated with that pain or that injury and then go on to have amputations – that I think we have a lot more experience in seeing.

Evans: So the amputation comes at the very *end* of the treatment, if you like, and only if it's desperate to do.

Jepson: Well, it's difficult for me to comment on the patients who come here as amputees, in the sense that they've had all their surgery done in Queen Elizabeth [Hospital Birmingham], and some of it in wherever the initial injury was, whether it be in training or, more likely, as a result of an improvised explosive device, which an awful lot of the patients are.

Certainly, limb salvage is always *tried* – that's my understanding of the way that teir initial treatment and their treatment on return back to England is always at the forefront, because amputation can always be done any time after that, so limb salvage is always attempted first.

But there are also this cohort of patients, not a huge cohort, of patients who have been discharged, but then have a chronic pain issue, which they find that living with this chronic pain and the disability and impairment that comes with that and their lack of participation in the things they want to participate in, whether it be aspects of sport, or whether it be lifestyle with their children at home, or whether it be work, means that amputation is a way forward for them within civilian life. *But* the amputation is from a service-attributable injury, which I think is also an important delineating factor.

But I think, like [for] all patients, you have to be extremely careful [when considering] who would benefit from an amputation, and that involves meeting amputees, meeting other patients, a lot of in-depth discussion with the team, and also quite a bit of psychology input as well to make sure that someone's prepared for that *loss*, because losing a limb is very much

the same as other grief reactions. The trauma of going through losing your limb is a very significant one.

Evans: Somebody who hasn't been through this might say, 'oh, once you get your prosthetic [or] your false leg, everything will be back to normal. You'll be walking again, you'll be playing football, you'll be running in the Paralympics and things like that'. It's not like that. There's much more to it.

Jepson: Yeah, I couldn't express *enough* how true that is. You know, I saw a patient earlier on today and his words to me were, 'I can do everything – I can run, I can walk, I can walk up and down stairs, I can box, I can keep up with everyone, but when I take my leg off, all I see is a disabled man'.

That brings it home, really, about how you can do all the prosthetics and a man can achieve, or a woman can achieve, all the things and more, that they were doing prior to the amputation, but when the prosthesis comes off, then they feel vulnerable and they feel the same level of loss that they felt initially. And that can be very psychologically difficult to deal with.

Evans: From what you're saying, then, the psychological support you give, as in all chronic pain conditions, is important.

Jepson: Psychology is extremely important in any patient with pain, especially chronic pain, because although we focus very much on the severe injuries that the war vets have, I don't think we should overlook – and I think we should also include – all the patients with chronic pain who haven't been injured in that manner because there are a great deal of reasons why patients may be in chronic pain. But psychology input, I think is extremely important and should be offered as a means of helping a patient with chronic pain cope with that pain.

Evans: Dr Fergus Jepson – and the support offered to his patients at the Specialist Rehabilitation Centre in Preston is given by counselling psychologist Candy Bamford.

Candy Bamford: How well people can adjust to wearing an artificial limb is determined by how comfortable they are wearing it – whether they've got any pain or not; it's determined by how confident they are in themselves to do it and it's to do with dealing with any trauma that they may have gone through.

All patients that are amputees – you can't have an amputation and it not be traumatic – the thing that makes it different perhaps for them is that they've had a totally different life to the one they've got now and it's a life that they haven't chosen. They're coming here from Headley,

their prosthetics are being done here and sometimes they're coming with pain. We use hypnosis here for pain, so out of potentially 800 people that I've seen in this building, over 400 use hypnosis CDs to control their pain, so that's an option that we go down at the beginning.

Sometimes it's about counselling to help them to adjust to not being in the military and just moving around and being civilian again. Sometimes that's as much as they can cope with at this time.

We also use EMDR, which stands for eye movements, desensitisation and reprocessing, and it's a form of psychotherapy that's used in the military. It's used [in] Afghanistan, Bosnia… because it isn't a talking therapy. It's a very quick therapy. Psychotherapy usually takes a long time; this takes a few weeks.

And what we're doing is reprocessing the traumas and by the reprocessing, we're desensitising them so that they don't forget what's happened, but it's not upsetting in the same way. So a lot of the military veterans have had EMDR here, but they won't sort of walk through the door and immediately have it. They need to be quite settled first before we start going back, because psychotherapy works on the principle that everybody is a product of their past, so it's not just what's happened to you in the military, there may be other stuff before that. But when they're ready, they'll come – they're not forced to do it. It's very much about what they need when they come in here, so it could be counselling, it could be hypnosis, it could be psychotherapy.

Evans: Just explain EMDR. Eye movement…

Bamford: …desensitisation and reprocessing.

Evans: Where does the eye movement come into this?

Bamford: Francine Shapiro, who devised EMDR, apparently se was quite stressed about something at work and she walked down a tree-lined avenue. And as she was walking down, she was looking left to right at the trees and noticed when she got to the end that she felt better. And that's really wacky, but as a result of that, she came back and started using principles [of EMDR] and researching it.

EMDR is probably the most researched therapy that there is because it appeared so strange. And so she started doing research on it and from that, EMDR evolved into what it is now. It's used worldwide in war situations, by therapists in hospitals. And it's really good for military

veterans because they don't have to talk about things – it's not a talking therapy, and so it works much easier.

Evans: Explain that – it's not a talking therapy, so what is the process?

Bamford: The process is that we use the eye movements and we'll start perhaps with a traumatic event that they've been through and how it makes them feel – they might feel that they don't trust people or that they're not good enough. So we start at that point and we use the eye movements going backwards and forwards in front of the eyes, so that they're going left, right, left, right, and then every so often we'll stop and say, can you just give me one sentence on what you're feeling at the moment? And they just say whatever's in their head.

And doing that, strangely, seems… because they're going with emotions, they're bringing up how they're feeling, they're bringing up the emotions... Trauma is an emotional response to an event. EDMR is an emotional therapy that matches that emotional response.

Evans: And how would you sort of judge the success of that then?

Bamford: I judge it by doing psychometric tests. So before somebody starts working with me, I'll give them one test to do that tells me how traumatised they are and another test that tells me how anxious or stressed they are at that time. I'll do a hypnosis session with them and give them a CD of that to calm them and to help them to cope while they go through it. When I see them on the second week, I'll retest them. And it will have dropped quite a bit just because the hypnosis is calming them. And then at the end of the EMDR, I'll retest again and you can see that the scores may have gone from 60-odd out of 80-odd to single figures.

Evans: I may by completely wrong here but my idea of what a military man, as a soldier in the frontline in Afghanistan or anywhere else in the world, is that they're not touchy-feely people.

Bamford: No. And *that* is the advantage of EMDR, because they don't have to sit and talk endlessly about things. They're not trained to do that. They're trained to… whatever's happened, just get on with it and just keep going. They are reluctant, initially, to come for EMDR and that's why they're not pushed. They come when they're ready. I see people at the moment that perhaps it's been five years since the incident that they were in – now they're ready to do it and they do it in 8 weeks, it's over, they're done. It has to be when the person's ready. And sometimes their family and friends want them to do it long before they're ready and it's about the office or themselves. You can't force people to do psychotherapy… You can't force people into counselling, let alone psychotherapy.

Evans: As many people with chronic pain conditions know – not just military veterans, but the 8.7 million with chronic pain conditions in the UK – if you go to your doctor with a chronic pain condition… If you're pain and he sends you to a psychologist [**Bamford**: yes], there's a danger of you thinking that he thinks you're mad.

Bamford: Yes, and I think that's the benefit of having psychology here, because the physios can talk to people about it, the doctor can, the people in the gym, Gregg and everybody else.

The staff here [have] experienced hypnosis, for instance, so they know what it's like. They're not sent somewhere to somebody that they don't know and they've never seen. And our patients here are sat in the waiting room waiting for their appointments, and they're all chatting together, or they've come in ambulances together. And so they talk to each other. They also have the amputee forums that they go on, so they know what each other are doing and they meet each other here. The military lads will meet each other here when they're all coming in.

They support each other – it's not just the staff supporting them here, they can all go in the gym in the morning and they'll all be supporting each other. And they're all amputees, so they don't feel like they're being stared at or that people don't understand what they need. If you go to a normal gym as an amputee, it's very difficult to get a programme together, because nobody knows what they should do. Here, they're all amputees.

Evans: What advice would you give to amputees who don't get to places like this? What should they be shouting for or thumping the table for?

Bamford: They need to be comfortable at the limb centre that they're at. If they need a psychology service, then they need to ask for that help, because so many times, I see people and they say, 'oh, I didn't know that you were here', and I say, 'well, if you need help, ask for it'. At most limb centres, there isn't a psychologist that's dedicated to the limb centre, but they do take psychology from the hospital that the limb centre's at, so they can ask for help, for counselling, they can ask for psychotherapy if they need it, for trauma. Because what being an amputee does, if you're a new amputee, that feeling that you have of being a new amputee, of feeling vulnerable that life's over – that might be triggering things from the past. They need help, they need psychotherapy – some trauma therapy to help them get through that so that they can have a positive outcome being an amputee and not stuck at home getting more depressed.

There was a white paper [that] came out in the 1990s that said all limb centres should have a counselling facility. So every limb centre since that white paper's come out should have counselling facilities available.

Evans: I think a very, very important thing to remember is there's much more to losing a limb, being injured, than just losing a limb.

Bamford: Yes. There's a psychological backlash to it. And people don't appreciate that. Very often, they'll think that they're going mad (a) because they can feel the leg that's not there, they can feel the phantom. And so they think they're going mad especially when they say to people, 'I can feel my toes, my toes are hurting and people say, you're stupid'. So nobody says anything. And it's not until they come to a limb centre here that they hear it talked about all the time that they realise *that's* why they need to access counselling, so that they know that what they're going through is perfectly normal.

All the feelings they're going through – the pain that they're getting, the phantom pain that seems odd when it's not there and it's moving around, the feelings that are coming up, the anger that's coming up. And when people are emotionally disturbed like they are being an amputee, where their whole life changes – it's like somebody's got their life and turned it upside down – that is a huge emotional trauma that they've been through, so their emotions are going up and down like a rollercoaster on a daily basis: anger, sadness, anger, sadness. And they don't know why one minute, they'll burst into tears; the next minute, they're throwing something across the room.

That level of unease, that up and down, is perfectly normal for all amputees. You can't go through having a limb removed and it not bother you. I've *never* had anybody come in here and think, 'it's nothing, this'. I've seen people who'll say 'I'm fine, I'm fine', but then you see them six months later and they've crashed. Not everybody goes through it the same way – some people will come in and say, 'oh yeah, I'm fine, I just need to get a leg, and that's it'. And then we make them a limb and that's when they realise how difficult it is. It hits people at different times.

Evans: Psychologist Candy Bamford. Now, as you'd expect, the Specialist Mobility Centre in Preston has its own gym for amputees. Army veteran Gregg Stevenson, himself a double amputee, is a personal trainer there.

Gregg Stevenson: On a foot patrol in Afghanistan in 2009, I lost one leg above the knee and one below the knee [from] stepping on an IED.

Evans: Can you tell me what the process was from getting injured to getting treated?

Stevenson: The army, after obviously many conflicts, realised that it was all about speed, so from point of injury, this helicopter was sent very quickly. It scooped me up off the ground, thanks to the fantastic care – immediate care – from my section. The helicopter then took me to Camp Bastion, which I'm sure you've heard of on the news. There's a huge camp out there, where the surgeons were waiting to prevent any infection and get me treated as quickly as possible.

Evans: And from there?

Stevenson: Once I was stable-ish, they then make a decision on whether you can fly, flew me back to Birmingham and then straight into Selly Oak Hospital, as it was called then, and dealt with – further operations, cleaning the wounds and whatnot.

Evans: So from point of injury to, let's say, being mended or being physically mended, how long would that have taken?

Stevenson: 48 hours?

Evans: That's absolutely incredible…

Stevenson: Oh it is, yeah, and I think that's why there are so many veterans still alive and living fulfilled lives now, because of the immediate care and the speed at which it was given… There's a reason why, you know, things like infection and whatnot would [have] come in if we hadn't been dealt with so quickly.

I was injured in 2009 on [Operation] Herrick 9, so that was a very active year in Afghanistan. There were quite a few of us, so we had specialist nurses on the wards, family support for the guys who wanted it. And then when I moved down to Headley Court, which is more of a rehabilitation centre [for] resetting, so once you've dealt with your immediate care, that's then when you progress to then think about things like learning how to walk or things like learning how to adapt to disability and that's where you can access psychological support, counselling, hypnosis and an array of things that the consultant can take you through.

Once I was discharged from the military, I became a service user, as well as a now employee [laughs] of this place. Candy is sort of our in-house guru of psychological support.

Evans: How long did you spend in Headley Court?

Stevenson: Just less than two years, yeah.

Evans: That's an incredibly long period to my mind.

Stevenson: Yeah. Yeah, yeah, it didn't feel like it because it wasn't a two years constant. It was sort of six weeks and then two weeks at home and then five weeks and then two weeks at home. And, obviously, I did not maybe realise it at the time but that was preparing me for life away from the military, as well as adapting my life at home, which is very important for people with disabilities… to realise, living in a northern town, that two up, two down might not be the best house to live in and the cobbled streets are going to take some getting used to. It was a way of me developing my life from going from relatively fit commando on the frontline to learning how to adapt my life to suit my needs now.

Evans: So how did you manage adaptation?

Stevenson: It was difficult at first. I think once I understood that perhaps everything I wanted to do wasn't attainable, wasn't a realistic goal, once I actually realised how to change my mindset that there were just as challenging goals... Maybe I had to learn not to relate everything to physical ambition as I did in my military career. But, yeah, just things like my job now – I still managed to pass the course as a personal trainer with a disability so that was quite a challenge but a huge achievement which I enjoyed doing.

Evans: So you deal with veterans here?

Stevenson: Yeah. We are a veteran-funded gym but it's accessible by all our patients who come here, so, yep, I see veterans, I see NHS patients, so it's a really nice mix and it's a fantastic facility to have an on-site gym. In those early days of rehab, it's important to perhaps develop muscle in areas that you haven't for a while for whatever reason – maybe you've been stuck in a wheelchair for a long time, or perhaps you haven't had a prosthesis for a while, or for whatever reason. So it's nice at that early stage we can get in the gym and develop the strength needed to operate a prosthetic or just maintain good core posture in the wheelchair, right through to perhaps someone who is further down the line who now wants to be a 100-metre sprinter and needs to develop some power and some speed in the gym.

So we see a real mixed bag of goals and again, it's often my job to rein in those goals into sensible ideas, but I'm guilty of it myself. I got my running legs and I thought, that's it, I'm going to go and run a marathon – maybe it was just about learning how to effectively run first

and then achieving a kilometre and then 10 kilometres. So that's a big deal in the disabled community, I think, to set realistic ambitions and goals.

Evans: And that's the same within the chronic pain community for everybody, not just veterans. It's learning how to pace yourself [**Stevenson**: yeah] and the psychological help you get [**Stevenson**: yeah] not to burn yourself out.

Stevenson: I couldn't agree more. It's what I see regularly and I've gone through it in my personal experience as well.

Evans: You seem incredibly well-balanced now. Are the veterans you see here and help tem go through the paces in different stages of their rehab?

Stevenson: Oh yeah, massively. I mean we're all different – maybe if you'd spoken to me two years ago, I wouldn't have been quite as well-balanced, but people are different and people take to disability differently. It might take someone… Just like every aspect of life, what to one person is a big deal, to another person is water off a duck's back, so there doesn't seem to be a set pattern of what affects people in what way, which makes us all weird and wonderful, which is brilliant [laughs].

Evans: That was army veteran and Personal Trainer at the Specialist Rehabilitation Centre in Preston, Gregg Stevenson.

I'll just remind you that whilst we at Pain Concern believe the information and opinions on ***Airing Pain*** are accurate and sound, based on the best judgment available, you should always consult your health professional on *any* matter relating to your health and well-being. He or she is the only person who knows you, your circumstances and therefore the appropriate action to take on your behalf.

Don't forget that you can download all editions and transcripts of ***Airing Pain*** from Pain Concern's website, which is painconcern.org.uk. You'll also find links and information on further support for military veterans.

In the next edition of ***Airing Pain***, I'll be visiting one of the NHS services that provides psychological support to ex-service personnel suffering with PTSD – that's post-traumatic stress disorder.

For those who also have chronic pain as a result of experiencing physical trauma, treating the one without or in isolation from the other can lead to both conditions spiralling out of control.

But finally, for this edition of ***Airing Pain***, I'll leave the last words to Candy Bamford and Gregg Stevenson.

After two years in Headley Court, when you left regimental life, when you left the army and got into civilian life, how did you find the transition moving from Headley Court – the army, if you like – to the NHS?

Stevenson: I think Dr Jepson and the team here have a fantastic set-up. I've been given a lot of empathy, I've been given a lot of time, I've been given a lot of funding to get my life to this level and I think it was quite a smooth transition. I know there are a lot of horror stories out there [laughs] and the veteran community can get a bit of a rap, expecting us all to be grumpy squaddies.

I'm not saying I haven't had a few surprises because at Headley Court, everything is a one-stop shop almost, so you get used to things getting done pretty quickly. So it was a little eye-opening, moving to the NHS and just maybe having to learn how to be patient. But I'm very fortunate to see it from both sides, as a service-user and an employee, and I can tell you that it's fascinating to see how so many people get such amazing care in one building. I don't know how it happens, to be honest – it's down to Dr Jepson's skills and people management and the way he is with us all that it runs so smoothly.

Evans: What advice would you give to veterans who aren't getting this help? What should they ask for? What should they demand?

Stevenson: I think veterans understand that there is support out there. I think it's not being ashamed to ask for it because I come across that very regularly in my job and also in my military connection network, that actually sometimes it's about the veteran being big enough to say, this is the support I need and actually doing the research, finding out where to go. I would also say trying to keep yourself physically conditioned and giving yourself the best shot – limiting alcohol, eating well, training hard. If you can do the things we know we can and we've been shown how to do, you give yourself the best shot.

Bamford: I spoke to a military veteran this morning. When he'd come from Camp Bastion to Birmingham and was lying in bed waiting for surgery, he thought he was never going to walk again. He didn't know about prosthetics. The army guys don't know any of that because they're active young men. And when that happens to them, they don't know about anything, they just think they're going to be stuck in a wheelchair for the rest of their lives. So information is important – people getting the information they need – because otherwise they lie awake at

night worrying, because nobody's there to tell them that it's okay. But somebody being there when they get to Birmingham to sit and talk to them and say there is life after being blown up; there is life as an amputee.

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