Airing Pain Programme 80: Suffering is optional

Improving treatment for veterans in pain and facing the challenges of civilian life.

'Pain is inevitable, but suffering is optional.' A motto tattooed onto the arm of a wounded veteran which, although easier said than done, is good advice for anyone living with pain. But how can ex-service personnel get the support they need to manage the pain and psychological trauma resulting from what are often horrific injuries?

Producer Paul Evans finds out in this the first edition of Airing Pain's miniseries on former members of the armed forces who live with pain. Infantry veteran Michael Clough, whose injuries left him with complex regional pain syndrome (CRPS) and requiring the amputation of his leg, shares his story of the difficult transition from military hospitals to NHS care. Claire Stephens, CEO of the charity Wound Care for Heroes, and herself medically-retired after injury, outlines how care can be improved.

We also hear from pain management specialists with military backgrounds about the challenges faced by this patient group. Vincent De Mello explains why ex-servicemen in pain often feel abandoned and says that the effects reach beyond the individual to the whole family, while Dominic Aldington discusses the problem of veterans feeling their pain is disbelieved by civilian clinicians.

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 edition is the first in a series of programmes to support military veterans living with chronic pain. It's funded by the MacRobert Trust and Forces in Mind Trust.

Now, how do military personal who've suffered injury and chronic pain resulting from it, cope with that transition from army life and healthcare to the outside world. Dr Winston De Mello is a retired colonel in the army with twenty years of service behind him, now he's Pain Consultant at Wythenshawe Hospital in Manchester.

Dr Winston De Mello: To answer that question I need to give you an example of how a patient within the military set up would be treated. If a soldier in a battalion is ill, he goes to the medical centre. But attached to the medical centre would be a physiotherapist, so if he has a back injury, that back injury would be treated quickly, because as far as the

commanding officer is concerned, he wants a full strength of fit men. So there is a quick response and, if they need specialist help, they will go to the secondary care facility that's closest to that battalion. So the chronological chronic development of pain is minimised because you tackle it early.

If you come in to civilian practice it's a bit of a lottery: will your GP triage you to somewhere else, what kind of quality. But you don't have control because in the military your employer is also your provider, also your doctor, also your cook, also your provider of uniform and also gives you a job and looks after your welfare. So that whole holistic coverage is lost when you come into the NHS.

So a soldier adjusting to NHS life after a period of time within the military realises he's now just in the queue. And if you miss the opportunity right at the beginning, you can see how the chronicity and the psychological sequelae of that, plus perhaps financial when you're not fit for work, or because somebody assumes that you're able to do a job of some kind because you're physically able. So ex-soldiers with emotional scars, or psychological trauma would find it hard to adjust to this narrow minded approach to what is fit and what is unfit.

Evans: So those emotional traumas will feed into the chronic pain?

De Mello: Very much so. It's self-propelling. It's like putting petrol on a fire, it's just going to make it worse and worse and worse. And as a general rule, say, for back pain, we reckon your best chances of recovery are within the first six months from initial trauma. By two years you're unlikely, this is for plain backs, remember some of the soldiers that get wounded you're talking about horrific injuries. Some of them.

So it is complex and the secret is getting in early and getting a multidisciplinary approach. So it's not just the doctors, but the physiotherapists, the social worker, the psychologist, the rehab expert, the social worker to get the benefits that he needs. And also the emotional support, working with others also in the same conditions so they feel they're not alone and abandoned.

Evans: But feeling alone and abandoned is something I'm sure many military people who are pensioned off, if you like, after some horrific injuries, feeling abandoned I'm sure is something many people feel.

De Mello: Well forget about the soldiers wounded, just take somebody like myself who's done some time in the military, and then comes into civilian practice. I found that adjustment very difficult. When I was in the military everything was structured and I knew my chain of command and everything was set in stone. When you come into civilian practice that is a

huge change. Now imagine a soldier is also wounded and that therefore compounds the situation even further. That makes the adjustment hugely difficult, not just for the soldier, but for the partner, for the family, the children. So it's like a cancer, it spreads across the whole family and social fabric. It is very, very frightening.

Evans: Dr Winston De Mello.

Michael Clough was injured in a parachute exercise in Afghanistan in 2012. An accident that eventually would cause him to lose a leg.

Michael Clough: When I was actually in Afghanistan I was selected to be part of an elite unit called the Brigade Reconnaissance Force, but I didn't have my parachute wings because it's generally Parachute Regiment soldiers that are in that particular force. So I was actually doing my P[egasus] Company jumps when I was injured. When I came into land I actually hit the floor at an awkward angle and I sustained an open fracture to my left tibia and fibula on my left limb.

So I had reconstructive surgery, which was what they call an 'ex fix frame', which was an exterior fixation which screwed into the bone to basically hold the leg back together. And that was the first procedure that I had done. Unfortunately, it really didn't work, I developed a lot of infection problems with it and also chronic [complex] regional pain syndrome from the scar sites, from where my injury was.

Evans: Where were you treated? Within the force, within the army, or by the NHS?

Clough: I was treated by the armed forces, so I was treated at Birmingham Queen Elizabeth Hospital by military surgeons. They did all my procedures, all my operations that I had, from the start through to the very finish.

Evans: Once you'd had the procedure, putting your leg back together, what happened then? Was the pain gone? Did it get better?

Clough: From the actual injury perspective, the mechanics of my injury, that actually repaired quite well, as in the break sites repaired quite well. But the problems that I was left with was more like infection, because I had an open fracture to my left leg and the bones were exposed for quite a while before I was actually picked up by the ambulance and taken to a clinical environment, I obviously contracted a lot of viruses from that, a lot of infections, just generally down to the environment what my bones were exposed to. And the infection type that I got was the bone infections called osteomyelitis, which is the main infection what I've had problems with ever since.

Evans: And what problems have you had?

Clough: So osteomyelitis would have been like a blood borne infection into the bone, it causes severe pain into the area where the breaks were. And it causes the skin to become sort of untouchable, so you struggle to be able to touch the site area whatsoever, whether it be soft touch or hard touch. And it also becomes quite responsive to cold as well, so I really did struggle in winter time and just with any sort of touch on the actual problem area that I had.

Evans: What treatment did you have for that?

Clough: At the start off point, when I was diagnosed with [complex] regional pain syndrome, the first procedure they do at Headley Court, which is the military rehabilitation centre, is they send you to see the occupational therapy team, before they pump you full of medication, which is one of the solutions, they do try a lot of the mirror therapy procedures, desensitisation techniques that they use. Unfortunately, none of these techniques seemed to work for me and unfortunately I ended up going down the medication route, which was obviously done under consultation, after trying two weeks of different therapies under occupational reasons.

Evans: Did the medicinal route work?

Clough: Yeah, the medications that I took definitely seemed to block the signal of pain that I had. It was six months of trial and error, depending on what types of medication and types of dosages work for me, some of them had serious side effects. The sort of drug what seemed to be the best balance for side effects and to relieve my pain, its main side effect is it does make you feel very drowsy in the morning, you can't function once you've taken the medication, which made it quite hard to do rehabilitation through the daytime.

Evans: What sort of psychological support did you have going through all this?

Clough: Psychological support was more from the lads who were going through the same experience as me at Headley Court. At Headley Court they have a unit called the MTBI unit, which is relation to your psychological state of mind, but I didn't really feel that I wanted to go down that path and talk to people in relation to that side of my feelings as such you could call them. I just preferred to talk to the pain consultant about that, because he actually understood more than anybody the types of pains that I was suffering from. He was one of the only people who I felt sort of believed the pain that I was in as well.

Evans: That pain consultant was Doctor Dominic Aldington, who for almost 25 years with the army medical corps, provided the specialist pain services at the Defence Medical Rehabilitation Centre at Headley Court. He was expert advisor on pain to the Surgeon General for eight years. So from the time and place of injury, what's the process of getting the casualty back to Headley Court?

Dr Dominic Aldington: The chain of care goes from the pre-hospital environment, where the individual looks after themselves and their buddy comes to help them and the combat medic will come along and then various other assets, depending on what's available in that location, will be called upon. They'll then be evacuated back to somewhere like a field hospital and then from the field hospital they'll come back, usually to the UK via a flight, particularly the Royal Air Force. At the moment our casualties go to the Queen Elisabeth Hospital in Birmingham, where the more acute side of their care will be dealt with. Although low level rehabilitation will start even whilst they're in Birmingham, the mainstay of it will occur when they get to Headley Court.

Evans: So at what point would they get to see you, a pain doctor?

Aldington: They would first come across a consultant anaesthetist who should be quite well versed in management of acute pain, on the MERT (medical emergency response team) helicopter then at Camp Bastion. They would also have consultant anaesthetists available on many of the flights back to the UK, and when they get to Birmingham they'll be more available. So the acute management of their pain by experts should not be a significant problem.

Consultants in pain management tend to be called upon for more persistent type pains, or awkward ones. So we would visit the patients on the wards in Birmingham when they got there, but of course many of them we wouldn't need to see again, they've been managed well. So within Headley Court the pain clinic existed and its role was very clearly to support rehabilitation, so we would have patients referred to us if our rehabilitation colleagues felt that pain was impeding the patients progress.

Evans: That was Colonel Aldington? [Aldington, yeah] What was different about him?

Clough: The difference with him is he actually listens to you, so he starts the session off by asking you what kind of pain you're in. And I noticed that while he's asking you these questions in relation to the pain he's also looking at your body language to see if you're fidgeting, if you're in discomfort. And he'd actually say to you, 'I've noticed that you are

fidgeting a lot, so therefore there is signs of pain there, not just from what you're telling me but based on your body language as well'.

He'll then go through the medications that you're on, what types of therapy you've considered, what you actually believe in. If you don't believe in something, it's very difficult then to accept that type of therapy. So I'll use hypnosis as a type of therapy: I don't believe in hypnosis as a person, so when I try to go to a therapy session that is based around hypnosis straight away I've got a barrier up against it and I can't relax or settle down when I'm with a hypnotherapist.

Evans: So Colonel Aldington, he was managing you, you tried a hypnotherapist, what else was he doing?

Clough: Before they go down the medication route he did try every other option, from mirror therapy, hypnotherapy, discussion groups, desensitisation courses, he tries all them types of routes first, because they do know that medication is the last resort before they do surgical procedures. And we did discuss things like root stimulators, to cause another signal to block out the pain signal that you're receiving at the moment. But for me, unfortunately medication was the one that worked for me out of them, the whole list.

And I think one of the good things, like we say with Colonel Aldington is that he does listen to you, if you do say medication is the thing that works for me then he will try and come up with the best medication package to suit you and what you want to achieve. So rather than just saying to him, 'I just need medication', he'll try and found out what you want to achieve from your rehabilitation and then he'll give you medication to suit what you want to achieve.

Evans: So the treatment for your pain, within the army, was first class?

Clough: Very, very good yeah, first class.

Evans: Now how did you find it when you came into the civilian world?

Clough: My first appointment with my GP, the first thing that he looked at was the level of medication that I was on. In my opinion he didn't really read my notes from the military, because what he tried to do was refer me straight on to doing desensitisation courses and mirror therapy. And if he'd have read my notes he'd have seen that I've already been through all these procedures before and they didn't work for me.

And I understand that some people believe you need to revisit these things every so often to see if they do work for you, but with my level of CRPS (complex regional pain syndrome), if somebody asks you to revisit something that you've already done, it can cause you quite, I

don't know, not a form of anxiety but it can cause you to be quite frustrated with these people that are asking you to do these things again. When you're frustrated your pain does increase, and it just becomes like a vicious circle.

So in my opinion I think your GPs do need to read your medical notes from the military a little bit more carefully and understand that you have already been through these pathways before, that the military just aren't throwing you out because you've got pain, they've tried to resolve the problem, but it hasn't worked and then you've ended up in civilian life with the pain problems still attached to your body really.

Evans: I haven't been in the military life, but I'm guessing that having worked in the military life, attitudes and mindsets are completely different to civilian life?

Clough: They are yeah, I mean, in relation to the military I think it's, if you say that you are in pain, especially coming from like an infantry background where it's embedded into you from the day that you join the military that you're a fighting soldier, people carry on with broken bones, sprained ankles, it's just a part of the way of life that's embedded into you that you continue to fight. That is installed into you from the day you walked through the door at training camp. So if you turn round to a clinician at Headley Court and say you have got severe pain, they know that you have got severe pain, that you're not just sort of saying you've got severe pain for the sake of it, you have actually got severe pain of some type.

Evans: Michael told me that in the army you're trained to go through pain barriers. The actual training, as far as he was concerned, was that you just keep going, if you've broken your ankle you keep going and going and going. So the point he was making was, when he said 'I have pain', army doctors like yourself believed him. Getting to be believed in civilian life is very, very difficult, whereas there was no problem in the army.

Dr Aldington: Isn't that disgusting? What a terrible thing for anyone to say of doctors anywhere, that we don't believe people. But it's true. One of the problems we have is most UK doctors have less training in pain than a vet, so is it any wonder most of them aren't very good at it.

Evans: Now you're a pain consultant in the hospital in Winchester, how does that differ from your job in military?

Aldington: That's a very good question and gets to the nub of many things. Very few of my patients are in the military and being in the military isn't just a different job it's a way of life. Patients in the military who have pain will also have a threat to that way of life. If you have pain, you're often not able to fulfil the fitness regimes required. So there's this threat to your

fitness and thus your continued employment, that adds a dimension that we rarely see within civilian practice. There are obvious differences over average age, we tended to see a lot more young men within the military than you would normally do as a civilian.

But there are also differences in what it means to the patients to have these pains and what the effect of the pains are going to be. Because pain isn't just ouch, that's the easy bit, it's the unhappiness, the anxiety and the frustration that goes with pain that is the bit that ruins everyone's lives.

Evans: At some point some of your patients would have to leave the forces, they might not be able to carry on with their careers, or maybe not in the way that they joined for. [**Aldington**: Yeah, yeah.] What is the transition from military pain care, to civilian pain care?

Aldington: The military do not provide healthcare for veterans, so their healthcare requirements are expected to be met by the local civilian infrastructure, which for many is the national health service, but of course it's different between England, Wales and Scotland. Their primary care is taken over by their local GP and the GP would then arrange forward referral to the local pain service, if that's what they wish to do.

Evans: Was there much communication between your pain doctor in the army, and your new GP?

Clough: I believe that the pain team in the military, Colonel Aldington and Sarah Lewis, the nurse, I think they will have provided the GP with enough information. The only trouble is that I think that the transfer of information is all done paperwork wise. I know it's probably very difficult for the GPs and the military doctors to do this, but I believe a phone call would represent far better than paperwork being submitted via email would be, because you can't tell a story via written paper, I think it's very difficult for them to explain somebody's pain condition via a written text format. I think it would be better for them to ring them up and say, 'I've got a soldier who is leaving the military now, he's got a severe pain condition, this is what we've tried, these are the paths we've gone down with him and his pain condition is real'. I think that ten seconds of talking there says more than two thousand words would do on a written text page.

Evans: That was Michael Clough. He's being helped in his recovery by a charity called Wound Care for Heroes. It was co-founded by its CEO Claire Stevens and Professor Lieutenant Colonel Steve Jeffrey to develop a national network of complex wound management services to support the NHS in providing lifelong support and care for those discharged from the armed forces.

Claire joined the Queen Alexandra's Royal Army Nursing Corps as a Captain, however an injury brought a premature end to her military career. The transition from army to NHS was not smooth.

Claire Stevens: My notes were not transferred, ultimately there's this hole within your medical records and I started to actually think 'ok, I'm from a medical background, I know how to fill this gap'. What happens to people who've been fairly critically injured, how is this transition occurring. So the second gap that we noticed with care is, particularly the Afghanistan conflict, the military have developed excellence in their skill, knowledge and progression of how things are managed and, of course, the NHS have not necessarily been geared up to accept some of those patients back into civilian life. And by nature of what they've been through, the injuries they have sustained, where, and some of the underlying issues with the injuries, the NHS needs support to give them the knowledge, skill, to enable them to look after, particularly the traumatically injured veterans.

And what evidently was really missing was a single point of contact. So if you've had any level of trauma, whilst you're in a system it's absolutely fine, but when you're discharged out it's very difficult to get back into that system, so you'd have to have a GP referral. And what we did in a retrospective audit was find out that sometimes it was up to 18 months that people were having to wait. By that point of time your wound requires a lot more repair, and it's a lot more costly. So by having a single point of contact, which is what Wound Care for Heroes provides, it means that we are able to refer and get people into clinics within 48 hours, straight into the military expertise, where they'll be seen by some of the Colonels and Surgeons at RCDO. And what that means to the veteran is that they're seen very quickly, their wounds are addressed, their pain issues are addressed and they have bypassed all of that being passed and referred and referred and referred. And once they're on our radar they're on our radar for life.

Evan: What I thought was the big issues with military veterans was PTSD, post-traumatic stress disorder, that's the big thing that seems to get all the headlines, but not wounds.

Stevens: No, absolutely I couldn't agree with you more on that. There's been a lot of media coverage for PTSD for many years now and I think generally the public recognise that PTSD is an issue. But wounds, I think from a general public perspective, people know that if people are injured in active service or even if you're injured during training – because some very nasty traumatic injuries occur during training exercises – but generally you know that they are taken from battlefield into Camp Bastion and then were evacuated out to Birmingham, that the care they received was excellent.

But the perception is they're healed, they're put back together, then they're discharged. And very often the public will say to me, 'oh do they have wounds then?' And I think some of the wounds, they're not visible, that is a little bit like PTSD in one respect. So if you have an amputee, that visual aspect, you tend to see that in the media a lot, but there are many, many types of wounds that have lifetime consequences. Patients who have suffered burns require scar management and more reconstructive surgery.

It's about recognising that there is an ongoing need. Some people might be healed for three years, five years, ten years and then suddenly bang, something occurs. As Wound Care for Heroes we can monitor that process by putting them in one of our triage pathways and try to prevent some of those wounds from occurring. But when wounds do occur they can come straight to us and we can get that process moving much quicker.

You know it would be actually quite interesting to see if we addressed all of the pain issues correctly and if we addressed the physical injury properly, would we actually see a reduction in PTSD.

Evans: That's Claire Stevens of Wound Care for Heroes. Further information can be found on their website which is woundcare4heroes.org.uk

So, from our two ex-army pain consultants now working within the NHS, what's the advice to colleagues?

De Mello: In the British Journal of Pain there have been recently, in the last two years, articles on military aspects of pain problems and in those articles they have crystallised into a summary a checklist. Why is a soldier different? What resources were available to him in the military and what are available outside? So I think anyone who's interested in this can either speak to one of his colleagues in the reserves and get this information. If they do just that it would make a huge difference.

Evans: And to those facing life out of the army?

Aldington: I keep being reminded of one of my patients who had tattooed on his forearm, 'pain is inevitable but suffering is optional'. I think you need to try and make sure you become that survivor and not the victim of what's happened. And you need to recognise that no matter what it feels like, it's not the end, it's just the start of a new chapter. There will be resources you can call upon for support, and it's probably a good idea to get those arranged or at least make your introductions now, so whether that's unit welfare, or whether it's the Legion or one of the other benevolent funds.

Evans: Doctor Dominic Aldington. He's now Consultant in Pain Management and Clinical Lead for the Hampshire Hospitals NHS Foundation Trust pain services. He points out that he is still able to see veterans through the NHS if they get referred to him and the best and quickest way to be seen is through the choose and book system at the private hospitals in Winchester or Basingstoke. Although run through private hospitals the cost to the taxpayer is the same as being referred to any NHS pain clinic. Look on their website, which is thepainteam.com and contact the practice managers for details.

As always I'll just remind you that whilst we in Pain Concern believe the information and opinions on ***Airing Pain*** are accurate and sound based on the best judgement available, you should always consult your health professional on any matter relating to your health and wellbeing. He or she is the only person who knows you, your circumstances and 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, where you'll find links and further information and support for military veterans.

In the next edition of ***Airing Pain*** I'll be looking at issues faced by veteran amputees, but I'll end this edition with a story that Doctor Winston De Mello told me about one of his patients:

De Mello: He was a man in his forties, I had no idea that he was an ex-soldier, he came onto the burns unit having set himself on fire and it's only through chatting one day one of the nurses brought to my attention he was an ex warrant officer, which is a very high ranking position to be in, I think it was the engineers.

And when I got to know him a bit, after the second or third visit to him on the burns unit, I just let him know that I was then still serving in the military. And I pointed out that he had given up and had gone down to such a low level, even though his daughter did everything she could possibly do to help him, was for me the catalyst for change and I said to him, 'you could at least do me the courtesy, when we next meet, you give me the courtesy that I think I've earned and that you've earned and I will show you the same respect'. And he had a think about it, and he said 'fair one'.

And the next time I met him he was more positive, he was well dressed, he had shaven, the physiotherapist now found him very compliant, but over the period of his last six weeks of his two month stay he sat down, worked out a strategy, how he was going to help his daughter's sandwich making business. So from being half empty he was now half full and for me that

was so pleasant, because actually there was no medicines involved, it wasn't medical, it was just trying to switch the cognition of my glass being half empty, it's actually half full.

So we focused on his daughter and how it was impacting on her, the business could have been better run if he turned up at work on time and that kind of thing. So small goals, achievable targets and he's achieved it. So he's turned his life around.

Evans: So giving back to him that responsibility, or the pride of what he was doing when he was in the forces. Giving all that back to him was what he needed.

De Mello: Correct. But I'll also tell you that's what I needed, because the last time I saw him to discharge I asked him one favour: I said 'I would like to see your medals'. And when he came in he had his corps blazer, with his medals pinned in and he's even marched in and gave me the due courtesy of a salute and for me that was a chapter that I will always value and I think that is why I'm so proud of the military.

Contributors

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- Michael Clough, army veteran
- Lt Col Dr Dominic Aldington, Consultant in Pain Management and Clinical Lead, Hampshire Hospitals NHS Foundation Trust
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