



IMPROVING THE LIVES OF OUR MOST SERIOUSLY INJURED VETERANS

Policy paper
December 2018

**HELP *for*
HEROES**

OUR VISION

Help for Heroes is committed to collaborating with the government and others to improve the lives of all wounded, injured and sick Veterans and their families, so that all are able to live secure and healthy lives with purpose. This paper is the first of a series of proposals setting out where we think the government should be doing more. Our aim is to make sure no one is left behind.

PROPOSAL

Help for Heroes believes the Government should appropriately fund the Integrated Personal Commissioning for Veterans (IPC4V) project to ensure the most seriously injured Veterans and Serving Armed Forces Personnel are able to get the support they need to improve their quality of life.

Executive Summary

At least 12 Veterans in the UK are so seriously injured they are in the top tier of the Armed Forces Compensation Scheme (AFCS) for wounded, injured or sick (WIS) Veterans. These individuals need specialist 24-hour care and support. They face a constant battle to make sure their long-term care, rehabilitation and social needs are met, are appropriately funded and expertly co-ordinated. Much of the support and therapy they need is not routinely provided by the NHS or the local authority. Additional financial support is essential if they are to receive the help they need to significantly improve their quality of life.

In many cases these people are the unexpected survivors of conflicts whose lives were saved due to modern medical advances and improvements in battlefield first-aid. In the past most would have died due to their extensive injuries. Many have survived complex injuries including multiple limb loss, brain injury and serious mental health conditions and will require specialist support through a complex care pathway for the remainder of their lives.

We believe these individuals should be able to go to sleep at night without worrying about their future support needs.

JOE'S STORY



After being shot in 1996, Joe* was left with life-changing injuries and in need of 24-hour care and support. He was unable to carry out the usual activities of life: He could not get into or out of bed, shower, wash or feed himself or carry out any fulfilling or social activities. The impact of his injuries was not just physical but psychological through his complete loss of independence.

His injuries required ongoing medical treatment in 2015. During surgery, he suffered a stroke, which increased further his need of support. He was left with a right-sided paralysis affecting his face. The stroke also restricted his speech and head movements.

Despite his serious care and support needs, statutory care is only provided for three hours in the morning. Joe's mother, Karen*, gave up her job as a teacher soon after he returned home. His father left his job soon after. Together, they have looked after all his care needs for the remaining 21 hours in every day.

Karen and her husband are now well in to their 80s, and every day the family lives with the worry about how Joe's needs will be met when they are no longer able to help him.

Joe is now 47, but due the complexity of his condition and the age of his parents, he is currently unable to thrive in his local community or spend time with people of his own age. He rarely leaves the house and is unable to participate in holidays away from home. Joe still wants to engage and has shown an interest in both local and national events that he would like to participate in to improve his quality of life,

but he needs additional support which he currently cannot get through the NHS. His home needs adaptations to allow him to move more freely. Small changes, like the introduction of an adaptive environmental control system, would allow him to do simple things like turn the heating up or the lights on and off, and give him a little more independence.

IPC4V, – if properly funded – would enable Joe to get this additional support so that he can thrive even with his life-changing injuries. For example, he could use the additional funds to procure this adaptive environmental control system and to get a support worker to take him out of the house once a week to engage in social activities. His parents could be given the opportunity to be his parents again and not his carers. They would be able to look after their own health and enjoy more fully their remaining time with him. Importantly, it would give Joe and his parents the peace of mind that, when his parents are no longer with him, he will be cared for appropriately and, hopefully, within his own home.

* Names changed

Summary of Recommendations

- The IPC4V scheme needs to receive full government funding to ensure those who are Very Seriously Injured and have very complex needs as a result of their injuries are able to access the care and support they need.
- A well-informed and professionally qualified caseworker should be responsible for identifying the needs of each person who is Very Seriously Injured.
- An independent grants board – overseen by the Head of Service Personnel Support – should release the money as advised by the caseworker.
- The grants board should be separate to the IPC4V Steering Group but also include third sector, NHS, social services, and a Veteran advocate. It should meet quarterly or as required.
- Funding should not be backdated but those eligible now should be able to receive additional funding to cover their ongoing needs.
- We estimate the scheme would require the commitment of around £600,000 per year, but we would like to see some degree of flexibility to ensure those who need funding support are not without.
- The scheme should also be available those whose health deteriorates in future years as a result of their injuries to such an extent that they require 24-hour care or support. Eligibility for this additional funding should be assessed by clinical experts, with the caseworker remaining responsible for identifying need.
- The funding must not lead to a reduction in care provided by NHS or local authorities. The IPC4V Steering Group (which already exists) should report annually on this, with clear recommendations for corrective action if required.
- The government should ensure that any additional funding payments made under these arrangements are not considered as income for the purposes of assessing care cost allowances and other benefits.

Background

There are an estimated 2.5 million UK Armed Forces Veterans residing in households across Great Britain.¹

The vast majority of Veterans go on to lead fulfilling lives after they leave the Forces, but some have injuries so complex that they will never fully recover. These individuals have such extensive injuries, which previously they may not have been able to survive, that their therapy needs and associated support are very difficult to predict. As a result, they are not covered by any existing recognised NHS Care Package and many simply do not have their more complex needs properly met.

The Chilcot Report states that individuals with complex injuries should be treated by the government as a group with specific clinical needs, in recognition of their service and on clinical grounds, with specialist care arranged and provided more consistently.

Scientists looking at the effect of the injuries sustained by Very Seriously Injured (VSI) Veterans suggest they will have a shortened life expectancy due to the severe trauma and the serious impact of their injuries on their minds and bodies.²

We cannot change their medical conditions, but we can ensure these Very Seriously Injured Veterans regain their sense of self-worth, self-esteem and self-confidence to live a purposeful and meaningful life. We believe that in a civilised society, they deserve it.

1 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/694148/20180327-UK_AF_Suicide_National_Statistic_2018_O.pdf

2 Emily Mayhew- A Heavy Reckoning, War, Medicine and Survival in Afghanistan and Beyond, Wellcome Collection & Profile Books LTD, May 2017)

Complex needs

This top tier is acknowledged by the Armed Forces Compensation Scheme (AFCS) as “those who experience the highest degree of dependency on others to remain alive, and consequently qualify for the highest need for support (essentially, 24-hour medical care)”.

The government accepts this group require additional support, which is why the Integrated High Dependency Care System (IHDCS) was set up in July 2016 by former Veterans Minister Mark Lancaster. This system has since been renamed Integrated Personal Commissioning for Veterans (IPC4V). It is designed to provide a personalised approach for the clinical, health and social support requirements of these VSI Veterans. However, many of the complex needs of the very seriously injured are not met by the current scheme, and our primary concern is how these can be met and be funded in the long term.

While in service those who require 24-hour care are supported by the Defence Medical Services. However, once medically discharged from the military their care and support is dependent on their local NHS and Social Services. For many Veterans, their transition to these public services is seamless. However, the NHS is only funded to provide basic clinical care and limited additional therapies. Although this is delivered to a high standard, the Clinical Commissioning Groups are not funded to provide the additional specialist care, equipment and therapy which will allow those Veterans with long term complex needs to have a better quality of life. Where there is a personal health budget, the individual is forced to choose between therapies, as not all can be afforded. We believe they should have access to all the therapies that will aid their Recovery.

The full support these individuals require is not provided by the NHS and they and their families therefore have to self-fund these additional needs where they can afford to do so. Examples of the additional therapies needed include neuro-physiotherapy, neuro-rehabilitation assistance and specialist clinical equipment³. One example is EyeGaze, which enables a Veteran to access their computer or communication aid using a mouse controlled by the eyes and provides a small degree of independence. In some cases, this can cost in excess of £30,000 per year. With their high level of dependence, employment is not a realistic option for these Veterans and they therefore struggle or find it impossible to pay for the additional care and support they need.

Many of these very seriously injured Veterans are determined to live as full a life as possible. Sadly, their life-limiting or life-changing conditions and complex needs cause high levels of anxiety and stress. This can be overwhelming not only for the Veteran but also for their family members, who are often the primary care givers.

The IPC4V care system has no additional funding and no individual within government formally responsible for its governance and administration. This is leading to lengthy delays and those who need it the most are not getting the support they need. The Ministry of Defence, through the Surgeon General's Office, currently provides some additional funding, but this is not sufficient or sustainable and it falls out-with their formal responsibilities and remit.

Additional therapy needs

Although a Personal Healthcare Budget may currently be made available, the budget is limited. Therefore, many therapies needed to improve the quality of life of these Very Seriously Injured are not covered or they are forced to choose between therapies. For example:

- Neuro Physiotherapy is not funded;
 - Neuro Psychiatry and Neuro Psychology is provided for first twelve months but with very limited funding thereafter;
 - Physiotherapy and Hydrotherapy is provided for a limited period only;
 - Speech Therapy is normally funded only for the first twelve months;
 - Funding for Neuro Rehab Assistants is very limited (if any);
 - Deep Tissue Massage is not funded;
 - Support for tailored social activity is very limited and only if carers are in attendance;
 - Daily Care visits and overnight cover is funded at the minimum level, often relying on family members to cover the gap as our case study shows.
- * Only therapies identified in NICE guidelines would be eligible for funding.

³ See Annex A

What can the Government do?

The Armed Forces Compensation Quinquennial Review (AFCQR) 2017 recommended the introduction of a supplementary tier of compensation which would better meet the needs of those few Veterans whose injuries are so severe and complex that they require 24-hour care and support.

As this would only benefit those in receipt of compensation from the Armed Forces Compensation Scheme, and not War Disablement Pension, we recommend that provision of appropriate additional funding for the IPC4V scheme would be a better, longer term solution.

The individuals covered by this scheme are proud and driven. Giving them responsibility for their own care and support needs, and therefore a sense of control over decisions affecting them, would give them greater peace of mind and resilience because their wellbeing and quality of life would be more in their control, rather than in the hands of strangers. For this to happen, they need to be given the resource to do so. We believe the best way to do this is for the government to provide additional funding to reflect their additional injuries and therapy needs. We set out further detail below on how this could be done.

The numbers are so small that this should be affordable. However, more importantly, we believe it is a matter of principle that the government should recognise and support the enhanced needs of those with complex injuries caused by their service. Any moves to limit eligibility only to those injured after the policy is implemented would be a disgrace.

The additional support currently being provided by Help for Heroes and other charities to close the gap for these complex cases should be used to inform the Grants board of the additional funds required to allow these Veterans to thrive, not just survive. Each case would have an advocate to ensure their needs are being met.

Any changes in funding should not be backdated, but rather those eligible now should be able to receive this additional funding to cover their ongoing needs.

Given the nature of the injuries and their propensity to deteriorate rather than improve, a grant system would be more appropriate than a lump sum and would allow for adjustments to individuals' care as their needs change. A deterioration of their condition may mean they require more therapy or further intervention. It is also possible that timely and well-targeted intervention could lead to the requirement for less funding if individuals are able to become more independent, as we have evidenced is possible in some cases. Allowing recipients the opportunity to request a review would allow for this flexibility.

The funding must not lead to a reduction in care and support provided by NHS or local authorities. The IPC4V Steering Group must ensure this is a priority and should be required to report annually on this with clear recommendations for corrective action if required.

The Government should ensure that additional funding payments must not be considered as income for the purposes of assessing care cost allowances and other benefits. We are aware that the Government has taken steps to ensure Armed Forces Compensation Scheme payments are not considered as such, but know some local councils disregard this policy in certain cases and this should not be allowed to happen.

Eligibility Criteria

To be considered eligible an individual must require 24-hour care or support due to a life limiting illness or injury that occurred during service. Eligibility will also be subject to an assessment of need completed by a relevant third party, in conjunction with the individual or their primary care givers. In line with the NHS IPC4V criteria, eligibility should not depend on a particular diagnosis or condition but should be due to service attributable injuries or illness.

Funding and support should be tailored to an individual's requirements and made available to meet a range of needs which are not met (or not met fully) by statutory provision. Areas that should be considered include (not exclusively):

- Speech and Language Therapy
- Specialist Equipment such as EyeGaze
- Case Management costs
- Financial Planning
- Adaptive sports
- Psychological Interventions
- Education
- Career Guidance
- Welfare advice and guidance

Once an initial assessment of eligibility has been made the case should be passed to the Very Seriously Injured (VSI) team to confirm eligibility and follow the funding pathway.

Costings

Help for Heroes estimates between 12 and 20 Veterans would be eligible for IPC4V and therefore this additional support. To ensure the appropriate care and support is available, we estimate the board needs to have access to £360,000 to £600,000 per year.

This represents 0.002% of the total Ministry of Defence annual expenditure, but the impact this additional funding would have on the quality of life of those affected would be very significant indeed, giving due recognition to their service and their ongoing desire to live secure and healthy lives with purpose. They deserve one less battle to fight, and these very affordable proposals would enable that.

SIMON'S STORY

Simon, 32, of Newport Shropshire suffered a serious brain injury when a Land Rover he was travelling in drove over an improvised explosive device in Musa Qala, Helmand Province on 6 December 2008. His heart stopped beating at the scene of the attack, starving his brain of oxygen, whilst medics fought to keep him alive.

He survived, but his family was told by doctors that his brain injuries were so severe he would remain in a vegetative state for the rest of his life. Simon, who was serving in the Royal Electrical and Mechanical Engineers, also suffered a broken jaw, shattered pelvis, collapsed lungs, and broken back in the explosion. He remained in a coma for 44 days before waking to continue his long road to recovery.

When Simon, who also completed tours of Iraq in 2003 and Northern Ireland in 2005, needed to make critical adaptations to his home as a result of his physical injuries, he was faced with having to stop his speech and language therapy to afford it.

Simon was completely dependent on 24-hour care and support for all his needs, provided by Simon's Mother Lynne and other family members. Statutory care was provided by two carers, albeit inconsistently, for a set period throughout the day, but not overnight. This had to be provided by the family staying at Simon's house overnight, every single night. Statutory service had delivered the clinical support they could, but Simon's injuries meant he needed additional physiotherapy, occupational therapy, and speech therapy, for which he had to pay himself.

Simon rarely left the house as this meant a family member and the carers would all need to be in attendance. He had none of the privacy or independence which you would expect a young man of his age to have. Simon was surviving but not thriving.

Using LIBOR funding, Help for Heroes stepped in and arranged for a Case Management Team to recruit and monitor a consistent and qualified care team to provide continuity of care. This has relieved stress from the family and allowed them to become family members again. It may mean in the future that Simon's mum can go back to living in her own home and regaining her independence too.



The LIBOR funding has also ensured that Simon can receive the right level of Psychological and Psychiatric support, which has improved his mental wellbeing and morale. Because of this input Simon now feels that he wants to get out more and socialise in the community.

Simon is one of the most seriously injured who were not expected to survive. Armed Forces compensation is intended to recompense for pain and suffering. However, Simon lost much more than that. He lost his independence, his privacy and his chance of a normal life. **A small level of additional support is having a huge impact in improving his quality of life.**

The LIBOR funding will run out in three years. We believe the government should now step in with a sustainable, long term solution for individuals like Simon.

Annex A – Therapies and estimated costings

Neuropsychiatry

Psychiatrists are doctors trained to treat the physical causes of mental health disorders. Neuro psychiatrists have additional training on the effects of damage to the nervous system, and how this may impact mental health.

Neuropsychology

Psychologists look at the relationship between the physical brain and its various functions, dealing with topics such as sensory perception, memory and mental health conditions.

Neuropsychologists have additional training on the assessment and rehabilitation of people who have suffered damage to the nervous system.

Physiotherapy and Neurophysiotherapy

Physiotherapists help to restore movement and function when someone is affected by injury, illness or disability. Neuro physiotherapists have additional training on the effects of damage to the nervous system, and how this may impact their mobility and function.

Speech and Language Therapy

Speech and Language Therapists help support individuals with speech or eating and swallowing difficulties arising from their injury. They teach verbal techniques and provide exercises to support rehabilitation.

Deep tissue massage

Deep tissue massage can help realign muscles and connective tissue. It is especially helpful for individuals who have a chronic medical condition impacting on their ability to move their muscles.

Hydrotherapy

A type of physical therapy that is carried out in a specialist hydrotherapy pool. The water can help relax and support the muscles and joints, while providing resistance to help an individual gradually become stronger.


Neurorehabilitation Assistant

A Neurorehabilitation Assistant supports in the delivery of a rehabilitation programme produced by an individual's medical team. They have specific experience in supporting individuals who have damage to their nervous system, and how this may impact their rehabilitation.

Estimated annual cost of therapies

Support provided varies depending on the individual but may include: personal care such as washing or dressing; housekeeping; nursing and healthcare. They may also be able to provide care to enable short breaks for unpaid family carers, or more general support to leave the home.

Therapy	Cost
Neuro Psychiatry	£5,798
Neuro Psychology	£9,200
Neuro Physiotherapy	£4,170 for weekly session
Physiotherapy	£1,820
Speech and Language Therapy	£4,500 home visit once a week
Deep tissue massage	£2,340
Hydrotherapy	£2,548
Neurorehab Assistant	£12,000
Daily Care	£26,280



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