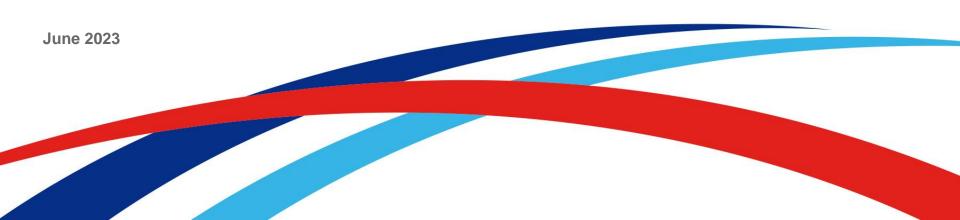




The Veterans Mental Health and Wellbeing Service

South East Region

## Research Courage for carers



## With thanks to



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NHS

#### Berkshire Healthcare NHS Foundation Trust

### **Berkshire Healthcare NHS Foundation Trust**

Lead provider for NHS veterans mental health services in South East England.

#### berkshirehealthcare.nhs.uk



## The Ripple Pond

The Military Family Support Services charity.

### theripplepond.org



### **PS Research**

Independent social research and evaluation consultants. **personinsight.co.uk** 

## Foreword



Julian Emms, Chief Executive Berkshire Healthcare NHS Foundation Trust



We commissioned this research to hear the seldom heard voices of those who support military veterans with mental health needs to help them and our patients from the armed forces community have better outcomes.

Teaming up with The Ripple Pond to do this has helped us better understand what matters most to not only those we already support but the many hidden carers across the country who could also benefit from NHS services and who may be reluctant to ask for help - and what we can do to change that.

The emerging insights from this are already informing improvements to our Op Courage veterans mental health and wellbeing services, such as recruiting a specialist family liaison worker, creating our new regional website **opcouragesoutheast.nhs.uk** and developing resources that are tailored to the needs of those who support veterans. This is all designed to offer additional support for families and carers, to empower them to continue to care for their veteran as well as helping them to maintain their own health and wellbeing.

Where the themes from the research are applicable to the experiences of carers in general – or to other health and care services – we've been able to share the lessons learnt across other NHS services too. This is a prime example of our Carers Charter in action - which is our pledge to develop a culture of identifying and working in partnership with carers to support the carer's own wellbeing and enhance patient care.

## Foreword



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## Rodger Cartwright, Chief Executive The Ripple Pond

More positive outcomes for injured veterans will be achieved if coordinated support and care are provided for both the veteran and their immediate "family" support network.

> This wonderful report opens the door to that reality; we all have a moral responsibility to ensure that it does not gather dust but is translated into positive action. I also urge policymakers to study the document very carefully as supporting and caring for "families" is a really effective use of finite resources.\*

"

\*The Ripple Pond does not place a rigid definition on family.

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# Summary of key findings

## Key findings theme #1 context of caring



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## 1 Carers of veterans tend not to define themselves as a 'carer'

• And this can present a barrier when looking for support or trying to access support.

### 2 Day to day life can be tough for the carers of veterans

- Carers are often juggling many other responsibilities, including small children and work
- Carers talk of feeling isolated, helpless and emotionally exhausted
- Caring for their veteran is having a negative impact on the mental health of the carers and on the family
- In particular, carers report living with **constant stress**, exacerbated by the unpredictability of their veterans' conditions.

## 3 Caring for a veteran has unique aspects

- Veterans often have very complex conditions
- The **'military mindset'** can create its own difficulties, particularly as veterans feel they should be able to be self-sufficient and cope, they can struggle to relate to 'civilians' and also that the boundaries on acceptable behaviours can be blurred.

## 4 Carers try to be involved in the support process but are often excluded

• And they feel that **not being involved has a negative impact** both on the care the veteran receives and on the support they can provide to their veteran.

## Key findings theme #2 accessing support for veterans



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## 1 Most have tried to access support for their veterans but the experiences have not been positive

- Many have approached several different services and organisations and whilst there are pockets of effective support, no
  one service or organisation stands
- Several veterans have not been able to access support as they have been deemed too complex or there has been insufficient funding/capacity

### 2 Healthcare professionals who are veterans themselves and veteran charities were most useful

- Veterans tend to respond best to those who have military experience
- Carers spoke most highly of charities that use outside interests to engage veterans, e.g. sport, dogs, horses

### 3 All have faced barriers when trying to access support for their veterans

- Carers often feel that they are not given a voice and veterans themselves can be reluctant to accept they need help
- Carers feel knowledge of PTSD in particular is low across the NHS and this lack of knowledge can mean that veterans are deemed too complex to treat and get passed between services

## Key findings theme #3 accessing support for themselves



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## 1 There appears to be little, if any, support for carers of veterans and their families

- The over-riding focus is on the veteran, and any support carers have accessed has not been linked to any specialist support for carers of veterans
- Carers are not often signposted to any support for themselves
- Carers can be so focused on their veteran that they **do not look for support for themselves**, and they are not sure where or how they would be able to access support for their mental health (other than through their GP)
- There is very little, if any, support for children of veterans with Post Traumatic Stress Disorder (PTSD)
- Most of the carers heard about the research through The Ripple Pond, so it is perhaps no surprise that they report that the
  main support for carers of veterans is The Ripple Pond, particularly the peer support through their social media groups.

## 2 Carers feel more information on who to contact and how to support veterans would be helpful

- Carers often feel that the best support for themselves is to be better equipped on how to help support their veterans
- Many carers initially had no idea who to contact or what support exists, and have to search for support themselves
- Looking for support can be difficult when they are not sure what is causing mental health problems
- Information on existing services and organisations, the typical process of accessing support and information on how to recognise and support veterans with PTSD would be particularly helpful.



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# Background and methodology

## Research objectives and methodology



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• NHS Veterans Mental Health and Wellbeing Service, Op Courage, is designed to provide treatment and support specifically tailored to the needs of former service men and women (and reservists) and their families.

## **Research objectives**

- A need for qualitative feedback was identified to understand the attitudes and experiences of family and relatives of Armed Forces veterans who have accessed or could potentially have accessed the dedicated NHS mental health service for service leavers and reservists, in particular:
  - The experiences of family carers and relatives of veterans accessing support for their mental health and wellbeing
  - A dedicated section of the Op Courage South Central website and what this should include

PS Research was commissioned as the independent research partner to moderate the qualitative feedback and produce a summary report of findings.

## Methodology

Berkshire Healthcare NHS Foundation Trust (BHFT) developed a detailed questionnaire to gather information from carers and to collect contact details of carers who would be willing to take part in the qualitative stage of the research. The survey was distributed via multiple partners, most notably The Ripple Pond. The initial plan was to conduct:

- Two virtual focus groups (duration: 90 minutes) of between six and eight participants and
- Four one-to-one in-depth interviews (duration: approx. 45-60 minutes).

## **Evolution** of the project



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#### **Initial fieldwork**

- Unfortunately, the response to the questionnaire was not as good as hoped, with **ten** people in total responding. All potential participants were invited to a focus group. Of the seven who agreed to take part, only three participants participated with the second group being converted to a one-to-one interview.
- All seven remaining respondents were invited to take part in a one-to-one interview and two of these then took part in an
  interview, taking the overall fieldwork total before Christmas to one mini-group of two participants and three individual depth
  interviews. Fieldwork was conducted w/c 6<sup>th</sup> and w/c 13<sup>th</sup> December 2021.

### Interim review and project extension

- Following the production of an interim summary report and a subsequent review by the project team, it was that decided further feedback was required. The questionnaire was therefore re-distributed in January 2022. A total of six carers responded and four participated in a focus group on the 19<sup>th</sup> January. One survey respondent was unable to take part in the focus group but provided some feedback via email.
- This report provides a thematic summary of the responses from both the 16 responses to the initial questionnaire and the subsequent qualitative research with nine participants.



## What did the research cover?



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### Interviews and focus groups

During the qualitative interviews and focus groups, participants were asked to share and discuss:

- The extent to which they identify as a carer
- Their experiences of any support accessed by their veteran (with a focus on their own involvement in the process)
- What support they have received themselves and what advice or support would have been helpful for them to have received.

### Feedback on carers resources

Participants were also shown:

- Two potential Op Courage South Central website pages (currently in development) and
- A carers' form and asked to provide feedback on these.

It should be noted that the introduction to the carers' form was amended slightly for the final focus group based on the interim feedback.



## Who took part in the research?



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#### Relative to the veteran

All but one participants are the **partner/spouse** or ex-partner/spouse of a veteran; one is the child of a veteran.

## Age and gender

- All but one of the participants are female; one male respondent
- Ages ranged from 30 to 68.



## **Services represented**

- All three services were represented: the veterans of six participants served in the British Army; two served in the Royal Navy and one in the Royal Air Force
- One participant had also served in the British Army themselves.



## Care provided

- Almost all participants have supported their veteran for more than five years, one has been supporting their veteran for between three and five years and one for one to two years
- Five provide help or support to their veteran for 50+ hours a week
- All say they provide psychological and emotional support, all but one provides practical support and two provide physical support to their veteran.



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# Day to day life can be tough

## Carers of veterans tend not to define themselves as 'a carer'

## Most recognise that they play a caring role



• There is an acceptance that part of their daily lives involves 'caring' for their veteran...

"I suppose I am a carer because I have to do things for him that he can't do, but I don't like being labelled a carer. At the end of the day he is still my partner, my husband"

"My definition of a carer is **people who work in the community, doing home visits**, that kind of thing"

## The carer label feels too inappropriate and too narrow

First and foremost, they are their veteran's partner/spouse/child:

- The care and support they provide is just part of this relationship
- The term 'carer' has connotations of paid care and of providing more physical/personal care, i.e. a paid domiciliary care worker
- A couple of participants feel distinctly uncomfortable being described as a carer.



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### From the survey:

Participants were asked whether they think of themselves as a carer:



(score of 1 = not at all; 5 = totally)

- Nine chose a score of 1 or 2, indicating they do not think of themselves as a carer
- Four chose a middle score of 3
- Three chose a score of 4 or 5, indicating that they do see themselves as a carer

## Caring is just one (big) part of their busy lives



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### Most carers have many other responsibilities

- Many carers support their veterans for over 50 hours a week, whilst also managing work and other caring responsibilities.
- Almost all participants in the qualitative research have other caring responsibilities, namely small children (including some with special needs), and almost all work either full or part time alongside caring for their veteran.
- Several also have their own disabilities or health conditions to manage.



## Providing support is generally a long-term situation

 Most participants have been caring for their veterans for more than five years. Two of the older participants have been supporting their husbands with their PTSD and mental health conditions for over twenty or thirty years.

## **Case study**

One participant works full-time, has two small children, two dogs, is studying for an Open University degree and cares for her husband who has a traumatic brain injury, spinal injury and PTSD.

## Caring for veterans can impact negatively on them and their family



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## Carers talk of feeling:

- ...Isolated
- ...Helpless
- ... Emotionally exhausted

## And both caring and their veteran's conditions have a huge impact on the family

- Carers feel guilty that their children 'miss out' on their time and attention and on normal family activities
- Carers say that their children carry a lot of stress due to their parent's mental health conditions and behaviour
- Older children can end up supporting the veteran too (e.g. with physical tasks).

"We miss out on lots of family opportunities that we would find stressful and every outing must be planned with precision. My **children's mental health is affected** by the constant mood swings. They can't have friends over for fear of him losing it."

parent."

"It is so **isolating** as you are **exhausted emotionally** and physically from having to

do so much. It's as if you're a single

"I don't think the caring thing affects the family unit because I just do it automatically. What affects the kids is **when my husband has his low days**."

"It is **extremely emotionally exhausting** – used as an emotional punchbag and **walking on eggshells** constantly."

## Many feel their mental health is being negatively impacted



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## Carers live with constant stress

- The unpredictability of their veteran's mental and physical health conditions, particularly PTSD, can make life hard.
- Not knowing when veterans will experience a flashback, have a downturn in their physical health or have what is often described as 'an episode' means that carers (and their children) live with constant stress, are unable to ever fully relax and feel they are always 'walking on eggshells'.

### This can overwhelm at times

- Coping with their many responsibilities, coupled with the unpredictability and the fact that situations can quickly escalate can mean that carers sometimes find it difficult to manage their own stress levels and can find the situation overwhelming.
- Despite this, there is a wide-held attitude that 'this is life' and they have to just keep going and deal with whatever happens as best they can.

## Most carers say their mental health has suffered

- Participants spoke of the toll that caring for and supporting their veteran has taken on their health, in particular on their mental health and a couple of participants have themselves felt suicidal at times.
- For some others, this long-term and often relentless stress has been a key factor in their marriage breakdowns and they have separated from their partners.



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## Caring for a veteran has unique aspects

## Veterans often have complex conditions



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- The majority of the participants taking part in the research support veterans who suffer from PTSD and/or other complex mental health issues and they are neither qualified to do this or given much support to help them to do this.
- In addition, a couple of participants report that their veterans have addiction issues.

"He was drinking so much that his doctor said don't stop drinking because that will do you harm, but he took that as a licence to continue drinking."

"I was in the Army and even then I struggle to understand the complexity of his condition." "There's **so much complexity** to their mental health because of what they've been through, what they've seen, what they've done."



## The military mindset can create its own difficulties



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 Veterans have been trained to behave in a particular way

"Civvies don't get **the mentality and communication methods** used by the military. They can't draw on past experiences to connect or begin to understand what a veteran has been through."

## It is difficult for them to change this behaviour after leaving the forces

 Civvies' often don't understand their experiences and therefore their behaviour "Everything in the forces teaches you how to be separate from one another. How to be separate and **self sufficient** for months. No-one after those 20 years gives you tips on or counselling on how to be together"

"To others the language he uses and the way he behaves **seems aggressive** and rude however much of it is **just how soldiers communicate**.

## The military mindset can create its own difficulties



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## The military mindset can create its own difficulties



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 This can compound misconceptions which then influences civilians' behaviour

"People think that everyone is mad, bad and sad that comes out of the army, and they're not, they're just **broken and exhausted**.

 Veterans can be reticent to speak to people without military experience

"I can see my dad switch off when he talks to someone where he feels that he should have more respect, that they clearly **don't get where he's coming from**."

## Taboos around mental health can be more of a barrier



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Whilst taboos around mental health may be lessening, their influence can still be strong for veterans

• The taboo around mental health is potentially stronger amongst veterans given their military mindset and carers feel veterans themselves find it hard to admit they need help.



"My dad is very old school. **He will not consider himself to have any form of mental health problems.** Nor does he see himself as an alcoholic, but he is a very high functioning alcoholic.

And he can be **very aggressive if challenged**, so that is a barrier when trying to support him. I also think he has early onset dementia but I can't have those conversations with him. I have written to the GP but I can't get help unless my dad goes for help." "I think they are **taught to not say anything**, to put up with a lot of pain and a lot of suffering and just try to carry on. I think that is part of being in the military. So my partner will fake that he is OK around the doctors and say that he is completely recovered."

## Boundaries around acceptable behaviour can be blurred



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## Veterans often behave and expect people to behave as they would in the military

- In general, behaviour that is considered 'normal' within the military can be deemed unacceptable by civilians
- Some carers say veterans can sometimes struggle to accept things work differently from when they were in the military.

## Abusive or acceptable?

However, it is clear from some of the feedback that:

- It can be difficult for carers to establish whether behaviour that may be related to PTSD should be considered 'acceptable' or if it is in fact abusive
- Carers feel that that abusive behaviour is sometimes excused by themselves, others and healthcare professionals because veterans have PTSD.

"To the NHS, it might seem odd that [veterans] don't know how to pick up a prescription from a doctor's surgery, or that they don't expect to have to wait for an appointment. It's **all instant in the army**.

"Constant questioning of **whether I should allow and accept** the behaviour and attitude."

"We all end up with secondary PTSD and are **subject to unseen abuse** which is deemed OK because he's got PTSD so it's not his fault."



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## Accessing support for veterans: experiences

## Most have accessed support for their veterans

### From the survey:

- 10 of the 16 report that the person they care for has accessed NHS services
- 11 have accessed voluntary, third sector or non-statutory services
- The most common type of care the veteran has accessed/is accessing is mental health at home – accessed by ten

Other types of care accessed include:

- Mental Health at a hospital (3)
- Outpatient care (3)
- Physical Health at a community hospital (2)
- Physical care at home (1)
- Other mental health support (1)
- Overall, 13 of 16 rate their experiences of trying to access support as very poor or poor; two rate it as 'neither good nor bad' and one as 'very good'

13 out of 16 rate their experiences of trying to access support for their veteran as 'poor' or 'very poor'





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## Many have approached several different organisations



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## Care may start in the NHS but can include many other organisations

- Although for many, the care journey starts either with being admitted to hospital or with contacting their GP, most have reached out to several different organisations seeking support for their veteran, including:
  - Combat Stress
  - PTSD Resolution
  - Royal British Legion
  - Help for Heroes
  - The Warrior Programme
  - Local veterans hubs
  - Mission Motorsport
  - Services Dogs UK
  - Horseback UK
  - RFEA Project Nova
  - Private therapists

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## Experiences have been very mixed

- The usefulness of the care and support received from these organisations has been varied. No one organisations stands out as being excellent.
- Some veterans have not been able to access support from charitable organisations either due to a lack of funding or capacity to take on new people or because they are deemed to complex to support.

## Carers try to be involved but are often excluded

## Currently, the involvement of carers in their veteran's care tends to be:

- Recognising that their veteran needs support, and encouraging them to seek support
- Seeking and joining support groups and charities
- Making appointments (when allowed), collecting medication, taking veterans to appointments
- Attending appointments although this only seems to happen on rare occasions

#### Most want to be more involved in helping their veteran access support

• Several have tried to be more involved (e.g. to book appointments or attend sessions) but have been unable to do this.

"I know that I get a certain amount of access to my husband's medical knowledge because I am down as his next of kin. But then **the GP won't let me phone up on his behalf**. I am not allowed to book an appointment for him."

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## Carers try to be involved but are often excluded

## From the survey:

- Seven of 16 said they did not feel listened to (score of 1 or 2)
- Seven gave a middle score of 3
- Two felt totally listened to (score of 5).
- 12 of 16 were not involved as much as they wanted to be in the care or treatment of their veteran (score of 1 or 2)
- One gave a middle score of 3
- Three felt they were involved (score of 4 or 5).

12 out of 16 were not involved as much as they wanted to be in the care or treatment of their veteran



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## Carers feel that not being involved has a negative impact

## Excluding carers has a negative impact on:

#### ... the care the veteran receives

• Healthcare providers don't get the full, potentially more truthful picture without speaking to spouses/partners (which carers feel should be done separately).

"I think they should speak to the spouses separately. A lot of veterans will **say what they think the doctor wants to hear**, and that is not always the truth. They are quite self-centred and don't want to admit something is wrong, so doctors **don't get the true picture** of what is actually happening.

### ... the ability of the carer to support their veteran

 It is difficult for carers to support their veteran when they have not been given any training or advice and they are not able to attend sessions. This can be particularly evident when their veterans have attended a session and discussed their experiences and carers are then left to deal with 'the fallout'. "My wife will come out of these deep CBT sessions and I have to deal with the fallout. I've had no training."

## Within healthcare crisis support and lived experience have helped



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### Experiences of healthcare have been mixed

- A couple of veterans who have accessed the NHS crisis team have found this has been useful.
- For others, the most useful support (both from within the NHS and from private therapists) has been from doctors/therapists who have had military or similar experiences themselves.
- Veterans appear to relate better to those who are veterans themselves or who have similar experiences (e.g. expolice).

"We paid privately to see a psychiatrist who specialises in PTSD treatment. He is used to dealing with veterans, and it was like a lightbulb moment. His approach was very different to the NHS. But even after this diagnosis, the NHS said no, we know best, we have his notes. **They didn't listen**." "We found a private therapist who was an ex policeman. Finding someone my husband **could relate to** helped."

#### **Case study**

- NHS initially diagnosed him with multiple allergies
- During an appointment for a different issue, the GP referred him to mental health team but he wasn't diagnosed with PTSD
- Paid privately to see a psychiatrist and PTSD specialist who diagnosed complex PTSD.

## Veteran-specific charities have been helpful



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## Outside of healthcare, the most useful support for veterans has come from veteran-specific charities.

• Carers spoke particularly highly of charities that use outside interests to engage veterans, e.g. sport, horses, dogs.

## Case study Mission Motorsport

"They use a common love of cars, to get people engaged. Getting them to do activities and they don't necessarily realise that they're getting help by engaging with people and doing things they didn't think they could do. They don't want to be told that there's something wrong with them. It has to be something they come to terms with, and they understand and realise themselves. Mission is just fabulous because they guide them and make them feel they own their own recovery journey. They learn to take responsibility for themselves."

## Case study Horseback UK

"Horses are hyperaware of emotions and the veterans build up a relationship with the horses and it teaches them about themselves and what they are like to live with.

"That was a turning point for my husband, and I didn't think there would be after all these years. He's not even interested in bloody horses. But without a doubt, it has made the single biggest difference."



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# Accessing support for veterans barriers

## Carers feel like they are not given a voice



#### **First to notice**

• The carer is often the first person to recognise that their veteran is struggling and in need of support.

#### No idea where to turn

- Initially, carers have no information and no idea where to turn.
- When they do reach out for help, they are usually unable to access support – the veteran has to be the one to ask for help

### Consent



- Even if their veteran has given their consent for their partner to be involved in their care and for information to be shared, this does not mean they can ask for support on their behalf
- Several say that services still require the veterans to consent on each occasion, and when they are in crisis mode, the veteran may retract their consent.

"When he comes off his medication or disappears, I don't know where to turn. Any support I have tried to access, i.e. Army Welfare, SSAFA, has required him to consent."

"I'm allowed to be very involved because he has given his consent, but then as soon as he has a bad turn and I contact them for help, they won't discuss it with me until they have spoken with him and got his consent again. Then because he is having a bad turn, he will say 'don't speak to her, I'm leaving her' and withdraws his consent. So I can't get the help when we are in a crisis, it's like **a constant merry-go-round**. He has attempted suicide before, so what happens if they won't speak to me and won't help and then he goes and commits suicide?"



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# The veteran can be reluctant to accept the help they need



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• In order to access care, the veteran has to recognise that their mental health is suffering and has to ask for support themselves. Due to a combination of factors, this can be difficult:

"I would tell my husband that he had PTSD but he would say he had his flashbacks under control. I think it was **just easier for him not to get help** because then he would have to address a lot of things he would probably rather not address."

"The veteran [is the biggest barrier]! Often they are **proud** and do not want to access support." "I think I recognised quite early on that she had some sort of PTSD. I didn't realise how severe it was, but I definitely recognised it. It took her time to realise it. You can't force people to talk to someone, you need them to be willing to accept help."



# Carers feel awareness of PTSD & veterans issues in the NHS is low



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Low awareness of PTSD and that veterans are likely to be in crisis when they are seeking help

- Carers say that there is low awareness that veterans often only accept they need help and seek support when they are at, or almost at crisis point and that even in these situations, the may adopt the military mindset and may not be open with healthcare professionals.
- Unless they are threatening to commit suicide, several shared experiences of veterans being given inappropriate support:
  - Often told to try self-care techniques first
  - GPs seem unsure where to refer veterans
  - · Passed from one service to another without concrete support being provided

"When I was researching into it a few years ago, the internet wasn't very useful. **Every** website basically says try some self-coping techniques. And when you speak to someone in person they try to push you back to some initial coping mechanisms but by that point you have tried all that and you need some proper help." "When he went to the NHS in a very vulnerable state, he was prescribed country walks with OAPs and told not to stop drinking (because it would be harmful for him to stop) but he took that as a green light to carry on." "There is no understanding or awareness of PTSD. The referral system is broken and **too many areas/professionals get involved** so no-one takes responsibility."

### Lack of knowledge can mean veterans don't access timely support



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"Veterans are often exposed to trauma that most people don't even want to think about. My husband once was referred to a counsellor who stopped him mid-session stating **she had not been trained to deal with the things my husband was describing** and couldn't help him."

#### Passed 'from pillar to post'

- Several carers report that their veterans have been told they are too complex
- Due to a lack of knowledge or training they have been passed to several other different services without actually receiving support



"In 2019, he told me of a detailed plan for suicide...I reached out to a charity specialising in offering counselling and they said there was nothing they could offer me. I tried IAPT and was **devastated by the lack of understanding**."

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### Lack of knowledge can mean veterans don't access timely support



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"Her PTSD is related to, it **requires a high level of security clearance**...I have tried to get that through to the NHS or (charities). They don't seem to understand that she doesn't have the option to just go and talk to any psychiatrist."

"When it reached crisis point, he did try and contact various charities that we were signposted to but **none of them would help him** because **he wasn't in the UK**."

#### Other barriers to access

- A couple of veterans have been unable to access support as they can only speak to healthcare professionals with appropriate security clearance
- And one participant had found that their husband became ineligible for any support once they moved abroad, despite serving in the British Army for ten years.



### Lack of knowledge can mean veterans don't access timely support



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Not involving or listening to carers, coupled with a lack of understanding of what the veteran is dealing with can lead to very troubling situations

#### Case study A veteran in crisis

"I have really struggled to get people to listen to me. In July last year, he said to me, I'm really unsafe, I can't talk to you, I'm scared of what I'm going to do to myself or you. I must have rung five different places and each one told me to ring someone else. In the end, I rang for an ambulance, but they wanted to call the police. So I ended up taking him to A&E and they were really good and he was put with the crisis team and they were so helpful...

"Then he stopped taking his meds but I didn't know and he was in a really bad place, shouting and smashing things. I rang the community mental health team who he is under and I was really distressed and said I really need to speak to you, but she didn't ring me back. She waited till her next therapy session with him and asked for his permission to speak with me. I didn't want any information from her, I just wanted to tell her I was severely concerned about him. Then about a week later he had to go back into the psychiatric hospital for his own safety.

"He has a mental illness that stops him from accessing help. He will not speak to people, I have to do it for him and they won't listen. There is no-one I can contact to say I'm struggling to get through to him at the moment."



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## Accessing support for their own mental health and wellbeing

### There are barriers to carers accessing support for themselves



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#### All *their* focus is on the veteran too

- Carers often feel that if someone could 'just fix' their veteran, then their own mental health would automatically improve, therefore the focus should be on the veteran
- They don't always feel deserving of support because the veteran is suffering more
- They are often too busy caring for the veteran to consider that they might benefit from support



#### Lack of information/awareness of support

• "If anything is stopping us from getting help it would just be lack of information."

### Low expectations that they will receive support

• If they struggle to get their veterans' support, what chance do they have as a carer of a veteran?

"I've asked for help but there are about 3 billion waiting lists. I am worn out by it. I feel broken at the moment. I've had to push and push to try and get support. I did ring up Relate but that was £65 a session and I can't afford that. I've asked Help for Heroes for family support and I am on a waiting list."

#### "Families don't have access to veterans services so

fall into normal community NHS mental health support, which is non-existent in our area. I don't need tablets, I just need my husband fixed!

"Other than Ripple Pond, **I don't know where I could go as a spouse** other than the GP. I definitely became more anxious about life since he left the forces but I'm not sure some generic Talking Therapies service would understand or even if I would meet the criteria for support."

# Carers feel there is very little support out there for themselves



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#### The focus is always on the veteran

Most services and organisations appear to focus solely on the veteran and their needs.

#### Any support received for their own mental health has not been from a service providing support to carers of veterans

Several carers have reached out for support for their own mental health but there does not appear to be any support linked to being a carer of a veteran.

#### Most carers feel joint therapy sessions would be useful

However, very few have been offered these despite requests.

#### And several mention that children of parents with PTSD are often forgotten but they would benefit from specialist support

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"Once you are looking for support, **you are not looking for yourself**, it's always focused on them. Someone once told me to make sure not to take on their problems, but in the end, I did.

"My experience is that the veterans support is separate to mine and I feel like the veterans support (when therapy starts) needs to liaise with me more and not refuse to speak to me when my veteran is having a meltdown and shutting me out. It would help if the therapist worked with us jointly rather than individually."

"I think my children could do with support as well. They're forgotten in all of this. **Kids that have parents with PTSD need some sort of respite**, some sort of normality."

### The Ripple Pond's social media groups are a source of support



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### There are mixed views on whether carers have found groups such as The Ripple Pond helpful.

#### These groups are seen as most helpful for:

- Giving reassurance that there are other people in the same situation
- Members signposting others to services and providing useful advice on the support process

### However, some find the support they provide is limited and some aspects unhelpful

- Can become a negative echo chamber where people go 'to moan and sound off'
- Members are 'diagnosing' each others veterans
- A minority feel that negative and potentially abusive behaviour by veterans is validated and enabled
- As with veteran charities themselves, they are aimed at and consist mainly of females, therefore male carers can feel unwilling to engage

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"The Ripple Pond is quite cathartic, it's **a safe place** where there's always someone on your side who understands what's going on."

"I have tried to seek out people in a similar situation to speak to but **as a male, I am in a really small minority**. Only thing I found useful was the Band of Sisters Facebook group. You can say what you are having trouble with, it might be a war pension application or finding help with mental health, and people who have already gone through it will list different people to contact."

From what I can see looking at the Ripple Pond Whatsapp group, everyone in there is suffering some form of emotional or verbal abuse from their other half. And it is like validating or enabling that abuse by saying it is because they are a veteran....However when I was in the middle of it and trying to get out, **it was really helpful to know I wasn't alone.** 



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# Improving the carers' experience

### **Carers want more information**



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#### What carers feel would have been helpful at the start of their journey:

- An understanding that when people start the process of looking for help, they **do not necessarily know** what their veteran is suffering from (and therefore do not know what they should be looking for)
- An understanding that the first time they start looking into accessing support, they may be in crisis or close to being in crisis (therefore being advised to apply self-help techniques may be inappropriate)
- Information on how to recognise potential conditions, e.g. PTSD
- Who they should contact in the first instance
- ✓ What to expect (usual process/steps) in the process of accessing care

#### From the survey:

- Half rated the information they were given as not being easy to understand (score of 1 or 2, when 1= not at all easy to understand):
- Six gave a middle score of 3
- Two felt the information was easy to understand (score of 4 or 5)



### **Carers want more information**



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- Links to organisations to contact for help, both for their veteran and for themselves
- Online/in person training sessions on how to support veterans, e.g. on how to deal with flashbacks
- An emphasis on the importance of looking after themselves and of recognising that they may benefit from support as carers
- The importance of making sure all healthcare professionals are made aware that the cared for person is a veteran and that they are caring for a veteran, as this is not always asked and notes are often not transferred between services (and not always transferred from the military)
- Guidelines on what should be considered unacceptable/abusive behaviour

### Peer support is valued both for the veteran and for themselves



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#### In terms of support (and not information), peer support and respite would be the most useful to carers

Peer support outside of social media groups can be difficult to find, although when found, can be very helpful.

- The male participant mentioned that he has tried to find peer support but there are not many men in this situation. He has also found that many peer support events are geared towards female carers (e.g. pampering weekends) which he understands as the majority of veteran carers are female but they do not appeal to him.
- Through a local 'Veterans Hub', one participant had found someone they could talk to and share experiences with who they felt understood their situation and had found this very helpful.

"Sometimes, I just want to go and sit in a pub, in that sort of atmosphere and be brutally honest about how shit it can be. I don't have that release, and it bubbles over when she is having a bad day, and I feel like I can't take it anymore and we have a flaming argument. If I could offload it, I could carry on again."





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### Who we are

Op Courage, The NHS Veterans Mental Health and Wellbeing Service is provided in South East England by:

Berkshire Healthcare NHS Foundation Trust

Working in partnership with:

- Sussex Partnership NHS Foundation Trust
- Walking With The Wounded

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### Contact

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