

MS

MUTUAL SUPPORT

ARMED FORCES MULTIPLE
SCLEROSIS SUPPORT GROUP

Newsletter

June 2023

WHEN YOU HAVE MS

NOTHING IS EVER SIMPLE



Multiple Sclerosis Society. Registered charity nos. 1139257/
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Newsletter Deadline:

Tuesday 29th August 2023

Cover Photo:

A lot of us will know exactly how this feels

FOREWORD

I have to review/renew my Personal Independence Payment award every three years, why? I don't know! But, I always feel stressed and frustrated by it every time.

So I was interested to read a recent Facebook post on our group page from Joanne Bland asking for tips on submitting her application. She received plenty of good advice, but there was one particular piece of advice from Peter Forrest:

Remember the criteria for not being able to do something is:

- 1) Can I do it when I want to?
- 2) Can I do it as often as I want to?
- 3) Can I do it for as long as I want to?
- 4) Can I do it in the way I want to?

If the answer to any of these questions is 'NO' then list the things that stop you. Also list any assistance that you need and any aids that you use.

An example I use is: I use an Alexa device to control the lights, because I can't get up to switch the lights on/off when I need to.

Disability aids do not always carry labels. If you always use a steak knife because it helps cutting up food. Then you are not always able to cut up your own food and either have to ask for a different knife or for help. This is certainly a criteria I will keep in mind.

There is an extremely useful PDF aid memoir from the MS Society on page 4. If you are applying or renewing your PIP then I strongly recommend that you read this booklet first.

Our Spring residential weekend meeting in May proved to be a really great success again. Our events team [Jill](#), [Anita](#), [Silke](#), [Laura](#) and [Rachel](#) really work together so very well to produce a new fresh approach to bringing you an informative meeting balanced with a bit of fun as well. Now that the restrictions of the pandemic are behind us, the events team are more determined than ever to bring you an event that will always be better than the last. Your feedback is telling us that we are 'getting it right' just now. However, we won't allow that make us complacent, we are always receptive to new suggestions and ideas, so please don't hesitate to contact us if you have something you wish to suggest. See page 13 which shows just some of pictures taken at the last meeting. If you haven't been before, then hopefully we can encourage you to come along in the future, we would be so pleased to see you, as we know that you will leave feeling newly enthused and excited about what you have just experienced.

We have a problem with our email system at the moment, this is only a temporary situation and we hope to have it rectified soon. In the meantime, if you need to contact any member of the coordinating team, please give us a call instead, all of our numbers are shown on the back of this newsletter.

Bill Land (editor)



Be sure to visit our Mutual-Support Facebook group for the latest news and views.



Armed Forces Pension Upating

The annual uprating for All Armed Forces pensions for the financial year ending March 2024 is 10.1% in line with the Consumer Price Index (CPI) announced in October 2022

Note that those receiving pensions for less than a year will receive a proportion of the full increase, depending on how many months your pension has been in payment during that year.

The Pension Increase (PI) comes into force on the first Monday after the beginning of the new tax year – so, for 2023 it comes into effect on **10th April**.



Guidance

War Pensions uprating for financial year ending March 2024

The Ministry of Defence has announced the new War Disablement Pension rates for the financial year ending (FYE) March 2024. The rates are set out [Here](#)

Additional information can be found in the [Veterans UK](#) section on **www.gov.uk**

Thanks to Peter Mckernan for supplying this information.



Octopus



We're proud to fund the first ever multi-arm, multi-stage trial for progressive MS.

Octopus is a revolutionary trial that will transform the way we test treatments for progressive MS. A smarter way of testing potential treatments, it could deliver life changing new treatments up to three times faster.

The trial team have now confirmed the first treatments they'll be testing.

And **the first few people with primary and secondary progressive MS are taking part at University College London Hospital.** This is the only site currently open. But there will eventually be up to 30 sites around the UK.

You can register your interest in taking part in Octopus through the UK MS Register

The basic State Retirement Pension and the new State Retirement Pension are uprated by 10.1%.

The Standard Minimum Guarantee in Pension Credit is increased by 10.1% and the Savings Credit maximum is increased by 10.1%.

Premiums paid to pensioner recipients of Working Age benefits are uprated to match Pension Credit rates.

Personal Independence Payments (PIP) are increased by 10.1%

Premiums paid to disabled people receiving working age benefits and to Employment and Support Allowance claimants in the Support Group, are increased by 10.1%.

The higher and middle rate invalidity allowances and age additions payable with Incapacity Benefit (IB) is increased from April 2023.

Any changes to Working Tax Credit and Child Tax Credit are effective from 6th April 2023 in line with the start of the new tax year.

Housing Benefit allowances for people of working age [Appendix A](#)

Housing Benefit allowances for people of State Pension Credit age [Appendix B](#)

Income Support rates [Appendix C - Annex 1](#)

Jobseeker's Allowance rates [Appendix C – Annex 2](#)

Employment and Support Allowance rates [Appendix C - Annex 3](#)

State Pension Credit rates [Appendix C - Annex 4](#)

Universal Credit rates (Monthly) [Appendix C - Annex 5](#)

Other contributory and non-contributory social security rates [Appendix D](#)

Non-social security payments and rates [Appendix E](#)



Royal Navy Family and People Support

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Pappa Rutts MBE



Here is an inspirational piece from Craig Rutter MBE, who now as a proud grandparent likes to be known as Pappa Rutts:

I joined the Army on 13th February 1989 and initially thought I would do nine years.

For the first six years I tossed it off and then thought I'll do twelve years to get the half pension. Before I new it, I was a Sergeant and now I had committed to 22 years. Then a Colour Sergeant and a Sergeant Major so I ended up doing 24 years.

I got out for a couple of years and was asked if I was interested in a Full Time Reserve Service job in Nottingham. I took this job but after only three years I was Medically Discharged because of Multiple Sclerosis.

Having now done 27 years. I would not change a thing other than this bloody MS, as some days I can't walk but my family get me through the bad times with humour and my wife putting me back in my box. I have had a top life and I have a fantastic family and lots of old and new friends. Thanks for reading my crap and remember don't put anything off until tomorrow that you can do today because tomorrow may not come.

Thank you Craig (Ed)

To follow Craig on Facebook find him here:

Pappa Rutts MBE



Claiming PIP

(Personal Independence Payments)

The MS Society has an excellent online downloadable PDF booklet that should be extremely useful to anyone making an initial claim for PIP or to those who need to complete a review of an existing award, There is also an especially useful pull out section that explains how the 12 PIP key assessment scores are evaluated.

Claiming PIP Booklet



Did you know, we are also on twitter?
Follow us @ twitter.com/mss_msupport



Wendy Karen Cunningham

25th May 1958 - 13th May 2023

It is with deep regret that we hear of the passing of Wendy Karen Cunningham. She joined the group on 15th June 1995. She passed away on the morning of Saturday 13th May 2023 at Queen Alexandra Hospital, Portsmouth aged 64, just as many of us were at the residential weekend in Derbyshire. Our thoughts are with Wendy's family and friends. She will be missed.



We've just had six new members join Mutual Support since our March newsletter, a very warm welcome to them living in Hampshire, Yorkshire, Suffolk and Shropshire. Greetings to you all! Our Team encourages all our members to share the information that you have experienced in your military careers and also your MS journey. Any questions you have can invariably be answered by the other participants of the friendliest MS support group in the world.

Five have Army backgrounds with four still in service, The new members are:

Andrea Keeling – SSAFA Case worker
Hannah and Talek Nightingale
Simon Pearce
Danielle and Guy Reilly

Members with Facebook accounts might like to know that Mutual Support has its own Facebook page. If you have not yet joined us there and would like to, please search for Mutual-Support, or click on this link: [Mutual Support](#). Apply to join and I will grant you access right away. It's a good place to ask questions and support each other, there are daily MS bulletins to read, some signposting, some banter and a good way of keeping in touch with each other.

If your dependent children are over the age of 18 (unless still in full time education) could you give me a message to let me know, so I can remove them from our membership list. Our benefactors request information about who they are funding.

Also, if you've changed your telephone number, postal address or email address, do keep me updated so we can keep you apprised of upcoming events. The easiest and quickest way is to email me: graham.duncan199@gmail.com

Graham (*Hunky Dunk*) Duncan
Membership Volunteer

Did you know?

Mutual Support was formed in 1991
We now have 1169 members



Trooping the Colour

The Sovereign's birthday is officially celebrated by the ceremony of Trooping the Colour (King's Birthday Parade).

In **2023**, this impressive display of pageantry will take place on **Saturday 17th June** by Regiments of the Household Division, on Horse Guards Parade, with His Majesty The King attending and taking the salute.

His Majesty King Charles III will hold the appointment of Colonel-in-Chief of the Regiments of Household Division.



Going abroad: Travel insurance and more



If you're planning to go abroad, these resources can help you plan ahead.

Find out more

- [!\[\]\(569ff5d1aa9137b5defb690d1175fea6_img.jpg\) Planning your break](#)
- [!\[\]\(59bff645cb030955f45f21c74e7ddbd4_img.jpg\) Travel insurance and MS](#)
- [!\[\]\(dd83808d77658902b474c9e02c5f52d1_img.jpg\) Vaccinations](#)
- [!\[\]\(987f007ec31dbf160273204c7c2fd496_img.jpg\) Travelling by plane](#)
- [!\[\]\(81fa0003d5fda42e000d07b0ffc66c38_img.jpg\) Travelling with medications](#)

Questions about MS? Call: **0808 800 8000** [MS Helpline opening hours](#)



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RECRUITMENT & RESETTLEMENT GUIDE CAREERS & TRAINING FOR SERVING ARMED FORCES & VETERANS



Whether you're still in uniform or have already started to prepare for life 'outside', QUEST – is your go-to guide to support you along your Forces journey. From your education options while serving, right up to resettlement and into civvy street, it's the only guide you'll need to find Funding Options, Training Courses, Enhanced Learning Credits Courses, University Courses, Careers and Transition Advice.

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SUPPORTING THE ARMED FORCES COMMUNITY



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OR EMAIL
via our contact form

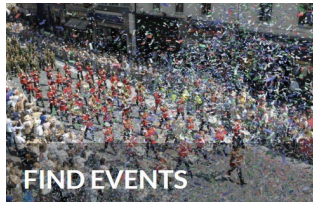


ARMED FORCES DAY

24 June 2023



ABOUT



FIND EVENTS



GET INVOLVED



BLOG



#SALUTEOURFORCES



AFD NATIONAL
EVENT

Contact details:

For specific events please see the [events page](#) for contact details.

For general enquiries, please email armedforcesday-events@mod.gov.uk

Reserves Day:

Reservists are everywhere, but you might not know it. So on Reserves Day, our Reservists wear their uniform in their civilian life. So, keep an eye out for them this year.

Links:

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Accessible Events for Summer 2023



This summer, Oceans of Hope UK in partnership with the Calvert Trust are offering [fully accessible sailing events](#) for everyone, especially those who might not be comfortable on our regular sailing boats. These are a great opportunity to get out there and push your boundaries, regardless of ability. Thanks to our generous benefactors, we are able to heavily subsidise all of our accessible sailing events.

Choose from an adventure and sailing weekend in the Lake District, day sailing in Torquay or the RYA Sailability Day at Swarkestone Sailing Club near Derby.

For those interested in venturing further afield, we're offering adaptable dinghy sailing in The Netherlands with Sailability in Hoorn.



Calvert Lakes Weekend

9th-12th June

[FIND OUT MORE](#)



Sail Days in Torquay

21st June, 18th July, 20th August

[FIND OUT MORE](#)



RYA Sailability Day Swarkestone

13th July

[FIND OUT MORE](#)



Dinghy Sailing in The Netherlands

1st July

[FIND OUT MORE](#)

MS-Selfie is a self-help resource for people with multiple sclerosis, listen to the above podcast about pelvic floor exercises by [Prof Gavin Giovannoni](#), Professor of Neurology at Barts and The London School of Medicine and Dentistry.

I spend a large chunk of my clinic time helping sort out bladder problems. There are so many questions about this topic. One of the treatments recommended to all patients with bladder problems is pelvic floor exercises (PFE). However, I have recently been asking patients if their continence advisors have formally instructed them on how to do PFE. Most patients respond by saying they were given an instruction sheet or referred to [NHS pelvic floor exercise](#) online or other online resources. What is clear is how few people have been adhering to the PFE regimen; I would estimate this to be less than 20% and probably less than 10% of patients.

If you don't know the answers to the following questions please continue to read the remainder of this article.

- Do you know how to do pelvic floor exercises and at what intensity?
- Have you adhered to doing your PFEs?
- Who should do PFE?
- Should men do PFEs?

Please note that various resources providing helpful instructions are available, for example, a patient education leaflet from the [International Urogynecological Association \(IUGA\)](#) and smartphone apps like the [Squeezy NHS pelvic floor app](#).

I would be interested to know which ones you have used and if you found them helpful. Please be aware that the evidence that Pelvic Floor Muscle Training (PFMT) works is overwhelming, which is why you should start doing it, regardless of whether or not you have pelvic floor dysfunction.



Pelvic floor dysfunction can also occur in men, and PFMT is a recommended first line conservative treatment measure. The following is from the [Pelvic Obstetric & Gynaecology Physiotherapy guide for men](#).



Conclusions: Moderate to high-quality studies showed the overall efficacy of PFMT in decreasing urine leakage and neurogenic bladder symptoms and increasing endurance and power of pelvic floor muscles. MS patients with lower urinary tract symptoms could benefit from PFMT in the short term.

General Disclaimer: Please note that the opinions expressed here are those of Professor Giovannoni and do not necessarily reflect the positions of Barts and The London School of Medicine and Dentistry nor Barts Health NHS Trust. The advice is intended as general advice and should not be interpreted as being personal clinical advice. If you have problems please tell your own healthcare professional who will be able to help you.

VAT exceptions

Seeing a recent FB post reminded me that we can get some goods/services VAT free. The rules regarding VAT-free items aren't straightforward, below are a couple of good websites that can explain it far better than I could.

There is a different set of rules for those over 60 who aren't classified as disabled, but may still be able to get a VAT reduction if you need certain mobility equipment installed in your home, you can benefit from reduced rate VAT, currently 5% rather than 20%.



Independent Living has a good guide:



HMRC rules

If you're disabled you'll generally have to pay VAT on the things you buy, but VAT relief is available on a limited range of goods and services for disabled people.



GOV.UK Get VAT relief on certain goods if you have a disability

VAT relief that may be available if you're buying goods because of your disability. This guidance explains how VAT relief works

- which goods can be bought VAT-free
- what HMRC means by 'disabled' and who qualifies for VAT-free goods
- how to prove that you qualify for VAT-free goods
- what to do if you think you've paid too much VAT

How to contact HMRC for more information:

Call HMRC for information about VAT reliefs available for disabled and older people. Telephone: **0300 123 1073**

Write to HMRC: Charities, Savings and International 2
HM Revenue and Customs
BX9 1BU
United Kingdom

Online:

VAT reliefs for disabled and older people - Enquiry form for an individual:



HM Revenue & Customs

www.tax.service.gov.uk/shortforms/form/

Download the HMRC App:

You can download the app from iOS or Android:



[App Store](#)

[Google Play Store](#)

Buttered Toast with Marmite.....Uhhmm

One thing I enjoy for breakfast is a simple piece of toast, which I like cool enough that when you spread your butter, it stays on the surface of the bread and doesn't soak into the fibres of the baked dough. If you are like me, then many times you are given concrete textured. When you are staying at a friend's house, or at one of our residential meetings, or perhaps happen to stay at a hotel, you are given one or more individual pads of butter that are so cold, often directly from the fridge and Impossible to spread. Can I offer you a tip that should help you in future, if faced with such a dilemma. What I do, is to form a toast tepee over the aforementioned pads of frozen-solid butter. The ambient temperature radiating from the tent of toast, should soften the butter sufficiently to facilitate the easy spreading of this most delightful dairy product, hence producing an edible piece of buttered toast.

I then like to crown this triumphant feat by completing my spreading efforts with a thin layer of Marmite!

Kim Bartlett April 2023



Multiple Sclerosis National Therapy Centres

Our member centres deliver life-enhancing therapies for people living with MS and other neurological or long term medical conditions.

They provide expert individualised support and a wide range of physical and holistic therapies to complement clinical treatment, as well as counselling, emotional support and an active social community.

How centres help

[Read more >](#)

Find a therapy centre

[Search >](#)

Therapies



Oxygen Therapy



Physiotherapy



Counselling



Complementary Therapies

50 centres... Providing 20+ therapies, supporting 15,000+ people ...every week

Email: info@msntc.org.uk





VETERANS'
GATEWAY

Information and support for veterans and their families

We are the first point of contact for you and your loved ones. Contact us 24/7 for help across housing, mental wellbeing, finances and more. You can contact our expert partners including Combat Stress, SSAFA and Poppy Scotland via our Self help section. And we can also refer you directly to our Referral Partners. Get in touch with our friendly helpline team by phone, chat, text and email.

Explore Self help



First 'Smart Centre' for blind veterans in the UK

Blind Veterans UK has unveiled a new 'smart' system at its centre of wellbeing in Llandudno, Wales.

Find out more



Ways to use our service

Use our Self Help resources to find information and advice or contact our advisors for support by phone or email.

Find out more



Making female veterans visible via The Female Veterans Transformation Programme

Did you know that female veterans tend to identify less with the term "veteran" compared to their male counterparts?...

Find out more



Other help available



Housing



Employment



Finances



Living
independently



Mental
wellbeing



Physical
health



Family and
communities

The first point of contact
for veterans seeking support



0808 802 1212



Live chat

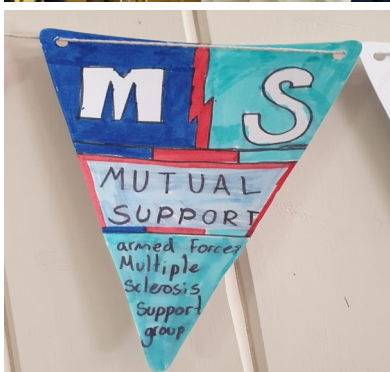


Text
81212



Email

Support & Respite Weekend - May 2023



Can cladribine slow worsening of arm and hand function in people with advanced MS?

At the last Support and Respite weekend a lot of members were particularly interested in the presentation given by Professor Klaus Schmierer of Queen Mary University of London and Barts NHS Health Trust.



There are currently no disease modifying therapies available for people with MS who can't use their lower limbs at all or can only walk short distances with the help of aids like crutches.

ChariotMS is a phase 2 trial testing whether cladribine can help people with MS maintain the use of their arms and hands.

Cladribine (brand name Mavenclad) is already licensed for highly active relapsing MS. It targets immune activity in the brain. Traditionally, it was thought this type of treatment wouldn't be effective in more advanced MS. But recent evidence suggests it may still be effective at this stage.

What happens in this project

ChariotMS will recruit 200 people who have an EDSS (Expanded Disability Status Scale) score of 6.5 to 8.5. This means they can't walk further than 20 meters with two crutches, or are unable to walk at all, but still have some use of their arms and hands.

Eligible participants will be randomly assigned to take either cladribine or a placebo (dummy drug) that they will take as a tablet over the course of 24 months.

To work out whether the drug is effective, the researchers will use a test of arm and hand function called the nine hole peg test. They will also be collecting MRI scans of participants to see whether cladribine shows an effect on lesions in the brain.

Can I get involved?

Yes! If you have advanced progressive MS and an EDSS (Expanded Disability Status Scale) score of 6.5 to 8.5 the researchers want to hear from you. EDSS 6.5 - 8.5 means you can't walk further than 20 meters with two crutches, or are unable to walk at all, but still have some use of your arms and hands.

You have to be 18+ to take part in this trial but there is no upper age limit. You can live anywhere in the UK. There will be 20 trial sites including locations in London, Belfast, Cardiff and Edinburgh.

To find out more about taking part, email the trial team at chariot@qmul.ac.uk.

How will it help people with MS?

Thanks to research, there are over a dozen licensed disease modifying therapies for people with relapsing MS, and some emerging for early progressive MS. But traditionally, clinical trials for MS have not included people who are dependent on a wheelchair to get around. And drugs have only been licensed if they improve walking ability.

ChariotMS will allow some people who have never before been eligible for a clinical trial to take part in one. And if cladribine is shown to slow the worsening of disability for people with advanced MS, it could mean this group of people will eventually have access to a treatment for the first time.



Scooter Social Group

For people with mobility scooters
and powered wheelchairs



Scooter group meetings on the first Saturday of every month at
[Thornes Park, Wakefield](#)

Meet up for a picnic and a drive around Thornes Park with plenty of opportunities for a natter. Accessible toilet available. Get outdoors and get to know new people. Give us a call and join in.

For more information or to book on for a taster day, please call or email:



07426 71 66 77

wakefield@opencountry.org.uk

www.opencountry.org.uk/wakefield



Making Sense of MS

If you have been recently diagnosed with MS, our Making Sense of MS core book contains introductory information that may be helpful.

GET MAKING SENSE OF MS



Explore our publications

Our wide range of free publications and information sheets cover everything from diagnosis and symptoms to living with MS and treatments. Available to download or order printed copies.



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MS Enquiry Service: 0800 032 38 39

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Sign Up TODAY for our **FREE** monthly Newsletter

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Stay up to date with all the latest additions to Disability Grants. And that's not all.... it also includes deadlines for grant applications, useful resources and other snippets.

Presented in bullet points it is easy to read and quick to scan so you can see at a glance the information that is relevant to you.

So whether you are disabled, a parent of a disabled child, a carer or a professional supporting anyone with a disability there will be something for you each month.

Colouring Book for Kids

Find out more about our colouring book with positive images of children with additional needs.

[CLICK HERE!](#)



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Testimonials

"Disability Grants is an absolutely outstanding place to find all the support we need for our disabled children. It's accurate, up to date and very easy to use. Sky Badger will be shouting it from the rooftops!" - *Naomi Marek, General Manager, Sky Badger.*

"What a great website.....why has no-one done it before!" - *Rachel Dewis, mother of a disabled child.*

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Erskine Veterans Charity

@ErskineVeteransCharity

ERSKINE *Caring* for Veterans since 1916

Scotland's Largest Veteran Charity

How we can help our veterans

Care Homes

Erskine Care Homes are centres of care excellence, set in comfortable surroundings.

[Find out more](#)

Activities Centre

Erskine's Activities Centre aims to enhance the quality of life and wellbeing of Veterans in the community.

[Find out more](#)

Transitional Supported Accommodation

The Transitional Supported Accommodation is to support Service leavers and Veterans whose life or transition plans have been disrupted.

[Find out more](#)

Assisted Living Apartments

Assisted Living Apartments provide accommodation and services to elderly or disabled veterans and/or their spouse.

[Find out more](#)

MS*
REGISTER

Log in

Register

Menu 

How many people in the UK are living with MS? How do the different types of MS affect different people? Are there regional differences in how people with MS receive treatment?

Currently, the answers to these fundamental questions are largely unknown. With an estimated 100,000 people living with MS in the UK, more data needs to be gathered about the physical, environmental and social effects for people and carers affected by the condition.



Blind Veteran's UK

Rebuilding lives after sight loss

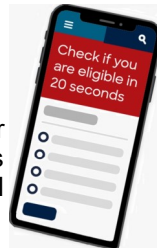
Blind Veterans UK helps vision-impaired ex-Servicemen and women to rebuild their lives after sight loss.

We provide rehabilitation, training, practical advice and emotional support to veterans regardless of how or when they lost their sight. We're here to help blind veterans regain their independence and live the life they choose.

[Play audio described version](#)

Try our new eligibility checker

Not sure if you qualify for support from Blind Veterans UK? Use our new online eligibility checker to find out. Answer a few simple questions about your service record and sight loss and in just a few seconds you'll know if you can apply for our support.



Apply for support

Do you have a vision impairment and a service record?
Find out how to apply for support from Blind Veterans UK.

[Find out more](#)

Don't want to apply online? You can apply by post

Would you prefer to print an application form, fill it out and send it to us? You can download our form below. If you don't have access to a printer, call our support team on **0800 389 7979** and they can send you a form in the post.



[Download application form](#)



A M S P
Public Group



A M S P

By Aiden Garner

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Legal advice service for people with MS

Sometimes you may need legal advice to help you know if you are being treated fairly, to understand your rights in a situation, or to challenge unfair practice. Our legal advice service can help.

We work with the Disability Law Service (DLS) to provide free, confidential legal advice to people affected by MS. In England and Wales you can get advice on employment, disability discrimination, and community care. These services are free of charge to everyone affected by MS.

Call our **MS Helpline** on **0808 800 8000** to find out more.

> [Learn more about our legal advice service](#)



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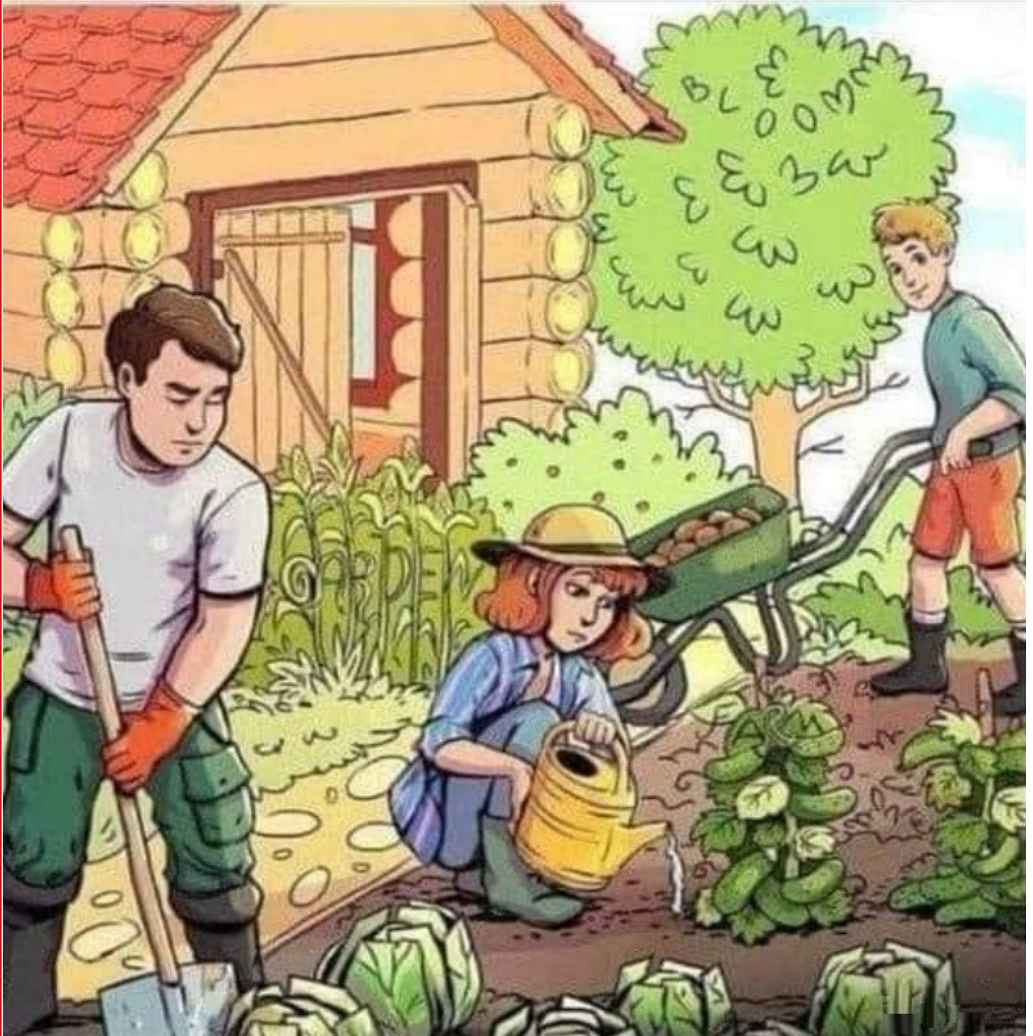
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Find three words

Can you find the three English words hidden within this picture? Good luck!



These kind of images are used much more now as a tool to exercise the mind of those who are concerned about their cognitive abilities. It has been long thought that 'Brain Exercise' is just as important as physical activity in staving off the effects of ageing.

Learning another language is an excellent way of keeping the brain active. Perhaps you think this might be too difficult for you, but there are a few apps available now that can help you to learn at your own pace in an enjoyable and rewarding way. **DUOLINGO** is a free app that is very effective. Why not give it a try? You might be surprised! It is available to download at:





Mutual Support would like to thank these charities and everyone else who support us; your contributions enable us to do the good work that we do - Thank You.



**GREENWICH
HOSPITAL**
SUPPORTING THE ROYAL NAVY SINCE 1694



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The Army's National Charity



THE HOBSON CHARITY

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