MS
MUTUAL SUPPORT
ARMED FORCES MULTIPLE SCLEROSIS SUPPORT GROUP

New Year 2025

UPON

Reflection

Officers & Gentlefolk

Patrons

Dr Faraz Jeddi MBBS, MRCS(Ed), AFRCS(Ire), Pg Dip In RM
Dr Anita Rose B.A. (hons), D.Clin Psy., AFBPsS, C. Psychol

President

Air Commodore Mike Barter CBE Honorary

Life President

Air Vice Marshal TB Sherrington CB OBE

Vice Presidents

Col Paul Cummings
Air Commodore R Merry MB BS FRCP MRCPsych RCOG

Honorary Members

Roger Langdon MBE
Lieutenant Colonel C S MacGregor KRH
Stephanie Millward MBE
Alastair Hignall CBE
Simeon Grundy

Newsletter Articles please send to:
Guy comms@mutual-support.org.uk

Contents

Orbat

Preface: Upon Reflection

Not so much an editorial as a gentle apology about progress. Procedural delays in the recruitment process through the MS Society for a Newsletter Editor, then personal change of circumstances at the time of compilation for the new recruit, dictated what was to be a Christmas edition has become a New Year ‘Holding’ Edition. I mention this background because these kinds of issues are part of the fabric of a life with MS. Often the rippling side-effects of the many dimensions to the disease, living with the disease and the complications that are the substrate of living a human life in itself, don’t go away because one has the disease and has to react to living with the condition while issues with ’normal’ life still go on. Reflecting upon 2024, ‘tho, and the opportunity it allowed for healing my mind, leaves plenty of optimism for the coming year.

Guy.

Morning Prayers

Group Coordinator Message

Depending upon the time that this message is transmitted, you will either be getting ready for Christmas or will be on the annual diet and fitness program. I hope you all get the opportunity to relax, unwind and spend time with loved ones over the festive period. This time of year can be very difficult for a lot of people, so I am sure you will join me in wishing those deployed and their loved ones a peaceful break. Also we are part of a family that looks out for each other during hard times as a result of service life or just life. Please reach out if you know someone struggling and make sure they know there are people who care.

Mutual Support continues to provide pastoral care for members with 2 x Wellbeing weekends every year. The Coordinating Team are continually looking for other facilities to allow us to reach new and existing members as we recognise the location and current facilities are not ideal for everyone. We are going to a different venue in September 2025 (more details to follow). Another change will be the introduction of an annual award to a member who has performed well in voluntary work for Mutual Support, which will be presented at the Wellbeing Weekend.

Finally, I’d like to take the opportunity to thank the Coord team for all their efforts in 2024 and to all the Mutual Support members for being part of our special family.

Merry Christmas and Happy New Year.

Fundraising Volunteer

The life-blood of our community is fundraising. With fundraising in mind, we are desperately in need for fundraising volunteers. The role is not too onerous. Nor time consuming; regular fundraising keeps this wonderful group on its feet and gives a fabulous feeling of making a significant contribution.

If you feel that you are able to offer your services as a fundraising volunteer, or can organise fundraising events or activities in your locale then please let us know, we'd love to hear from you.

Contact
Jim on :
co-ord@mutual-support.org.uk

Or Julie on:
admin@mutual-support.org.uk

Membership Report January 2025

As of 24 Dec 2024, we have the following in our membership:

- Presently have 1179 members, of which 530 have MS.
- Of those 530, 54 are still serving personnel of the Armed Forces.
- 373 are former serving
- 97 are dependents with MS.
- We still have seven civilians who are honorary members etc with MS.
- There are 220 females and 311 males with MS.
- We have 648 children, spouses and partners, without MS.

Mutual Support has had six new members join us since our Sep newsletter – a very warm welcome to all.
The new members are:
Louise Budgen
Sadie Cooper-Jones
Holly Cooper-Jones
Rochelle Baker
Michael Folliard
Charlotte Blackburn
I'm still waiting for four other people to return their application forms to me.

Facebook

- There are 380 members who belong to our Facebook page.
- Most popular day for FB comments or reactions was Thursdays in the past 60 days.
- Most popular times for FB interaction has been between 1600and 1700 hours

Graham (Hunky Dunk) Duncan
Membership Volunteer

Daily Orders

Happy New Year & Welcome.

This is not so much a full-fledged Newsletter as a ‘holding’ device for the change of editorship. I would like to pass on both my personal thanks and the gratitude of the organisation to Bill Land for his sterling work in collating, publishing and distributing the Newsletter.

A little about me: my name is Guy Mortenson (said a la Michael Caine). I was diagnosed with PPMS in October 2014, a diagnosis that was missed in ’06 with symptoms which, in retrospect, were clearly MS.
I spent the eighties in the British Army’s Intelligence Corps, some of the nineties in the RAFVR as a Photographic Interpreter. Seven years at Heathrow and twenty in an IT career that ended with a diagnosis and spiralling mental health problems. Six years at Uni went a long way to arresting that free-fall. My introduction to Mutual Support was when the then chair, Suzanne Crighton intervened in a housing issue on my behalf.

The Newsletter Plan

My initial thoughts, and these are offered as a starting point which can be altered, dropped, evolved, depending upon the organisation’s thoughts or needs, is to search for articles under four main groupings. Not every edition will have content from each grouping, but as more content arrives to rotate through headings as an organisational product for publication. These groupings have been arrived at from my own experiences and observations, and the many difficulties and challenges of living with MS. But also celebrating still being alive.
Any organisation newsletter depends upon stories and content input about, from, and by people. In a covert attempt to attract your contribution, I’ll explain below, previous experience in a different arena means I realise it is often difficult to tempt people to contribute, for many and varied reasons. So, to start with I’ll look to break content into these four functional components and go off seeking stories of interest. Hopefully that lends itself to an intelligence operation.

1 MS, its effects and a holistic existence

This main grouping will be themed around the University of Tasmania’s free course, Understanding Multiple Sclerosis, which they run online twice a year. These broad brush-stroke topics are:

i Biology and Pathology

- the immune system
    * inflammation
    * neurodegeneration
    * demyelination

    * breakdown of demyelination
- Pathology: its causation in symptoms

ii Diagnosis and Symptoms

- diagnosis
- technologies
- types of MS
  PTSD (this is my addition, see under Mental Wellbeing)

iii Demographics

- geography
- gender

iv Risk Factors

- non-modifiable
- modifiable
- effective goals
    * exercise

v Disease Management

- monitoring
- symptom management
- Behavioural
- DMT’s

vi Living with MS

- carers, friends and family
- living alone
  *disability benefits and interaction with the state

*This can be a delicate and ‘touchy’ subject and is not meant to be an invitation of criticism or attack. Many support organisations, including local councils, are underfunded, understaffed or constrained by organisational or individual norms and processes. However, in my experience, sometimes lack of knowledge, unclear advice on methods of approach and different application and interpretation of systems in different geographical areas can have a major impact on mental health.

2 Co-morbidities.

I recently underwent radiotherapy treatment for prostate cancer with a prediction based on blood results of five years of life remaining. There were complications for me owing to the fact that high blood numbers meant it had most likely spread out of the pelvis but options for chemotherapy were limited. This limitation was because of the uncertain condition of my nerves and or immune system. As you can imagine, worry and uncertainty can often cause side-effect problems that are not conducive to a healthy recovery.

In my case, post therapy tests seem to indicate the tumour was caught before it had spread. But, treatment caused a further problem for me that was not identified by oncology nor urology. It was identified in an urology consultation by the person who had given me a lift. The urologist was puzzling over my on-going bladder problems (my bladder held twice as much liquid as a 'normal' bladder ought, four times the trigger to urinate). 'What about MS?' asked my lift. The urologist slapped their head with a 'Doh!' sound. 'Of course!' They said. 'MS!'

Later, research shows there is information available about co-morbidities (additional diseases or conditions along with MS) but as I started my third cancer journey, a visit to A&E owing to pulmonary embolisms in both lungs and tissue viability problems in my right leg (excessive swelling of the calf and ankle) I knew nothing about the effects and risks caused to other treatments by an underlying condition like MS.

3 Mental Well-being.

A diagnosis that went something along the lines of
this is what you've got
it will put you in a chair
it shouldn't alter your life expectancy
Off you go. Next!

left me in the atrium of Gloucester Royal somewhat bewildered. This coincided with the loss of my job, in retrospect I can see how clearly the two were linked, and a descent into mental and emotional meltdown. Me? A wheelchair? Nah, I'm a warrior. Elite Army. High level rugby. A chair? Nah.

— the disease wasn't listening to my objections.

There was a whole world of low-level shame that I was going to have to get used to, falling over in the High Street again, soiling my pants in a bar and having to make the walk home knowing my rear would be highlighted by a stain. There are few preparations for the damage and hurt these events can have on our emotional stability and self-respect value systems. And, like Covid-19, it can come with a long tail.

In the course of a difficult recalibration, I was encouraged to go to University where I worked out how Creative Expression, in my case writing, but it could be dance, sewing, art, photography, whatever, can lead us out of darker times by our own volition (not intervention by support organisations like counselling).

On the back of my PhD from the School of Creative Writing and English at the Uni of Gloucestershire, I put together a course on writing memoir which I had started teaching at the cancer centre in Newport on the Isle of Wight. Now I need to leave the island so won't be continuing the course in the new year, if anyone would like to engage in the course (and test it for me!) I am more than happy to guide you through writing a memoir, or any other kind of writing for well being. Even if it's just to leave many funny and unusual stories of life in the military for friends and family, it can be an excellent exercise for mental health. Please get in touch.

4 Creative Industries

I've seen a couple of films and read a few books where MS gets a feature. A 'walk-on' part somehow doesn't sound a correct phrase. I'm hoping to start a review section, or pass on recommendations, if anybody has read anything or seen a film that touches on life with MS. Now I've just got to remember what they were. X + Y comes to mind, with Asa Butterfield and directed by Morgan Mathews (2015).

It's interesting that I am a writer for whom MS has removed my ability to hold a pen in my right hand. I am a cook for whom it's removed the fine-grained motor control needed to chop an onion. The process of adapting ('adapt and overcome' as a friend's email signature block says) and the mentality it takes to do that, I believe is worth sharing. It's a learnt skill, not free with our DNA if we're lucky. Others can learn (Winston Churchill said I love to learn, I hate to be taught), if one can find a 'voice' with which to share. Often we don't know how to go about looking for that voice, let alone how to share it. Sometimes there's a therapy in sharing, not just inherent in the activity of expression itself.

With a PhD in poetry, I'll save you those insights, but with plenty of other experience and knowledge of Creative Writing in other modalities, I would like to see if it generates any interest or feedback; I'm going to serialise a novel I have written about life with MS. I say 'I'm going to', that's if there is any appetite for some different kind of content in the Newsletter and a different / new direction for part of it. Got to try it to buy it, I guess. The prologue of The Silence of Sound is included below.

Fiction: The Silence of Sound

Prologue

Mattäus Jordan — 'Fingers' to his few remaining real world friends — pretty much gave up on sex the night of the awkward incident. The night the air was sucked out of the room. The night the walls, unconstrained by their ally's lack of curtains, were stained by, yet captured, sodium yellow street light as if all-body tattoo'd. They flashed bright white. The night the calf of his right leg morphed into quick-drying cement. Instantly. He was unfamiliar with mens' night noises, but surely she wasn't. The way the woman's eyes sprang open from an inch away. An out-of-body 'huh?' By both of them. The look of alarm made him pretty sure his primordial scream was a new one on her. His leg snapped into its triangle shut then straightened fast like a sprinter out of the blocks. All without his will. He pushed into the press-up position, tangling with the duvet in his hurry to get out of bed. Full body weight, rolling onto her thigh, causing her too to yelp. Hopping, as best his mangled body would allow him. She sat up, pulling the duvet across her chest like women do in movies. So they did that in real life too? Abandoned clothing captured his foot: he crunched face-down onto the floor, head just missing the radiator. He lay, a washed up jellyfish. Sobbed.

Sometime later, when the earth tilted the sun into the northern hemisphere to launch daffodils, and the metaphor of clocks was marched forward, their eyes had met briefly, passing each other in the gun-fighter part of town: the Lower High Street. Both looked quickly away — maybe with weak smiles as they sort distance in time and space from the incident. He conceded the point of giving up on sex even though he'd been falsely convicted. Upon multiple reflections, 100,000 internal replays, he also conceded his flailing wouldn't have been awarded even a 'Sev-hen!' in a TV dancing competition.

They both knew the cramp had not been the most awkward part of the incident.

Pavements in St Paul's are tight, 1920's traffic-load tight. Squeezed like a stood-on hose. Just wide enough for a pram, or a wheelchair sometimes, impassable on bin days. The roads are narrow too, cholesterol-vessels made more so by cars parked on both sides, between them spaces wide enough to shuffle side-ways. Everything is squeezed, even time is squeezed like toothpaste. Ranks of two-bedroomed terraces converted for students. Students have cars now. Young couples both split-level upstairs and down, with stretch-marked mortgages.

Just down this road is a pub. A night or two or three after 'Awkward-Incidentgate', Jordan is sitting at one of the few tables left out stranded in the evening. When they clear space for music night, punters stand. It pays to get there early. As in, like, opening time. Packed as garlic in a press, they gawk at whichever band is playing. Music steals the air. It shuffles candle flames, ripples the window blinds, takes over the minds of people; causes them to puppet loosely with their feet stuck in place. Eyes vacant. Mouths open.

Jordan can take or leave the music, happiest in silence, compromising when music owns the pub like the disease that owns him.

Earlier was ciggy time. Before he'd lose his seat. He pulled the front door of the pub just as a woman was coming in. Human-bleached air rushed out. She passed. She didn't flick her eyes, nod her head; nothing. Just absence.

'Don't mention it!' he called to her retreating back.

She paused, turned. 'I won't.'

He went out with a shrug.

Now, looking up through the noise, he sees the same woman lean towards him across the table. Lip reading more than hearing a register different from the music, she asks can she sit? He waves a dissonant hand, mouthing 'of course'.

'Great band,' she shouts; a guitar riff stops with a flurry of hands and the main room of the pub lets out its held breath trying to remember how next to inhale.

'Yeah.'

'Next one's a cover.'

'Right.' He looks at his glass, not empty enough to escape. Bloody half-full glasses.

The drummer finds his banging-foot. Guitars come out of hibernation. Chords gate-crash the ceiling. She starts to slap the table in rhythm with a kind of all-body pumping from her hips. His cider oscillates. He picks it up, clutching it to his chest.

"Today …" she shouts out over her shoulder. He assumes it is singing, it's magically in time with the band's point man. The music big-bangs and expands into the pub, he hasn't anticipated the start of a communal Lord's Prayer. 'Don't look back in anger …' she screams across at him. 'Don't you know this one?'

'No.'

'Dude, it's Oasis.'

'Right.'

'Greatest band in history.'

'Yeah, I heard.'

She stares at him. Standing, she leans across the table again. Close to his face. ‘Damn.’

He feels spittle colonises his skin.

‘Swipe left, loser!’

It is at times like this that shame shape-shifts out of the depths, expanding its membrane, osmosises itself through his skin to paint itself on his face as bright as the light at the end of Jay Gatsby’s pier. If that’d been red.

‘Ok,’ he says to a reprised retreating back. As if he knows whatever that had meant.

Contact the Team

Jim Watson
Group Coordinator
07951 037 008 co-ord@mutual-support.org.uk

Julie Russell
Administration Volunteer
07812 738 607 admin@mutual-support.org.uk

Jack Russell
Finance Volunteer
07855 434 921 finance@mutual-support.org.uk

Graham Duncan
Admin Volunteer (Membership)
01993 844 136 membership@mutual-support.org.uk

Jill Watson
Events Volunteer (Manager)
07506 272916 eventsmanager@mutual-support.org.uk

Anita Rose
Events Volunteer (1)
events1@mutual-support.org.uk

Silke Land
Events Volunteer (2) Hosting
07746 603 711 events2@mutual-support.org.uk

Allocated Events Volunteer (3) Childcare
events3@mutual-support.org.uk

Fiona Dangerfield
Events Volunteer (4) Speakers
07814 112 437 events4@mutual-support.org.uk

Rachel Harris
Events Volunteer
07393 854 330

Guy Mortenson
Comms Volunteer (Newsletter)
07856 721 080 comms@mutual-support.org.uk

Stuart Davey
Comms Volunteer (Publicity)
07875 070 068 publicity@mutual.support.org.uk

Jason Wimpenny
Comms Volunteer (Social Media)
socialmediavolunteer@mutual-support.org.uk

VACANT
Fundraising Volunteer
fundraiser@mutual-support.org.uk

Andrew Williams
Support Volunteer
07958 524 298 stc1@mutual-support.org.uk

Helen Spear
Support Volunteer
stc2@mutual-support.org.uk