Volunteer Handbook

Overcoming Multiple Sclerosis
Welcome!

We are so excited to have you with us as our volunteer! We understand that the first few months in a new role can be exciting, challenging, and perhaps also a bit daunting. Don't worry, we'll be there to support you and make sure it all goes smoothly. You have already impressed us with your enthusiasm, knowledge and passion and we’re looking forward to getting you involved and developing your skills and experience. It’s normal to feel nervous and have lots of questions when you start something new - and that’s the same for volunteering. This handbook is your reference throughout your time as an OMS volunteer, covering the ‘need to know first’ information along with signposting to further material which you may want to come back and refer to throughout your volunteer journey.

Many of the links in this handbook will guide you back to the relevant pages on our OMS website. Your Volunteer Co-ordinator will support you through your induction and ensure you have everything you need to start in your role. If at any point you have questions or would like to highlight any areas you would like further information on, training or support, please just ask your Volunteer Co-ordinator.
1. About OMS

Overcoming Multiple Sclerosis (OMS) is the world’s leading multiple sclerosis healthy lifestyle charity. We are unique in our whole person approach and practical evidence-based focus upon self-management of MS, formulated as a holistic program. We are registered to work in the UK (England, Wales, Scotland), the US and Australia.

**Our vision** is a world in which every person with MS is empowered to take control of their health, is making informed lifestyle choices, and is living a full and healthy life.

**Our strategic goals** to achieve our vision are, to:

- **Inform**: We ensure people affected by MS are fully informed about evidence-based ways to help self-manage their MS.
- **Support**: We help people living with MS to feel supported through OMS Circles (our growing global volunteer community network). OMS Circles are accessible and responsive to the diverse needs of people affected by MS.
- **Empower**: We advocate for and with people living with MS and demonstrate how self-management and lifestyle choices are a vital part of living a full life. We influence policymakers and campaign to raise awareness of the importance and benefits of MS self-management.
- **Collaborate**: We support and contribute to the growing body of evidence around lifestyle choices and self-management of MS to help influence and create change amongst healthcare professionals and policymakers. We work in partnership with individuals, communities, healthcare professionals and other charities to create genuine and sustainable benefits for people living with MS.
Our values guide everything that we do here at Overcoming MS.

We are:

- **Evidence-based**: The OMS Program draws upon an extensive body of evidence of the benefits of lifestyle changes on the health outcomes and quality of life for people with MS.
- **Empowering**: We provide the tools to enable people with MS to take care of themselves and become active managers of their own health.
- **Community-focused**: We focus on building a supportive, positive and empowered community of people with MS.
- **Inclusive**: OMS is an inclusive and diverse community, which both welcomes and gives voice to the experience of each individual.
- **Collaborative**: We work within, and seek to influence, an active and well-developed field of research into the treatment of MS, as well as the expanding arena of advocacy for people with MS in relation to healthcare policy, access to resources and the benefits of self-management as a complement to medicinal therapies.
- **Dynamic**: As a small charity operating on a global scale, we value focus, efficiency and creativity.
2. History of OMS and Future Plans

History
The OMS program evolved from a list Professor George Jelinek wrote in 1999, a lifestyle of habits he would practice to keep himself well. The program was published in 2000 as a book, Overcoming MS, the charity was established in 2012 by Linda Bloom.

Key milestones for the OMS Program and the OMS Charity:

1999
- Professor George Jelinek creates the Overcoming MS program including recommendations for lifestyle and dietary changes.

2000
- Professor Jelinek’s first book, Taking Control of Multiple Sclerosis, is published.

2002
- First residential retreats are hosted at the Gawler Foundation, Melbourne, Australia.
- The Stop MS research study begins, people with MS attending retreats are asked to participate in a study. The study measures their quality of life at intervals of one, five, ten and twenty years after their retreat experience.

2008
- Takingcontrolofmultiplesclerosis.org website launches
- Facebook page is created

2010
- Professor Jelinek publishes Overcoming Multiple Sclerosis: An Evidence Based Guide to Recovery. This builds on his original book (Taking Control of Multiple Sclerosis) with a much increased base of research references and evidence base and a clearer layout.
2012
- **HOLISM study** starts (Health Outcomes and Lifestyle In a Sample of people with Multiple Sclerosis). This is the first study of its type to collect detailed lifestyle data from a large group of people with MS worldwide, correlated with health outcomes.
- The Overcoming MS charity is officially established by Linda Bloom, with the goal of expanding awareness of the Overcoming MS 7-Step Recovery Program.

2013
- First UK residential retreat is held at Launde Abbey, Leicestershire.
- First day-long OMS conference in Brighton, UK with 274 delegates.

2015
- Overcoming MS is registered as a charity in Australia and the US
- First Irish retreat at the Emmaus Centre, Dublin.
- First European retreat takes place in Austria.

2016
- A **second edition** of Overcoming Multiple Sclerosis: the evidence-based seven step recovery program is published worldwide
- Professor Jelinek, Dr Pia Jelinek and Dr Craig Hassed embarked on an ambitious program of events in Los Angeles, New York and Boston. The events were the first face-to-face interaction with the US MS community.

2017
- ‘**Overcoming Multiple Sclerosis Cookbook**’ is published.

2018
- **OMS Circles and Ambassador** program is created.
- **Printed booklets** are published in English, French, German, Dutch and Spanish

2019
- ‘**Living Well with MS**’ Podcast launches.
- Professor George Jelinek retires.

2020
- Gary McMahon, the CEO of OMS departs after eight years and the charity welcomes Grazina Berry as its new leader.
### Future plans

To achieve our vision, in 2021 we will be focusing on a range of activities and diverse projects. They’ve all been grouped under the headers of 4 strategic goals. But firstly, to achieve our goals we need to optimise our organisational capacity and capability, as follows:

**We will:**

- Make better use of data
- Gain a better understanding of our audiences following segmentation, incl. geographical
- Develop a clear OMSer journey map (the ‘funnel’) through our information and support offer
- Bring new colleagues on board, increasing our capacity in core areas
- Further develop and embed a new volunteer management process and bring new volunteers on board
- Consolidate information resources and improve our website
- Introduce new outcome measures and tools
- Continue to boost our governance — recruiting and onboarding new trustees
- Take policies from theory into practice
- Introduce SMARTer ways of working
- Develop a new Fundraising Strategy

**Inform:** To ensure people affected by MS are fully informed about evidence-based ways to help self-manage multiple sclerosis, we will:

- Undertake a Community Survey — to gather and analyse data about the needs and demographics of people with MS, following OMS
- Develop and launch a new webinar programme
- Develop and launch a new podcast programme
- Complete UAT and evaluate launch readiness of the New OMS App
- Improve web content and info resources for OMSers.
**Support:** To help people living with MS to feel supported through OMS Circles, we will:
- Bring new Ambassadors on board and support better the existing ones
- Working with the Community Engagement Steering Group, develop and launch a New Community Engagement Strategy
- Conduct our first Ambassador survey, analyse and utilise the results
- Launch OMS Circles Online, bringing existing Circles on board.

**Empower:** To advocate for and with people living with MS to demonstrate how self-management and lifestyle choices are vital for living a full life, we will:
- Launch a new Advocacy Group
- Organise our inaugural awareness raising campaign — linking to the International MS Awareness Day
- Begin to develop the OMS website area aimed at healthcare professionals
- Develop ‘Narratives of Hope’ that help inspire and activate new OMSers.

**Collaborate:** To contribute to the growing body of evidence around lifestyle choices and self-management of MS and create change amongst healthcare professionals and policymakers, we will:
- Convene a Research round-table
- Assemble a progressive Research Advisory Group
- Boost the body of OMS-NEU research and promote the OMS evidence base
- Develop and launch new partnerships (e.g. with MS Gym, HelloSelf)
- Establish links with the Samueli Foundation via the Bloom Foundation
- Contribute to impact-focused alliances, e.g. Neurological Alliance
- Help shape the Wellness programme at MS Academy/Raising the Bar initiative and influence the NHS/ healthcare system.
3. The OMS Program

**Diet**
A healthy diet is important in improving symptoms and preventing the progression of multiple sclerosis. Research shows that saturated fats and dairy are particularly harmful for people with multiple sclerosis (MS). A plant-based, wholefood diet that is rich in omega-3 while excluding dairy and minimizing saturated fat intake is critical in recovering from symptoms and living a long, healthy life.

**Sunlight & Vitamin D**
Vitamin D is important in both preventing MS and improving health outcomes for those who have MS. There are several types of vitamin D, however only vitamin D3 is helpful in MS. We recommend taking 5,000 - 10,000 IU vitamin D3 daily, however exactly how much should be taken will depend on how much sunshine people get.

**Exercise**
Exercise improves physical and mental well-being in people with MS. Regular movement improves flexibility, strength and fitness, prevents injury and correct physical problems caused by MS. Exercise also reduces stress and symptoms of depression. The right form of exercise will depend on a number of factors, including ability and preferences. It is recommended to aim for 30 minutes of vigorous activity, five days a week, however any regular physical activity is better than none.

**Meditation**
Managing stress is an important part of living with MS and meditation can help. Chronic stress and the inflammatory response it causes in the body can worsen the symptoms and progression of MS. Research has shown that meditation may also help with symptoms of depression and pain, and boost compassion and happiness. Evidence also shows that the more someone meditates, the greater the benefit. We recommend aiming for 30 minutes daily.
**Medication**
Choices around medication are highly personal. Medication is an important part of MS care, we believe that people with MS can make personal decisions about medication use.

**Prevention in Family Members**
Having a parent, sibling or child with MS puts people at an increased risk of developing it themselves. While it is not possible to modify genes, there are lifestyle changes that can reduce the overall risk of developing MS.
- Quit smoking
- Get adequate sun exposure and supplement with vitamin D
- Eat a healthy diet low in saturated fat, and supplement with flaxseed oil
- Keep stress levels down and exercise regularly

**Change your life, for life**
Making a choice to follow the diet and lifestyle principles recommended by the OMS Program means people are on course for a better, healthier life with MS. Maintaining the OMS lifestyle involves a fair degree of mindful change and awareness of its effect on their condition. In this sense, they have to take ownership of it and be your own self-champion. This means taking an active approach to their health and finding the support they need to make these life changes from family, friends and other OMS members.
4. The Value and Importance of Volunteers to OMS

Overcoming MS is looking to support as many people affected by MS as possible worldwide, and to champion our Overcoming MS program. This is where we need you! As a charity we work closely with people within our OMS community who share both their skills and time to help us achieve our goals.

5. OMS Circles and Circles Online

An OMS Circle is a community of people who share a belief in making positive changes to their diets and lifestyles to achieve a better and healthier life with MS. They meet regularly for events and outings, answer each other’s questions, and act as a source of support and encouragement for each other, in good and not-so-good times. OMS Ambassadors serve both as members and leaders of the group. More information here.

In March 2021 we launched OMS Circles Online. We have created an online area where people can talk safely and securely, and where they can decide how much they want to share with others and maintain their privacy if they want to, but also feel confident that their words will remain within the group. We built a customised platform and wanted it to be inclusive to those who don’t wish to use social media or share their contact details with other members or information with a third party. OMS are committed to keeping your information safe and we do not have any advertising on site.
6. How volunteers and staff work together

OMS values the contribution volunteers make to our work across all areas. We are now working with some 120 committed and talented volunteers who give us their time, share skills and expertise across a range of projects and areas as follows:

**Community Engagement Steering Group (CESG):** Formed by ‘super-ambassadors’ and chaired by a full-time volunteer. The CESG has been set up to work with the OMS Community Engagement Co-ordinator and OMS team to co-produce a community engagement strategy.

**OMS Ambassadors:** Volunteers who run local and regional support groups for OMSers called Circles. The Community Engagement Co-ordinator will manage the day-to-day relationship with Ambassadors.

**Comms Advisory Group (CAG):** A diverse group that is also the largest, covering a wide range of areas- input into our broader communications plan, advice on content, production of blogs, video content and editing, graphic design and others. Day-to-day interactions are managed by the digital team.

Two part-time Volunteer Co-ordinators, Hana and Sarah, are working with the OMS team in ensuring our volunteer management processes are in place and work effectively.

A new group of volunteers, The OMS Advocacy Group, with passion for advocacy and championing OMS to Healthcare Practitioners, will be recruited in 2021, to work with OMS on implementing our new advocacy goal.

A Research Advisory Group will also be formed from leading figures in neurology and research areas relevant to the OMS program, to ensure the OMS approach continues to evolve in line with the changing environment and evolving needs of the MS patient and supporter community.
7. How decisions are made within the organization

Our trustees, Linda Bloom, Tony Bloom, Marc Sugarman, Caroline Clarke, Professor Helen Rees Leahy, Allie Marwick and Dr Aaron Boster are responsible for controlling the work, management and administration of OMS on behalf of its beneficiaries. Helen and Allie have been recently appointed to champion advocacy and lived experience at Board level, while Aaron has joined the Board to represent the healthcare profession.
Policies & Procedures

Summaries of all key OMS Policies below. Full documents are also available on request.

OMS Conflict of Interest Policy
Conflicts of interest may arise where an employee, volunteer, Trustee, consultant or contractor of OMS has personal, business or family interests and/or loyalties that might conflict with those of the organisation. Where an individual has a major or ongoing conflict of interest he/she should offer to resign from, terminate the contract with or cease to be a volunteer for OMS.

OMS Health & Safety Policy
All OMS employees, volunteers and trustees should take care of themselves and others who may be affected by their actions or omissions, adopting a safe system of work at all times, using all safety clothing/equipment provided where necessary, and generally taking responsibility for their safety.

Equality, Diversity and Inclusion Policy
OMS is committed to preventing any form of discrimination and inequality in the workplace, across all of our activities, and to being compliant with the Equality Act 2010 and any other relevant legislation. This policy sets out how our organisation will promote equal opportunity and prevent all forms of unlawful or unfair discrimination, harassment and victimisation.

Volunteers have a duty to:
- act in ways that respect and value the diversity of others.
- attend appropriate training arranged by OMS regarding EDI issues.
- not discriminate against anyone accessing our information, support and community engagement programmes or other members of the organisation
- challenge any behaviour that could be interpreted as unfair discrimination and reporting appropriately.
**OMS Information Governance (IG) Policy**

IG is the framework of structures, policies, procedures, processes and controls in place for handling information in order to protect and use it to support compliance with legislative and regulatory requirements and good practice guidelines as well as business development.

In particular this policy aims to ensure that Personal Data is processed in line with the data protection principles and is:

- used fairly and lawfully
- obtained and used for specific and legitimate purposes only
- adequate, relevant and not excessive
- accurate and up to date
- not kept longer than necessary
- complying with the rights of Data Subjects
- kept secure through organisational and technical security measures
- not transferred outside the EEA without adequate protection

All permanent and temporary staff members, volunteers and individuals working on behalf of OMS with access to, or handling of, personal data must undertake appropriate IG training to their roles, on an annual basis and be familiar with the policy.

**OMS Safeguarding Adults Policy**

We will interact with PwMS and their families on a regular basis upon joining the OMS community, both face to face during meetings and events as well as online via digital platforms and social media. OMS is committed to safeguarding and promoting the welfare of everyone who reaches out for information and support. We believe that individuals should be able to live a life free from abuse and neglect regardless of gender, ethnicity, disability, sexuality or beliefs and have their rights and choice respected. We expect that all staff and volunteers will share this commitment.
OMS Risk Management Framework

In the pursuit of OMS business objectives, we will face strategic and operational challenges – substantial competition in the medical cause space, greater spotlight and public interest in charities, a tighter regulatory regime, increasing cyber risk, competitive fundraising environment, and others.

All staff and those acting on behalf of OMS are responsible for:
- adhering to the principles set out in OMS Risk Management Framework
- maintaining an awareness of risks and managing these in a day-to-day operation and through specific projects, in accordance with the framework.

Our Risk Management process is as follows, to:
- identify and understand the nature of risk
- assess the inherent risk impact and likelihood, also considering the speed at which the impact of the risk could materialize and whether the risk is project-specific
- identify mitigation measures and risk controls
- allocate an owner who has responsibility for the timely implementation of the agreed action plan
- report on progress in managing the risk and implementation of activities to address residual risk.
OMS Whistleblowing Policy

OMS is committed to being open, honest and accountable. It encourages a free and open culture in its dealings between the Trustees and those working in the organisation and on its behalf - both employees and volunteers.

This policy aims to help the Trustees and employees/volunteers to raise any serious concerns they may have about colleagues or their employer with confidence and without having to worry about being victimised, discriminated against or disadvantaged in any way as a result.

It is written in the context of the Public Interest Disclosure Act 1998, England which protects employees who ‘blow the whistle’ on malpractices within their organisation.

The policy is intended to deal with serious or sensitive concerns about wrongdoings such as the following (please note that this list is not exhaustive)

- a criminal offence, that may influence the ability to undertake the designated role, including one that arises from the Bribery Act
- a failure to comply with any legal or regulatory obligation
- a failure to comply with organisational policies and procedures
- a failure in the protection of children or vulnerable adults
- a miscarriage of justice
- financial impropriety, including failure to declare conflict of interest or receipt of a significant gift or hospitality
- a health and safety risk to an individual
- abuse of company property
- damage to the environment
- or actions intended to conceal the above.

The OMS Whistleblowing lead is Marc Sugarman, Trustee. Please only contact him in the event of a whistleblowing concern using marc.sugarman@starlizard.com
OMS Safeguarding Children and YA Policy

Whilst OMS do not provide services directly to children and young people, in our work we may have contact with children, young people and their families face to face, in meetings, during events and virtually/online, including social media channels.

OMS are committed to safeguarding and promoting the welfare of children and young people in all of our interactions with them. We believe that individuals should be able to live a life free from abuse and neglect regardless of gender, ethnicity, disability, sexuality or beliefs and have their rights and choice respected. We believe that the welfare of the child is paramount. We expect that all our employees and volunteers share this commitment.

Abuse may occur in all races, culture and social circumstances. It is also important to consider that someone who abuses an individual could be a member of their immediate or extended family, a friend, a neighbour or stranger to them, a member of staff, a volunteer or another member of the OMS community. It is therefore essential to remain alert to the possibility that abuse ‘can happen here’ and consequently staff and anyone acting on behalf of OMS are required to adopt an approach that is professional, open minded and that respectfully challenges others in order to facilitate this.

The OMS Safeguarding lead is Grazina Berry, CEO.

Complaints Policy

At OMS we are committed to working to a high professional standard and maintaining positive working relationships with our supporters, community members, donors, volunteers and members of the public. However, sometimes things can go wrong, and mistakes can be made.

If you wish to express dissatisfaction with how we provide our services, you have the right to make a complaint. So please take the time to tell us about it. If we are not getting something right, it is important to us that we know about it, so we can improve.
How do I make a complaint?
The first step is to contact OMS and ask to speak to the person concerned. If you would prefer not to use the phone, you can either write to us at our address — Overcoming MS, Thame House, Thame Road, Haddenham, Buckinghamshire, HP17 8HU, UK or e-mail feedback@overcomingms.org

What information do we need?
For all complaints, we will require the following information from you:

- The date of the situation that you are complaining about
- The nature of your complaint
- The reason you are complaining
- Any other information that may help us to investigate the complaint, for example, details of any other people involved in the situation or who witnessed it
- The best way to contact you.

Will my details be kept confidential?
We will take every reasonable step to keep your identity confidential. However, in order to investigate and respond to a complaint appropriately, it may be helpful to have full details of the incident which may include your identity. The individual at OMS responsible for dealing with the complaint will decide who involved receives this information. Those individuals will be required to keep any details confidential. If our employee treats this information inappropriately and this leads to a breach of confidentiality, they may face disciplinary action.

What happens next?
Your complaint will be recorded in writing on our Incidents Log, to make sure that it is followed up. Our goal is to acknowledge complaints within two working days.
Volunteer policy

Volunteering is a powerful force for change, for those who volunteer, the organisation and for wider communities. Volunteers offer organisations their support, expertise and innovation, enhancing impact and adding value.

Overcoming MS (OMS) values volunteers, recognising their contributions to the work that we do and the impact we create for and with people with MS. Volunteers are a positive additional resource and are not intended to replace paid staff. They complement and/or enhance the services provided by OMS.

At OMS we currently have the following volunteer roles:

- **Ambassadors**, volunteers who support groups of people with MS and OMSers called Circles. Due to the extent of their role, their recruitment and management process is separate to the regular and occasional volunteer management process and is overseen by the OMS Community Engagement Co-ordinator. The two processes will, however, complement each other. Ambassadors are asked to provide two references and are required to undergo a basic disclosure check (or equivalent depending on geography).

- **Regular volunteers** are recruited through our volunteer recruitment process and are asked to provide a reference. Depending on the intensity and duration of their role, they may need a basic disclosure check. This will be determined by the OMS lead for a specific project a volunteer will be involved in. Regular volunteers may be involved in supporting our ‘digital helpline’, organising events and contributing to specific projects on an ongoing basis.

- **Occasional volunteers** may volunteer only a few times a year, will need to complete an online application form and their volunteer agreement. Occasional volunteers may help OMS team with administrative tasks, producing social media content, blogs and other ad hoc small-scale activities.
A role description accompanies all regular volunteer and Ambassador roles and sets out the main activities for the role. Each volunteer will have an individual activity plan which clearly identifies the activities and tasks that the volunteer will undertake during their placement with OMS. This activity plan will be mutually agreed. Volunteers have the right to refuse to undertake activities and tasks that they consider unrealistic, beyond the scope of their role or when they do not have the relevant skills.

All new volunteers will be required to sign a volunteer agreement, which lays out general and specific expectations. It covers what we can expect from volunteers and what they can expect of us – including issues of mutual respect, confidentiality, etc. that are applicable to all volunteers. Disclosure checks and references may also be requested, dependent upon the type of volunteer role.
Supporting you!

Volunteer Agreement
Volunteers will be asked to sign an OMS Volunteer Agreement and return it to the OMS Volunteer Co-ordinator/s at volunteer@overcomingms.org before starting their role.

Support & supervision, including key contacts
OMS staff members or volunteer group Chairs will be primarily responsible for allocating volunteer tasks and liaising with you around specific meetings and role requirements.

OMS Volunteer Co-ordinator/s are here to support you as an OMS Volunteer and are there for you to raise any concerns throughout your time as a volunteer and make improvements to the volunteer programmes.

Hana & Sarah: Volunteer Co-ordinators
any queries and concerns arising during your role
Email: volunteer@overcomingms.org

Jo: Ambassadors and Circle Members
Email: jo@overcomingms.org

Sophie: Marketing/Comms Champions
Email: sophie@overcomingms.org

Lucy: Digital Manager
Email: lucy@overcomingms.org

VOLUNTEER HANDBOOK
Volunteer meetings, communications and training

Ad hoc meetings via Zoom will be organized by the Volunteer Co-ordinators to discuss problems and work towards solutions encountered across the volunteering process.

Volunteers can also connect through the Volunteer Group on the OMS webpage, and we intend to set up regular volunteer networking opportunities online.

We aim to recruit volunteers and use their existing skills for specific OMS projects. In the first instance, this Volunteer Handbook provides basic information. If there is a specific area within a project that requires volunteer training, then the project manager/co-ordinator will address this and ensure training needs are met.

Social Media Channels

Facebook
Twitter
YouTube
Instagram