**Support Groups and Organizations for Fibromyalgia in England**

* **Fibromyalgia Action UK (FMA UK)** – The principal UK-wide fibromyalgia charity (est. 1992, also known as Fibromyalgia Association UK). Staffed largely by volunteers (many are patients), FMA UK’s mission is to improve life for people with fibromyalgia . They provide extensive information resources and run national helplines. Uniquely, FMA UK oversees a network of **over 150 local support groups** across the UK, coordinated by regional volunteers. These local groups (often peer-led) offer empathy, meetings, and practical help in communities. FMA UK also hosts an online support forum and distributes free information packs/booklets for patients and health professionals. (Website: fmauk.org)
* **UK Fibromyalgia** – An independent community and magazine (the *Fibromyalgia Magazine*) that serves as **“the independent voice of UK fibromyalgia”**. UK Fibromyalgia’s website provides up-to-date info and runs a popular **online forum/Facebook group** with tens of thousands of members. In fact, their Facebook-based community has grown to **over 40,000 members** across various groups . They also maintain an interactive **Support Groups Map** for the UK, where users can find details of fibro support groups by region . *(For example, in Greater London alone, the map lists groups like “Fibro Comfort” (Carshalton & Morden, Surrey) and “Fibro Friends” with dedicated phone lines and meet-ups .)* UK Fibromyalgia invites local support leaders to submit their group info to keep the directory current. (Website: ukfibromyalgia.com)
* **Local Fibromyalgia Support Groups (England)** – Given the prevalence of fibromyalgia, many towns and counties have in-person or hybrid support groups. These are often informal associations or registered small charities. *Examples:* **Sheffield ME & Fibromyalgia Group** (South Yorkshire) – as noted, a combined-condition group offering peer support, welfare advice, and activities for those with fibro or ME/CFS . **Coventry Fibromyalgia Support Group** – founded 2007 by a patient, it meets **monthly in Coventry** (St. John’s Church) for talks, shared experiences, and social support. The group also engages in awareness and fundraising events (e.g. supporting Macmillan). **London Fibromyalgia Network** – in London, several neighborhood groups exist (e.g. “Fibro Comfort” in Surrey; “Fibromyalgia & CFS Support – Redbridge”; a Dulwich fibro group associated with FibroAwareness UK). These meet either monthly or maintain online contact (Facebook, email) and often have a volunteer leader. **Manchester Fibromyalgia Support** – (indicative example) an online-focused group for Greater Manchester area fibro sufferers (found via social media, providing Zoom chats and meetups) – and similar groups can be found in most regions. FMA UK’s regional coordinators can connect individuals to *“a support group near you”* , and the UK Fibromyalgia map is a handy reference to locate **dozens of local fibro groups across England**. Activities typically include regular meet-ups (or Zoom meetings), group discussions, inviting guest speakers (e.g. physiotherapists), and simply sharing coping tips in a friendly environment.
* **Online Communities (Fibromyalgia)** – **Facebook** is a major platform: FMA UK runs a public page and a closed **Fibromyalgia Action UK support group**. UK Fibromyalgia runs a large **private Facebook group** (40k+ members) as well as specialized subgroups, e.g. *“Men & Fibromyalgia”* and *“Young People with FM”* , to ensure tailored peer support. Additionally, there are patient-led groups like *“Fibromyalgia UK”* (independent) or forums on health sites where people exchange stories and advice. The fibromyalgia community is very active online due to the need for understanding and tips on managing pain, fatigue, and related symptoms. Many people find these 24/7 online groups helpful for immediate support on difficult days. (For instance, the **HealthUnlocked Fibromyalgia forum** and **Reddit r/Fibromyalgia** have UK contributors.)

**Support Groups and Organizations for Long COVID in England**

* **Long COVID Support** – A UK-based peer support and advocacy charity formed by people living with Long COVID . It began as an online patient support community and remains centered on its flagship **“Long Covid Support Group”** on Facebook (an international group moderated from the UK, with ~67,000 members) . This group is a *“warm and inclusive space”* for those suffering prolonged COVID symptoms to share information, validate experiences, and help each other through bad days . Long Covid Support became a registered charity in England (Reg. 1198938) and continues to campaign for recognition of Long COVID while providing peer connections. It has also established specific private subgroups on Facebook: a **Long Covid Carers** group (for family/friends supporting someone with Long COVID) and a **Long Covid Men’s Group** . All these groups are moderated safe spaces, open only to people with lived experience (patients or carers) to ensure trust and understanding. (Website: longcovid.org)
* **Long COVID Kids** – A UK charity focused on children and young people with Long COVID (and related post-viral conditions). Long Covid Kids represents families and offers support and resources for parents/caregivers of affected children . They run online support forums (including a Facebook group for parents/guardians) , and actively advocate for accommodations in schools and pediatric care. Since young Long COVID patients often struggle to get formal diagnosis or support, this group provides crucial peer support for families. (Website: longcovidkids.org; they also have regional parent “champions” and community events for families.)
* **Long COVID SOS** – A UK advocacy and support organization (registered charity) which campaigns for research, treatment and recognition of Long COVID. While primarily focused on advocacy (“SOS”), it also provides information and some support to individuals (e.g. webinars with medical experts, resources on rehabilitation) . Long Covid SOS gives patients a voice in policy and shares personal recovery stories for hope. (Website: longcovidsos.org)
* **Covid Aid** – *covid:aid* is the UK’s national COVID-19 charity, which supports anyone affected by the pandemic, including Long COVID sufferers. Covid Aid runs a free **online support community** with dedicated **Long COVID discussion groups** and even self-management courses. People can sign up to their platform (community.covidaidcharity.org) to access long COVID Q&A sessions, expert webinars, fatigue management courses, and peer discussions. This provides a structured online peer support option outside of Facebook. Covid Aid’s website also compiles practical advice on topics like breathing exercises, claiming disability benefits (PIP) for Long COVID, and mental health support . (Website: covidaidcharity.org)
* **Local Long COVID Groups / Community Initiatives** – As Long COVID is widespread, smaller local support efforts are appearing. Some examples: **NHS Clinic Support Groups** – Certain post-COVID rehabilitation clinics in England facilitate group sessions (either in-person or virtual) where patients can share experiences as part of rehab. These are typically led by occupational therapists or peer mentors. **Community Meet-ups** – In some areas, ad-hoc peer meet-ups have been organized (often by patients via social media). For instance, there have been local Facebook groups such as *“Long Covid Support Group: [Region]”* (e.g. a dedicated group in Scotland, Wales, etc., and likely equivalents in English regions). In practice, many English patients simply join the large national groups (like Long Covid Support on Facebook) since they draw members from all regions, but some cities have their own Facebook chats or WhatsApp groups for those who met through rehab programs. *Example:* The **Inverclyde Long Covid Support Group** (in Scotland) has run a community initiative called “Long COVID Stand Up” – similar grassroots efforts may exist in parts of England, though they are not yet formally catalogued. Another example is a pilot **Long COVID peer support project in North Wales** that created weekly virtual meetups for patients, which proved so helpful that it expanded to other chronic illnesses . In England, the *Mental Health Foundation* has highlighted the importance of such peer spaces for Long COVID sufferers to combat isolation and validate experiences . Patients in England can ask their local Long COVID clinic or check social media if any community group is active in their area.
* **Online Communities (Long COVID)** – By nature, Long COVID support has flourished online. Aside from the official groups listed above, there are independent forums and social platforms where people convene. **Twitter** (X) has a large #LongCovid community where patients and doctors discuss research and tips. **Reddit’s r/LongCOVID** forum connects people globally (including many from England). Numerous Facebook groups exist: e.g. *“Long Haul Covid Fighters UK”* (a UK-only group for long-haulers) and blended-condition groups like *“Long COVID & ME/CFS Recovery”*, etc., each with thousands of members . These groups provide round-the-clock peer support – from sharing symptom-management tricks (for brain fog, PEM, etc.) to simply listening on tough days. **Long Covid Support** (the charity) also provides an **online choir** (the Long COVID Choir) as an outlet for patients , illustrating the creative online peer activities that have emerged. The **Other UK groups** section on Long Covid Support’s site links out to Long Covid peer groups specific to Wales and Scotland, ensuring patients can find a community relevant to their region . Overall, the online realm has become a lifeline for those with Long COVID, especially when mobility or energy for physical meetings is limited.

**Support Groups and Organizations for ME/CFS in England**

* **ME Association (MEA)** – A major UK charity offering information, a helpline, and local group links. MEA supports people with ME/CFS through its **“ME Connect”** helpline (daily, 10am–12, 2–4, 7–9) and a comprehensive listing of local support groups . The charity also funds research and provides expert medical information. (Website: meassociation.org.uk)
* **Action for M.E.** – Another leading UK charity (headquartered in Bristol) supporting all ages with ME/CFS. It offers an **Information & Support Line**, advocacy services, and free online forums. Action for M.E. runs *“ME Friends Online”* (a forum for adults) and a **Young People’s Community** forum to help those with ME connect and reduce isolation. They also provide resources for carers and have merged with the youth charity AYME to support children with ME. (Website: actionforme.org.uk)
* **#MEAction UK** – A grassroots network advocating for ME/CFS patients. #MEAction UK facilitates online support and activism. For example, it hosts Facebook groups like *“#MEAction Living with ME”* and others for specific needs (e.g. a caregivers’ group, a Long COVID group, etc.). These are informal peer support spaces to share experiences and organize campaigns. (#MEAction UK’s Facebook support group is open to anyone in the UK.)
* **25% ME Group** – A charity focusing on the **severely ill** quarter of ME patients (often housebound/bedbound). It provides newsletters, advocacy and a contact network for those most severely affected. The group offers home-bound ME sufferers (and their carers) a range of support services by post, phone and online, acknowledging their high level of disability.
* **TYMES Trust (The Young ME Sufferers Trust)** – A UK charity dedicated to children and young people with ME. It provides parents and children with advice (e.g. an advice line, school liaison). (TYMES Trust has worked closely with Action for M.E. since AYME’s merger.)
* **Local ME/CFS Support Groups (England)** – There are many community-run groups across England where people with ME/CFS can meet (often virtually or occasionally in-person) for mutual support. These are usually volunteer-led by patients. *Examples:* **Oxfordshire ME Group for Action (OMEGA)** – offers local meet-ups and campaigns for services in Oxfordshire . **Bristol ME Support Group** – a long-running group (formed 1987, ~115 members) for Bristol and surrounding areas . They host monthly social meet-ups around the city, maintain a private Facebook group and even run activities like a watercolour class . **Leeds ME Network** – a self-help network for ME patients in Leeds (information via ME-pedia) . **Sheffield ME & Fibromyalgia Group** – a charity supporting those with ME/CFS *and* fibromyalgia in South Yorkshire; they provide advocacy, an active Facebook community (1,000+ members), and free wellbeing events (crafts, mindfulness, etc.). *Dozens* of similar local groups exist (often coordinated through MEA or local NHS CFS service contacts). The ME Association maintains the “most comprehensive listing” of local ME/CFS support groups nationwide – patients can search by area or ask MEA regional volunteers for nearby groups. Many groups transitioned to **online meetups** or support via Facebook/WhatsApp during the pandemic, which has increased accessibility for severely ill members.
* **Online Communities (ME/CFS)** – In addition to formal charities, patients connect in online forums and social media. Apart from the forums run by ME charities (mentioned above), there are large Facebook groups such as *“UK M.E. & Chronic Illness”* (peer-run, ~32k members) and international ME/CFS forums (e.g. Phoenix Rising, S4ME) that many in England use. These online groups are valuable for sharing management tips and reducing isolation. (Note: **HealthUnlocked** hosts an ME/CFS forum in partnership with MEA, and Reddit and Twitter also have active ME/CFS communities.)

**UK-Based Instagram Support Pages for ME/CFS, Fibromyalgia & Long COVID**

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| --- | --- | --- | --- | --- | --- |
| **Instagram Handle** | **Name** | **Focus** | **Description** | **Public or Private** | **Official or Community-run** |
| @meassociation | ME Association | ME/CFS | Raises funds for ME/CFS medical research and provides support, information, and campaigns for people with ME/CFS in the UK . | Public | Official (national charity) |
| @actionform.e | Action for M.E. | ME/CFS | Provides support and holistic healthcare services for people of all ages affected by ME/CFS . Offers advocacy and resources as a UK charity. | Public | Official (national charity) |
| @meactnetuk | #MEAction UK | ME/CFS | Grassroots volunteer-led network working toward health equality for people with ME (#MillionsMissing campaign) . Focuses on advocacy and awareness. | Public | Community-run (volunteer network) |
| @meresearchuk | ME Research UK | ME/CFS | Funds and commissions biomedical research into ME/CFS affecting people of all ages and backgrounds . Also provides news on research progress. | Public | Official (research charity) |
| @investinmeresearch | Invest in ME Research | ME/CFS | Independent UK charity energizing research into ME through funding, education, and advocacy . Hosts annual international research conferences. | Public | Official (charity) |
| @meactionscotland | #MEAction Scotland | ME/CFS | Grassroots volunteer-led movement in Scotland fighting for health equality for people with ME . Engages in advocacy and local activism. | Public | Community-run (volunteer network) |
| @hertfordshiremecfssupport | Herts ME/CFS Support Group | ME/CFS | Local community group (Hertfordshire) run by volunteers, providing self-help, peer support and social sessions for people with ME/CFS and post-viral fatigue . | Public | Community-run (volunteer group) |
| @sheffieldmefm | Sheffield ME & Fibromyalgia Group | ME/CFS, Fibromyalgia, Long COVID | Small registered charity supporting people with ME/CFS, Fibromyalgia **and** Long COVID in South Yorkshire & North Derbyshire . Provides information, local meet-ups and a point of contact. | Public | Official (local charity) |
| @fma\_uk | Fibromyalgia Action UK (FMA UK) | Fibromyalgia | The UK’s national fibromyalgia charity – raising awareness and providing support for those affected by fibromyalgia across the country . | Public | Official (national charity) |
| @ukfibromyalgiamag | UK Fibromyalgia | Fibromyalgia | An independent voice of the UK fibromyalgia community – a monthly magazine published for over 22 years, sharing stories, research news, and support resources . | Public | Community-run (independent magazine) |
| @fibromyalgia\_and\_me\_uk | Fibromyalgia & ME UK (Awareness Page) | Fibromyalgia | Community-run page **raising awareness** about fibromyalgia – sharing educational posts, quotes, and facts to help others in the fibro community . (Personal blog style page) | Public | Community-run (individual) |
| @fibromyalgiaukchat | Fibromyalgia UK Chat | Fibromyalgia | Instagram page for the fibromyalgia community, aiming to share experiences and encourage peer support (tagline: “Fibromyalgia is as unique and complicated as you are.”) . Often shares tips and personal stories. | Public | Community-run (individual) |
| @longcovid | Long Covid Support | Long COVID | UK-based **peer support and advocacy** page keeping people with Long COVID and their carers at the center of everything. Focuses on support, education, research involvement, and campaigning . Originated from a 40k-strong patient-led Facebook group and now a registered charity advocating for recognition of Long COVID in the UK . | Public | Official (charity) |
| @longcovidsos | Long Covid SOS | Long COVID | UK charity advocating for people impacted by Long COVID – focusing on **recognition, research, and rehabilitation** for this debilitating condition . Campaigns for government and NHS support. | Public | Official (charity) |
| @longccuk | Long Covid Connect UK | Long COVID (and Vaccine Injury) | Patient-led team uniting the UK Long COVID and Covid-vaccine-injured community with resources, emotional support and awareness initiatives . Aims to empower patients and share helpful information. | Public | Community-run (peer-led group) |
| @long\_covid\_kids | Long Covid Kids | Long COVID | Charity focused on children and young people with Long COVID and related conditions. **Led by patients, powered by community**, it raises awareness and offers support for families (uses hashtags #LongCovidKids, #LCandME) . | Public | Official (charity) |
| @longcovidscot | Long Covid Scotland | Long COVID | Charity and action group in Scotland led by people living with Long COVID. Advocates for Long COVID patients in Scotland and campaigns for better support and awareness of the condition . | Public | Official (charity & grassroots) |
| @longcovidwales | Long Covid Wales | Long COVID | A Welsh patient-led campaign offshoot of the main Long Covid Support group. Focuses on advocacy in Wales as part of the 40,000-strong UK Long COVID community . Works to influence devolved health policy and support sufferers locally. | Public | Community-run (volunteer initiative) |
| @longcovidadvoc8 | Long Covid Advocacy | Long COVID & ME/CFS | Non-profit social enterprise (patient-led) dedicated to the Long COVID *and* ME/CFS community. Follows a social-justice model to provide education, advocacy (e.g. runs the #PedanticZebra book club to discuss illness and disability topics) . | Public | Community-run (patient-led org) |
| @longcovidnursesandmidwivesuk | Long Covid Nurses and Midwives UK | Long COVID | An **advocacy group** for NHS nurses and midwives in the UK living with Long COVID. Founded by frontline workers, it highlights the challenges healthcare workers face and campaigns for support and workplace accommodations . | Public | Community-run (peer support/advocacy group) |

**University-Affiliated Support Groups for ME/CFS, Fibromyalgia, and Long COVID (England)**

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| --- | --- | --- | --- | --- | --- |
| University | Support Group / Initiative | Conditions Supported | How It Is Run | Format | Contact / Website |
| University of Worcester | Fibromyalgia Education & Exercise Support Group | Fibromyalgia | Student-led (Physiotherapy & OT students; 6-week pilot run) | In-person (weekly meetings on campus) | Email: McClellandclinic@gmail.com |
| University College London (UCL) | *Long Covid Solidarity* (UCL Students’ Union project) | Long COVID, ME/CFS (Chronic Fatigue) | Student-led volunteering project (peer “buddy” matching run by UCL student volunteers) | Online/Remote (matches people for email, phone or video support) | Website & sign-up: **Long Covid Solidarity** (UCL) ; Email: longcovidsolidarity@ucl.ac.uk |
| University of Bristol | *Chronic Health Condition Society (CHCS)* | Any chronic health conditions (including ME/CFS, Fibromyalgia, Long COVID) | Student society (student-led, under Bristol SU; organizes peer support events and buddy scheme) | Hybrid – regular in-person social events (accessible games/crafts nights) and peer matching | Bristol SU page (CHCS); Instagram: @chcs\_bristol |
| University of Exeter | Chronic Health Peer Support Group | Any chronic physical conditions (including ME/CFS, Fibromyalgia, Long COVID) | Student-led peer support group (trained student volunteers facilitate bi-weekly sessions) | In-person (bi-weekly meetings on campus, plus occasional social events) | Instagram: @chronichealthsupportexe (Exeter Guild page) |
| University of Exeter | Fatigue Social Group | Fatigue-related chronic conditions (ME/CFS, Fibromyalgia, Long COVID, etc.) | University wellbeing initiative (facilitated by AccessAbility staff; open to any student with fatigue/pain) | Hybrid – fortnightly meetings (alternating in-person on campus with online sessions via Teams) | Email: accessability@exeter.ac.uk (join mailing list for session info) |