

DISABILITY AIDS, ADAPTATIONS & SOCIAL CARE

Helping you cope with ME/CFS

ME CONNECT HELPLINE: **FREEPHONE 0808 801 0484**

by **Russell Fleming**
Communications Manager

INTRODUCTION

It is often a struggle to get through the day with ME/CFS. Illness severity and symptoms such as muscle fatigue, weakness, aches, and pains, can make walking or even standing difficult or impossible.

Sitting up in bed, sleeping, cooking, and cleaning, toileting, reading, communicating, attending to even minimal responsibilities, etc. can all make demands that you are not able to accomplish unaided.

From the severely affected to those whose symptoms have stabilised and who have returned to work or education, disability aids can help you to accomplish tasks more easily, gain a measure of independence, and improve your quality of life.

There is no shame in needing help. People with ME/CFS have just as much right to access disability aids as people with other disabilities. It might feel uncomfortable admitting you need help in this way but they can be a lifeline and allow greater independence.



Related leaflets:

- TWIMC letter on Disability Aids and Adaptations: <https://tinyurl.com/7s2kcsfc>
- Disability Classification and Illness Severity Definitions: <https://tinyurl.com/3kekehff>
- Prognosis, Permanency and Quality of Life: <https://tinyurl.com/yp9mddte>

AFFORDABILITY

There is a vast range of disability aids available. You will need to be cautious as the price of some items can be prohibitive, especially if you are on a low income or need to purchase a mobility scooter or electric wheelchair. Financial help is available to purchase some items, and some aids, while others can be provided via the NHS or social care services.

Mobility shops often allow rental of the more expensive items, so you can try them out and see if they are worth buying. Rental might also be more cost-efficient if you need the items for short-term use. Remember electric wheelchairs and scooters will need to be recharged and you'll have to store them somewhere safe, you might also need them to be collapsible for transporting.

The majority of items are affordable and can provide a lifeline especially if you are living alone. Visit the online disability aid stores and browse their product ranges to get some ideas. It is also worth noting that certain products do not attract VAT if you are disabled.

It is well-worth discussing your needs with a GP as the NHS might



Disability Aids, Adaptations & Social Care

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be able to help and a referral to secondary care might result in an assessment of your needs by an occupational therapist. This could result in the provision of a wheelchair or other aids and appliances, and you'll need a recommendation from a healthcare professional if you want to apply for a grant to make adaptations to your home.

If you are entitled to disability benefits, or receive a social care budget, the income these provide can be used to purchase disability aids and other medical supplies.

The NHS has provided a good online guide to the practical considerations of disability aids, and also reviews funding options. It would be a good place to start before you make any purchases:

■ Care and support you can get for free:

<https://tinyurl.com/mfjkj3t>

■ Walking aids, wheelchairs, and mobility scooters:

<https://tinyurl.com/keh2t4uc>

■ Household gadgets and equipment to make life easier:

<https://tinyurl.com/s3xp48jk>

■ Help at home from a paid carer: <https://tinyurl.com/72xkhykc>



WELFARE BENEFITS

The main reason you should consider disability aids is because they can be used to complete tasks that otherwise you could not. They can help you to overcome the limitations you have to conserve precious energy, allow greater mobility, and make daily life that bit easier.

But disability aids can also be used to demonstrate the extent to which your limitations are affecting your life especially when it comes to applying for certain benefits. If you need to use a wheelchair, walking stick, or a blue badge, for example, these can support your claim for reduced mobility, while the need for other aids can support the daily living component of benefit claims.

■ **Personal Independence Payment Guide:** <https://tinyurl.com/3c88rtwz>

■ **Employment and Support Allowance/Universal Credit Guide:** <https://tinyurl.com/3bck2a93>

■ **The Blue Badge Scheme:** <https://tinyurl.com/2sr2cxpd>

Disability aids can help you to use the toilet, to maintain personal hygiene, to be more comfortable in bed or when seated, to be more mobile around the home or in outside spaces, with reading, communicating, overcoming light and noise sensitivities, cognitive issues, using kitchen appliances, and in the preparation of food and drink etc.

DISABLED FACILITIES GRANTS

You could get a grant from your local authority if you need to make changes to your home, for example to:

- widen doors and install ramps,
- improve access to rooms and facilities – e.g., stairlifts or a downstairs bathroom,
- provide a heating system suitable for your needs,
- adapt heating or lighting controls to make them easier to use.

A disabled facilities grant will not affect your benefits, but how much you receive will depend on household income and savings above £6,000. The grants awarded depend on what you need and where you live but can be up to £36,000.



Grants are available, subject to qualifying criteria, in England, Wales, and Northern Ireland, but their availability is not always advertised, so it is best to contact your local authority in the first instance and before making any building plans etc.

■ For more information, visit the Government website: <https://www.gov.uk/disabled-facilities-grants>

■ There are different arrangements in Scotland: <https://tinyurl.com/2e2hmbdy>



SOCIAL CARE SUPPORT

If you are struggling to accomplish daily living tasks for yourself, or caring for you has become difficult for a family member or partner, then a referral to social care services could offer a good solution. You should speak with your GP who can make a referral, and get the process started, or you can make a direct application to your local authority.

If you are deemed eligible your local authority will conduct a needs assessment which is used to calculate a personal budget. This can then be spent on employing professional carers and/or equipment to increase your independence and quality of life.

You can choose to allow the local authority to retain control of your budget or take responsibility for it yourself. Different councils will have different procedures, and if you live in Scotland the process will be different again.



INDEPENDENT ADVOCATES

If you find it difficult to understand your care and support or find it hard speak up, you can ask your local authority for an independent advocate.

For example, they can help you:

- understand the care and support process
- talk about how you feel about your care
- make decisions
- challenge decisions about your care and support if you do not agree with them
- stand up for your rights
- write letters and attend meetings with you.

Advocates will support you during:

- assessments
- care and support planning
- safeguarding and reviews

They are independent of social services and the NHS.

Your local authority has to provide an advocate if you do not have family or friends to help and you have difficulty:

- understanding and remembering information
- communicating your views
- understanding the pros and cons of different options

<https://tinyurl.com/4fmt6v9b>



BECOME A MEMBER OF THE MEA

We have an excellent member's magazine and all we ask in return is a very reasonable subscription.

We rely on the support on our members and put their interests at the heart of everything we do.

We have kept subscriptions affordable because we know how much of a lifeline ME Essential magazine can be.



You don't have to be personally affected by ME/CFS to join the ME Association. Membership is available to carers, family-members, and anyone with a professional interest in the condition.

Annual membership costs:
 £18.00 (UK residents and BFPO)
 £24.00 (Mainland Europe including Republic of Ireland)
 £30.00 (Rest of the World)

Visit the website page to find out more:

<https://tinyurl.com/yu89nuzx>

THE MEA FACEBOOK COMMUNITY

We have a really busy and very friendly community Facebook page and encourage anyone who has a question about ME/CFS or living with this condition to contact us via Facebook messenger.

We will do our best to answer your question ourselves and signpost you to further information, but we can also post it to our Facebook page, anonymously if required.

This way others in our community can share their experiences which can help you to understand how they have found solutions or ways that might address these issues.

ME/CFS can be a very isolating illness to try and cope with, and sharing experiences can put you in touch with other people who will have encountered similar problems.

People with this condition are incredibly supportive and very generous in sharing their lived experiences – and you may find that in allowing your questions to be posted on our Facebook page, you can feel less alone.

<https://www.facebook.com/meassociation/>



CORNWALL COUNCIL

We have taken the information on this page from Cornwall Council so that you can read what the general process might be to obtain social care support. Find out who your local authority is and review the information you need to do to make an application:

You can visit the Government website and enter your postcode to discover the local authority responsible for your social care:

<https://tinyurl.com/cp33e69k>

NEEDS ASSESSMENT

A needs assessment is a chance for us to look at your social care needs and work with you to find out which services will best help you to maintain your wellbeing and independence. We will look at all your needs and create a support plan with you. There is no charge for a needs assessment.

Social care needs will be based on things you may need help with, such as:

- Making sure you eat well,
- Looking after yourself,
- Being able to move around your home,
- Being able to look after your home,
- Having contact with family and friends,
- Being able to access other community activities, such as work opportunities or education,
- Emotional wellbeing and mental health,
- Other caring responsibilities you may have,



- Supporting your family and friends to care for you.

You may be entitled to help with your needs assessment from an independent advocate.

WHAT HAPPENS?

Our assessor will visit you to talk about your needs and the services that can help you. You can have a carer, a family member or independent advocate with you at the visit. We'll send you a self-assessment form before our assessor visits. Your carer, family, friend, or advocate can help you complete the form if you wish.

On the form you should tell us about the things you can do and the things you need help with. You should also tell us about any help you get from your family and friends. We can offer them a carer's assessment to find how out much support and help they need to care for you.

If you can't complete the form before the visit, our assessor will go through it with you to make sure we have all the information we need to help you. If you agree, we may arrange a joint assessment with other agencies involved in your care, such as the health service.

WHO'S ELIGIBLE FOR HELP?

Your needs assessment will look at all your needs and check whether any of them meet the national eligibility criteria for adult social care. Our assessor will work with you to create a support plan for your eligible social care needs.

You will have eligible needs if you meet all of the following:

- You have care and support needs as a result of a physical or mental condition.

- Because of those needs, you can't achieve two or more of the outcomes specified in your needs assessment.

- As a result, there is a significant impact on your wellbeing.

Together we'll work out how much your independence and wellbeing is at risk if you don't have help.

NEXT STEPS

If you are eligible for care and support from us, we'll list all your needs in an assessment summary and agree a support plan with you. Your support plan will cover:

- What help you will get and who will provide it,
- When help will start,
- How often you will get help,
- Contact details of the team who make sure you get help,
- When reviews will take place to make sure we're still meeting your needs,
- Details of care needs that can't be met and why,
- What to do if you're unhappy with the service.

WILL I HAVE TO PAY FOR CARE?

You may have to pay something towards the support we provide. We'll work out a personal budget so you can organise and buy your own care and support. This gives you choice and control over the support you get. We'll also carry out a financial assessment to see how much you need to pay.

WHAT IF MY NEEDS CHANGE?

We aim to review your needs every year. You can also ask us for a care review if your needs change.



THE NICE CLINICAL GUIDELINE ME/CFS (2020/21)

The draft of the new NICE Guideline includes important information about the provision of disability aids and adaptations to people with ME/CFS.

The Guideline is a framework of recommendations to health and social care professionals in England, Wales, and Northern Ireland, but is also recognised in Scotland. You might find it helpful to discuss the following sections from the guideline with your GP - who can help with the provision of disability aids and initiate a social care needs assessment if required.

Publication of the Guideline is expected 18 August 2021. We will update this leaflet if any changes are made to the final version.

MAINTAINING INDEPENDENCE

If a person with ME/CFS needs support at home, conduct a social care assessment, record, and provide information and support on:

- activities of daily living,
- mobility, including transferring from bed to chair, access to and use of the toilet and washing facilities, use of stairs, and access to outside space,
- dexterity and poor balance, including avoiding falls,
- their home, including environmental controls to avoid glare from lights, loud noise, and temperature fluctuations,
- the feasibility of equipment and adaptations,
- access to technology, including online access,
- where to get financial support and advice, for example signposting to advice on money management and making personalised arrangements with banks or the Post Office to access personal finances, and how



to claim carers' and disability benefits and grants.

Give families and carers information on how to access training and resources about how to care for the person with ME/CFS.

AIDS AND ADAPTATIONS

Provide aids and adaptations identified in the person's management plan without delay, so that people can carry out activities of daily living and maintain their quality of life as much as possible.

Enable prompt assessment for funding for home adaptation. If the person is not eligible



for funding, continue to offer information and support in arranging home adaptations.

For people with moderate ME/CFS or severe or very severe ME/CFS, consider providing or recommending aids and adaptations (such as a wheelchair, blue badge or stairlift) that could help them maintain their independence and improve their quality of life, taking into account the risks and benefits. Include these in the person's management plan.

ACCESS TO CARE

The committee was aware that difficulties accessing care are intensified in people with severe or very severe ME/CFS, particularly when they need hospital care.

The evidence showed that, as a result of this, some people with severe or very severe ME/CFS have little contact with and support from health and social care services. To address this, the committee highlighted the flexibility and specific support needed by people with severe or very severe ME/CFS.

ME/CFS can affect a person's ability to carry out activities of daily living and maintain their independence and quality of life. The committee agreed that everyone with ME/CFS should be asked how their symptoms affect their independence and then a social care assessment carried out if needed.

The committee also made further recommendations based on their own knowledge and experience, including that:

- many families and carers do not know the most appropriate ways to support someone with ME/CFS and need advice on this
- people with ME/CFS often have difficulty getting the equipment they need to support their activities of daily living and maintain their quality of life.

■ From the draft NICE Guideline ME/CFS (Nov. 2020): <https://tinyurl.com/aatcs5t3>



COMMUNITY FEEDBACK

We asked the community about the disability aids they used and for energy-saving tips that help them live with ME/CFS. You might find their insights helpful.

I have a shower stool, grab rail for the toilet. Occupational health came out and gave me various pillow supports for the bed. The downstairs toilet is a godsend. I use crutches and am thinking of getting a scooter but have to process the fact that I need one!

I use a stick when walking and also have grab rails to help getting in and out of the bath and shower.

I have a bath-board and a head massager that helps with washing my hair. I also have a perching stool in the kitchen. I use a walking stick or crutches on worse days and a mobility scooter. An Alexa and smart bulbs for adjusting the lights without getting up. I also have a robot vacuum which is great as I couldn't get the normal vacuum around the house. I'm waiting on an OT assessment to see what else they recommend, but I think I probably need a grab bar and step in the bath as I'm struggling to get in and out.

A bed-frame to keep me in bed when I have disturbed periods of sleep and/or seizures, a special mattress for comfort, incontinence sheets and pants for sleep, supporting pillows, including one to keep legs separated, post-it note reminders of important things like medication times and doses, alarms to remind me of things I need to do or when to rest, jar openers, light-weight kettle which does one-cup, walking stick, wheelchair, comfortable lounge-wear, day-time bed downstairs, extra grabrails for the stairs, grabrails in the toilets, bath-board (vital), high seat (adjustable) with back to use in the kitchen when preparing meals, washing-up, etc. Frequent contact with family and friends to keep me sane. I would say wet-wipes are

one of the best aids as they mean I can do without a shower or traditional wash – get the ones from incontinence suppliers as they are bigger and do a much better job - and can be heated in a microwave. Also a good mouth-wash can mean I don't need to clean my teeth as often when I am feeling really ill.

Mobility scooter, neck collar, elbow and wrist supports, shower stool, perch stool, long handled grabber and dustpan/brush, padded cutlery, spine cushion for chairs, maternity cushion for bed, memory foam mattress with topper, three different tog quilts, fingerless gloves in bed.

A power chair made a huge difference to my life as it enabled me to leave my home. Indoors, grab rails along with a bath board or shower stool helped for washing as balance/fatigue is a problem. A perching stool for the kitchen was a good investment. A good O.T. can advise.

All the years when I kept needing to sit down when out, I had a stick that opened out into a seat. Used it everywhere. Mind you, I once sat down carelessly and went over backwards with my legs in the air!

Sun lounger/bed, not sold as an aid but means I can go into the garden or living room, both a few steps from my bed, in what was the dining room. Long grab stick to reach things at

bottom of bed or high up to save leaning forward.

A hospital bed. It makes things easier for eating and transferring if needs be. Better daytime posture with knees supported. Also makes it easier for husband to do personal care for me.

Mobility scooter when I was healthy enough to drive myself around in it. Now a wheelchair is essential. Bad orthostatic intolerance, so an extra little bed in the living room to use during the day. Shower stool and grab bars in the shower. Yoga mat to lie on in waiting rooms. Desks are the wrong height for my bed in the living room, so got a TV stand for my PC monitor, keyboard/mouse, and other stuff I'm using during the day.

Walk-in shower, perching stool, timer, easy-turn tin-opener in the kitchen. Tens machine, hand-knitted "gravity" blanket. Do black-out blinds count?

I use a flip stick. It's a walking stick that folds down into a bag and it has a handy seat to rest in in queues and when my legs and back and hips etc get tired.

Nap bed (aka sun bed to normal folks) that allows me to be as flat as possible whilst still having a raised head and dropped foot for OI and reflux and be in another room or the garden. Shower stool, power chair, wheely wagon with a seat for much shorter distances, walking sticks for ridiculously short distances, assortment of support cushions, bed cradle, bar stool with a back (so I don't fall off so easily) to sit on in the kitchen, sippy-lids and straws.

I've found using a wheelchair and having a blue badge so helpful. I've also just bought a mobility scooter.

A wheelchair is a must. Has been over the years. Hubby is also poorly now so can't push it. Bath aids. I couldn't do without the stair lift.



I use a rollator, mobility scooter and also walking stick and aides around the home. All have helped me preserve energy and on bad days enabled me to get around a little easier. I wish I hadn't been so stubborn and had started using them when physio advised.

Handles in the shower in case I get dizzy, a stool in the bathroom so I can sit when I get out, giant 'Alzheimer's' clocks help me keep track of the time, day of the week and the date, and a wheelchair for going out for long periods.

I have a cycling water bottle holder to attach to my wheelchair and a wheelchair waterproof zip up sleeping bag-style blanket for when it's cold, I have various jar, can and bottle openers, ice packs for my migraines, even one I can strap to my head if I need to be up with one, infrared heated blanket.

A bit embarrassing but a portable "urine bottle" for when I am bedbound which is most days and I haven't strength or mobility to get to bathroom. it's been the best thing I have bought, especially when I also have issues with bladder function and incontinence.

Wheelchair, mobility scooter, chair I use in the kitchen to sit while cooking, shower stool, noise cancelling headphones, flare noise reduction earplugs, round handled cutlery, shoe insoles, heated blanket, blue badge, free bus pass, radar key, sunflower lanyard, dosette (pill) box.

My son uses noise cancelling headphones and a weighted blanket and has lots of pillows (some to sit up in bed and one between his knees to sleep). He has heated hand-warmers which help his lack of circulation. He has a walking stick to aid him when he needs to. He uses polarised sunglasses outside. He has a carer who comes in to help him for two hours a week. A recliner chair is helpful, as are really warm, comfortable support slippers.



ME CONNECT
The Support and Information Service
for people affected by ME/CFS/PVFS
and Long Covid

3 WAYS TO GET IN TOUCH:
by phone, email
or social media private message





Freephone
0808 801 0484

For opening hours visit:
meassociation.org.uk/me-connect



HERE TO LISTEN
We are here to listen, validate and empathise with any issues you might be facing.



VITAL SUPPORT
We are here to help you reach an informed decision.



SAFE ENVIRONMENT
We provide a safe, confidential and understanding environment where you can be heard and understood.

We're here for you!



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ME Essential

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Extract from the new NICE clinical guideline draft:
"Do not offer people with ME/CFS any therapy based on physical activity or exercise as a treatment or cure for ME/CFS - by Russell Fleming"



THE NEW NICE DRAFT GUIDELINE
The new NICE guideline is welcomed with cautious optimism, Russell Fleming reports.

COVID VACCINES
Priorities, safety and making a decision - all in the enclosed leaflet written by Dr Charles Shepherd.

ME AWARENESS WEEK
The most important week in the ME calendar takes place from 10th to 16th May.

OUR CHRISTMAS APPEAL
Your support helped us to raise over £25,000!

INTIMACY AND M.E.
A sensitive discussion regarding the difficulties in coping with intimacy when you have ME/CFS.




The ME Association website shop:

The ME Association has the largest selection of free ME/CFS information leaflets in the UK on:

- Medical Management**
- Mental Health**
- ME Connect**
- Diet & Nutrition**
- General Information**
- Fundraising Leaflets**
- Benefits & Social Care**
- 'To Whom It May Concern' letters**

<https://meassociation.org.uk/fdwc>



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