



Caring

for somebody with M.E.



Transforming the world of M.E.



Introduction

This information is intended to give advice and guidance to anyone who has become a carer of someone with M.E.

It does not constitute or replace medical advice and should not be treated as such.

Around six million people in the UK are carers and it is estimated that over two million people become carers every year. A carer can be a partner, relative or friend of any age, who looks after someone unable to look after themselves on an unpaid basis.

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Understanding M.E.

What is M.E.?

M.E. (Myalgic Encephalomyelitis) is a chronic, fluctuating illness. It is also known as Chronic Fatigue Syndrome (CFS) and is sometimes diagnosed as Post Viral Fatigue Syndrome (PVFS).

It is estimated that there are up to 250,000 people with M.E. in the UK. It can affect men, women and children of all ages and from all social and ethnic groups. Anyone can get M.E.

How is M.E. diagnosed?

There is no medical test available to confirm a diagnosis of M.E. but doctors can identify the illness by taking a careful medical history and conducting tests to rule out other possible conditions.

The National Institute for Health and Clinical Excellence (NICE) has produced guidelines on M.E. for health practitioners. Visit www.nice.org.uk or tel: 0845 003 7783 to order a copy.

In Scotland, NHS Scotland has produced a Good Practice Statement for healthcare professionals, Quick Reference Guide for GPs and leaflet for patients, facilitated by Action for M.E. These documents are available on the NHS Scotland website, www.show.scot.nhs.uk and via links on our website, www.actionforme.org.uk. Or call us on 0845 123 2380.

What are the symptoms?

M.E. is a complex illness that affects people in different ways. It is common for symptoms to change and fluctuate during the course of the illness and it is important to remember that everyone experiences an individual mix of symptoms.

These may include persistent, debilitating fatigue, muscle and joint pain, flu-like symptoms, concentration and memory problems, sleep difficulties, digestive disturbances and increased sensitivity to light and sound.

Telling others about M.E.

One of the hardest things people with M.E. and their carers have to deal with is disbelief about the seriousness of M.E. Thankfully, now that the illness has been officially recognised, more people are better informed than they were 10 years ago, but it is still not uncommon to experience a lack of understanding and support when explaining that the person you care for has M.E.

"Sometimes we both feel that as we have a diagnosis of M.E. and there is no cure, we are required to sit in a dark room and put up with it." Duncan*, by email

"The truth is, many new carers will have to fight some hard battles with people who they would expect to support them – caring and health professionals – and if my experience is anything to go by, may not be successful." Sue, Cardiff

"My wife (who has M.E.) and I found that our fears that it could be something 'worse' caused angst that was removed by liaising with our doctor to eliminate other illnesses. This has also provided some interesting insights into factors affecting possible symptoms that we have been able to 'treat' and adjust our lifestyle to minimise." Duncan*, by email

Action for M.E. provides information about health services and M.E. in its booklet, *All about M.E.*

**Get advice from other carers through our forum
at www.actionforme.org.uk**



Family members, friends, employers, teachers, welfare benefits advisers, even some doctors do not always recognise the seriousness of M.E.

Try to remain confident and patient when you explain the condition to others. Many people don't know anything about the illness and this is often where assumptions come from. Remember not to doubt yourself or the person you care for just because other people are ill-informed about the condition. The better your own understanding of M.E., the more you will be able to dispel the misconceptions you may find in other people.

Further information

For more detailed descriptions of the condition and ways of coping with symptoms, see our booklets *All about M.E.*, *Pacing for people with M.E.* and if appropriate, *Your child and M.E.*

They may be downloaded from our website www.actionforme.org.uk or ordered by calling us on 0845 123 2380 (Mon-Fri, 9am-5pm).

"It would be useful to know as much as you can about M.E. as many people ask for explanations and clarification on the symptoms and the person with M.E. may not have the energy to explain." Marion*, by email

*Names have been changed throughout



Becoming a carer: what it could mean for you

Taking on a new role

"I found it very hard to adjust from having a child who was growing in independence, to a child who was once more completely dependent on me."
Jean*, Somerset

You may have found yourself in a caring role suddenly, or perhaps it has gradually increased over the years.

Either way your role and that of the person you are caring for has changed. In order to cope with these changes, your relationship will need to adjust. This can be very difficult at first as both of you struggle to reassign yourselves, facing many challenges along the way.

Both of you need to work together in order to make the most of your new situation and move towards a better quality of life. This means accepting the illness and its restrictions.

"It is important to emphasise that a caring/cared for relationship is a partnership. Good communications are vital. Both people in the relationship should be able to talk freely about what they find difficult, without allocating blame." Frankie*, Oxford



Your feelings

"I remember bewilderment, anger, resentment, helplessness and isolation, all stemming from love, concern and confusion about the condition. I shared the constant search for new remedies and the usually unspoken question – why me?" Roderick, London*

Becoming a carer can evoke many emotions in you that are difficult to accept. It is not unusual to feel a sense of loss for your past life or bitterness towards your new situation. These are perfectly natural feelings that you do not have to feel guilty about. You may not be the person with M.E., but you can still feel just as trapped, lonely and frustrated.

Acknowledging your feelings and discussing them is a vital step in the caring process and can be very helpful in developing and maintaining your new relationship.

You may find it helpful to talk through these emotions with someone. Our telephone support line provides the opportunity to discuss any problems or stresses you may be experiencing (see p 22 for details).

"I found this a very difficult journey myself. We all have to find our own way." Duncan*

Family

"My ill child was missing out on time with her friends, whilst my healthy child was missing out on time with her mum. I felt torn." Caroline, Sussex*

Your change in roles will affect your whole family, particularly if you are living with other relatives. When someone is unwell, inevitably the rest of the family will take a bit more of a backseat. This can often fuel feelings of guilt.

Try to involve your family right from the start. Explain the situation to them; tell them about the condition and how, for the time being, you will need to spend more time with the person who has M.E. If you can try to include them in caring, you will be spending time together, whilst also sharing the responsibility.

"I found it really helpful to arrange times when someone could look after my son so I could spend time alone with my daughter and concentrate on her." Debbie, Cardiff*

Work

If you are working as well as caring, you will effectively be juggling two jobs and this can be very stressful and demanding.

It will be worthwhile finding out if your workplace has a policy to support carers. Handing your employer some literature about M.E. may also be beneficial in helping him/her to understand the condition and the constraints you are under.

You may be thinking about leaving work altogether in order to care full time. This is a decision that needs to be thought through carefully as giving up work will mean a drop in your income and in the time you will have away from caring.

"A drop in income can cause untold stress for the carer (and the person with M.E.), as they may have the added pressure of struggling to pay a mortgage and bills." Kay*, by email

Think about other options available to you before leaving, such as the possibility of reducing your hours or finding a new job that is closer to home so you are able to get back if needs be.

If you do decide that leaving work is the right option for you, research the types of welfare benefits that you and the person with M.E. may be eligible for. Read our introduction to benefits on p 13 and contact Carers UK for a full list of potential benefits for carers (see p 18).

"Working part time can be stressful, but I do feel it has been good for my well-being to have a few hours a day where I am not being a full-time carer." Geoff*, York



Looking after yourself

The simple truth is that in order to look after someone well, you need to look after yourself. Your needs are just as important as theirs.

You may have found that your quality of life has suffered due to your new role and it can be all too easy to fall into a pattern where your needs are set aside on behalf of the person you care for.

“I think it is really important that we try not to let the illness overshadow everything or make our lives utterly dominated by it.” Mary*, Yorkshire

It is in fact a lot easier to cope with the pressures of caring if you are also caring for yourself. By maintaining both your emotional and physical health, you will be able to care to the best of your ability.

Consider letting your GP know you are a carer as they can often be a valuable source of information about medical and community services and support.

Accepting help

Coping with dependence is a huge responsibility and it can be difficult to overcome feelings of duty towards the person you care for. However, an essential part of self-care is to get support from others and this is especially important when you are living in a situation that is emotionally and physically demanding.

Accept help from your friends and family when it is offered to you. If you say you are managing, they may not think to ask you again, which could result in you missing out on an invaluable source of support.



Sources of support

Your GP or local authority Social Services department should have information about the help available to you in your area. Your local M.E. support group or carers' centre may know of other carers near you, with whom you can talk and exchange ideas. Search our online services directory for details at www.actionforme.org.uk or contact our office on 0845 123 2380.

"She became extremely dependant on me and found it hard to cope with periods of separation. This meant I did not feel able to make full use of the help offered." Anne*, Midlands

"I needed support but I didn't have the emotional energy to ask for or organise it." Phillida*, London

"A person with M.E. can become too dependent on a carer and this can have a depressing effect (at least my wife and I found this happened). It's important to talk about how M.E. affects both of you."

"Involving the person with M.E. in both their care and also the care of the carer provided my wife and I with an invaluable partnership. Yes, I am her carer – but actually we're in this together."

"Looking after yourself as a carer also gives the person with M.E. an opportunity to care for you." Duncan*

Taking a break

It is vital to take breaks away from the person you are caring for. Having regular time to relax and to do something that is just for you is crucial in recharging your batteries and maintaining your own life outside of caring.

"Very important, I learned the hard way." Richard*, by email

If you are concerned that the person you care for will feel uneasy having someone else around them, try to think of different ways that would take the pressure off you. For example, even something as straightforward as a friend preparing dinner could give you half an hour to spend on yourself.

"Getting into a regular routine of some time apart was a positive thing for both parties, although it did not always seem so at the start."* Kay

“For us it is imperative that the person I care for and I spend some time apart.” Kay*

*“I’ve found that both of us, together, having time away from the burden of her illness provides me with the most benefit. Time at a hotel with room service and no household chores, with all facilities close at hand, provides a time for us without M.E. impinging too much.” Duncan**

You may want to consider hiring home-help or taking a short break, either with or without the person you are caring for.

Our *Holiday and respite care* fact sheet provides details of places that our members have considered to be ‘M.E.-friendly.’

The Margaret Champney Rest and Holiday Fund gives small grants to carers, usually to give them a complete break whilst the person they care for is receiving respite care. All applications must be through a social worker, community nurse or similar professional agency. For information, write to: The Gate House, 9 Burkitt Road, Woodbridge, Suffolk IP12 4JJ. Tel or fax: 01394 388746. Email: ogilviecharities@btconnect.com

Community care for both of you

The person you care for may be entitled to a community care assessment from Social Services. This would look at the services that may be available to them and assess their eligibility. Some of the help that may be available could include aids or adaptations, help with personal care, day-to-day living or help with meals. Social Services should also look at your ability to provide care to the person having the assessment.

If you are caring for someone you can also request an assessment in your own right. This is to assess your own support needs as a carer and your continuing ability to provide care. Following an assessment the person that you care for may be able to get some extra help through Social Services and you may be able to get a break from caring.

If the person you care for is assessed as needing services, they may be able to get direct payments. This means they are paid a sum of money that they can use to buy in their own care. In some cases they may be able to employ their existing carer but direct payments cannot usually be used to employ a spouse, partner or close relative who lives in the same household (if you are in this position seek advice as there can be exceptions to this).

As a carer you may also qualify for direct payments in your own right (only in England and Wales). These are designed to give flexibility and can be used to help you sustain your caring role.

Contact your local authority Social Services department to request an assessment. You could also ask your GP to make a referral.

Adam cares for Kate who has M.E. He helped Kate apply for a community care assessment. Social Services arranged homecare to come and help Kate twice a week.

Adam now gets monthly respite care. This is a welcome break when he can go to a carers support group and share how he is feeling with other carers.



Welfare benefits that may be available to carers

What are you entitled to?

"Nobody tells you what is available, you have to find out for yourself." Roger*, by email

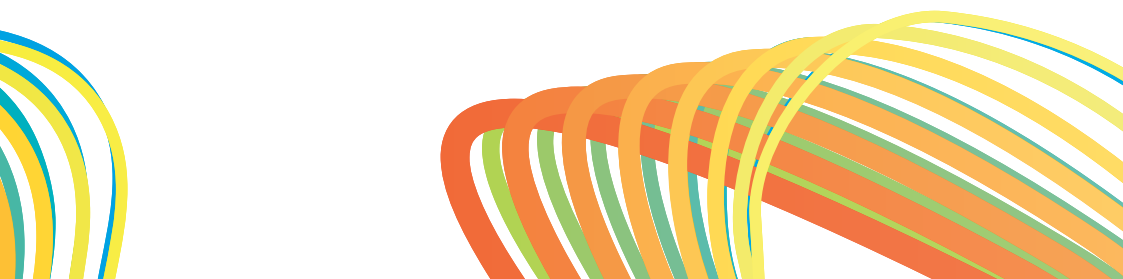
Benefit rules are very complex and subject to change so please use the following as a general guide and seek advice about anything you are unsure of.

If you are considering giving up work to become a full-time carer it is essential to seek advice about the benefits that you would be entitled to.

Carer's Allowance

This is the main state benefit available to carers. To qualify:

- you need to be caring for someone for at least 35 hours per week
- the person you care for needs to be getting the middle or high rate care component of Disability Living Allowance, Attendance Allowance or Constant Attendance Allowance
- you need to be 16 or over
- you need to be eligible to claim UK benefits and meet certain other residence criteria
- you cannot be in full-time education
- you can be employed but you are only allowed to earn a certain amount – this increases each year.



Claiming Carer's Allowance can affect the benefits of the person you care for. If they get the severe disability premium or addition, seek advice before claiming.

If you are already getting certain benefits you will not actually be paid Carer's Allowance but it can still be worth claiming as you may be able to get the carer premium or addition. This is an extra amount of money paid on top of certain means-tested benefits.

To obtain a claim form, ring the free benefit enquiry line 0800 882200.

NB. This booklet does not cover all the benefits affected by Carer's Allowance. Contact a carers organisation (p 18) or benefits advice agency (p 20) for more details.

Other benefits

In addition to Carer's Allowance you and the person you care for may also be eligible for other benefits such as Income Support, Employment and Support Allowance, Job Seekers Allowance, Pension Credit, Housing Benefit, Council Tax Benefit and Disability Living Allowance (this list is not exhaustive).

If you have dependent children you may be able to get Child Tax Credit. If you have a mortgage you may be able to get help with this through Income Support or income related Employment and Support Allowance.

Each person's circumstances are different and so other benefits may be available to you that are not listed above.

Eligibility for benefits also depends on your family circumstances, any savings you have and in some cases your National Insurance record as well as your status in the UK.

Action for M.E. Supporting Members can call our Welfare Rights helpline on 0845 122 8684.

Health costs

If you are on certain benefits you and the person you care for will be entitled to free prescriptions, dental care, sight tests etc.

If you are on a low income you may also qualify for some help with health costs.

For further information contact the NHS Low Income Scheme 0845 850 1166.

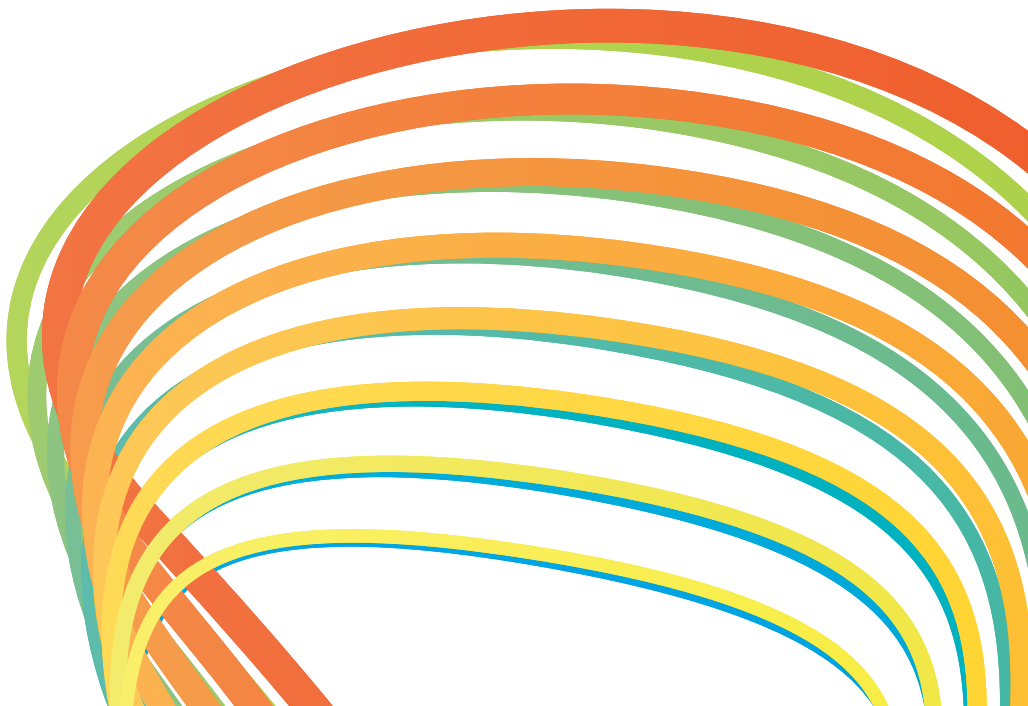
Further information

Action for M.E. produces information sheets on the following benefits:

- *A guide to benefits*
- *Disability Living Allowance*
- *Incapacity Benefit*
- *Employment and Support Allowance*

These and other publications can be found at www.actionforme.org.uk.

See p 20 for details of our Welfare Rights line and other organisations which offer advice.



Pointers and tips from other carers

- Look after your own health by taking breaks from caring, eating well and exercising.
- Research what services and support are available to you in your area – check out our searchable directory online at www.actionforme.org.uk or call 0845 123 2380 (Mon-Fri, 9am-5pm).
- Gain as much knowledge as you can about the condition by reading about M.E. and talking to other people who have experience of the illness. There is information and peer support available through our website. You may wish to consider joining your local support group – or our online community at www.actionforme.org.uk. And remember, there is always our telephone support line (see p 22).
- Research the available treatments that are out there for people with M.E. and think about what may be most suitable for the person you care for.
- *“Don’t be defined by the illness. Adapt to it, don’t be limited by it.”* Hazel*, by email
- You may like to keep a diary of times when there’s any sign of improvement in the person you care for (however small). This can be a helpful way of looking back on what has been achieved during harder times.

“Often our steps towards recovery were so small, it wouldn’t be until I’d look back that I would realise she was now able to walk for quite a bit longer than six months ago.” Nigel*, Surrey

“A ‘happy diary’ ensures you don’t lose sight of the good things however little.” Paul*, by email

“It is extremely important to stay positive, even in the darkest periods.”
Roger*

“Optimism about the possibilities for recovery helps us all to cope.” Mary*

- Trust the person with M.E. to be the expert on their own condition. Respect their opinions and try not to interpret their behaviour by guessing what they’re thinking.

“A carer may feel they must ‘cure’ their partner or they have failed. A carer needs to learn to accept the illness and respect the views of the person with M.E. without feeling they have no say.” Duncan, by email*

- Actively listen to the person you care for – and keep talking to them. By sharing your concerns and worries, your relationship will grow stronger.
- If the person you care for is your partner, *“Try to maintain some sort of physical relationship with your partner. Even a gentle cuddle or kiss shows them you love them regardless of current difficulties.” Kay*, by email*
- Focus on the present and any small achievement made by you and the person you care for.
- Include your family as much as possible and think of ‘M.E.-friendly’ activities for all of you to do together such as listening to music, if that is possible, or just talking (even if the person with M.E. is unable to talk, feeling involved in their family can be enjoyable, as long as you don’t tire them out).

“Join Facebook and be a part of Action for M.E.’s page. Both carers and people with M.E. can gain support, advice and friendship from others in the same situation. This may be something you could do together.” Kay, by email*

- Ask for and accept help from others.

Useful contacts

Carers organisations

Carers UK

Information and support on any issue for people caring for friends and relatives. Extensive details of the benefits available to carers and the people they are caring for.

CarersLine: 0808 808 7777
(Wed & Thurs 10am-12pm, 2-4pm)

England tel: 020 7378 4999
N. Ireland tel: 028 9043 9843
Scotland tel: 0141 445 3070
Wales tel: 029 2081 1370

Email: info@carersuk.org
www.carersuk.org

The Princess Royal Trust for Carers

Offers useful information and support for all unpaid carers throughout the UK.

Unit 14 Bourne Court, Southend Road, Woodford Green, Essex IB8 8HD

England tel: 0844 800 4361
Scotland tel: 0141 221 5066
Wales tel: 02920 221788

Fax: 0844 800 4362
Email: help@carers.org
www.carers.org

Crossroads Association

Provides practical support in the home.

10 Regent Place, Rugby CV21 2PN

Tel: 0845 4500350 Fax: 01788 565498
Email: communications@crossroads.org.uk
www.crossroads.org.uk

Community Service Volunteers

Recruits and trains volunteers to help individuals in need of support.

237 Pentonville Road, London N1 9NJ

Tel: 020 72786601

Email: information@csv.org.uk

www.csv.org.uk

The Margaret Champney Rest and Holiday Fund

Organisation that gives small grants to carers.

The Gate House, 9 Burkitt Road, Woodbridge, Suffolk IP12 4JJ

Tel: 01394 388746

Email: ogilviecharities@btinternet.com

www.theogilvietrust.org.uk

Online forums for carers

Action for M.E.

www.actionforme.org.uk

CFS care group

An email support group for those caring for people with M.E. at

<http://health.groups.yahoo.com/group/cfs-care/>

or e-mail: cfs-careowner@yahoogroups.com

www.cfscare.com

Carers discussion group email: richardsenior@onetel.net.uk

Government information

Caring for someone

Government site for carers including advice on support services, employment, money, work and health.

www.direct.gov.uk/en/CaringForSomeone

NHS 'Looking After Me' course (England)

A free course for adults who care for someone living with a long-term health condition, run by tutors who are themselves carers.

www.expertpatients.co.uk/course-participants/courses/looking-after-me

Advice on welfare benefits

Action for M.E. welfare rights helpline

Members only service providing information on accessing benefits, the Disability Discrimination Act, employment and insurance issues.

Tel: 0845 122 8648 (Mon 1-5pm. Tues 9.30am-12pm, 3.15-6.45pm.
Weds 1.30-4.30pm. Thurs 9.30am-1pm)

Carers UK (see p 18)

Citizens Advice Bureau

See your local telephone directory or go to www.adviceguide.org.uk for details.

Department for Work and Pensions benefit enquiry line

Tel: 0800 882200

Community Legal Advice

Tel: 0845 345 4 345 www.communitylegaladvice.org.uk

Tax Credit Office

Tel: 0845 3003900

Support for parents

Contact a family

Support and information to parents of children with any disability or long-term health condition, including rare disorders.

209-211 City Road, London EC1V 1JN

Helpline: 0808 808 3555 (Mon-Fri 10am-4pm, Mon 5.30-7.30pm)

Email: info@cafamily.org.uk

www.cafamily.org.uk

Parentline Plus

Provides a helpline for anyone parenting a child or young person in need of support.

520 Highgate Studios, 53-79 Highgate Road, London NW5 1TL

Helpline: 0808 800 2222 (24hr)

www.parentlineplus.org.uk

Support for young carers

Young Carers

Part of The Princess Royal Trust for Carers. Information and support for young carers, including discussion boards.

Unit 14 Bourne Court, Southend Road, Woodford Road, Essex IG8 8HD

England tel: 0844 800 4361

Scotland tel: 0141 221 5066

Wales tel: 02920 221 788

Email: youngcarers@carers.org

www.youngcarers.net

Support for older people

Age UK

Age Concern and Help the Aged join forces in 2010 to form Age UK, including Age Scotland, Age Cymru and Age NI.

England tel: 0800 169 6565

Northern Ireland tel: 0808 808 7575

Scotland tel: 0845 125 9732

Wales tel: 0800 169 6565

www.ageuk.org.uk

Anchor Trust

Not-for-profit organisation dedicated to helping older people live safely, securely and independently.

2nd Floor, 25 Bedford Street, London WC2E 9ES

Tel: 0845 140 2020

www.anchortrust.org.uk

Counsel and Care

Advice and information for older people, their relatives and their carers.

Twyman House, 16 Bonny Street, London NW1 9PG

Advice line: 0845 300 7585 (Mon-Fri 10am-4pm, except Weds 10am-1pm)

Email: advice@counselandcare.org.uk

www.counselandcare.org.uk

Action for M.E. helplines

Telephone support

Trained staff and volunteers who offer support, understanding and information to people affected by M.E.

Tel: 0845 123 2314 (please call for opening times)

Welfare rights

Members only service providing information on accessing benefits, the Disability Discrimination Act, employment and insurance issues.

Tel: 0845 122 8648 (Mon 1-5pm. Tues 9.30am-12pm, 3.15-6.45pm.

Weds 1.30-4.30pm. Thurs 9.30am-1pm)

Administration & membership

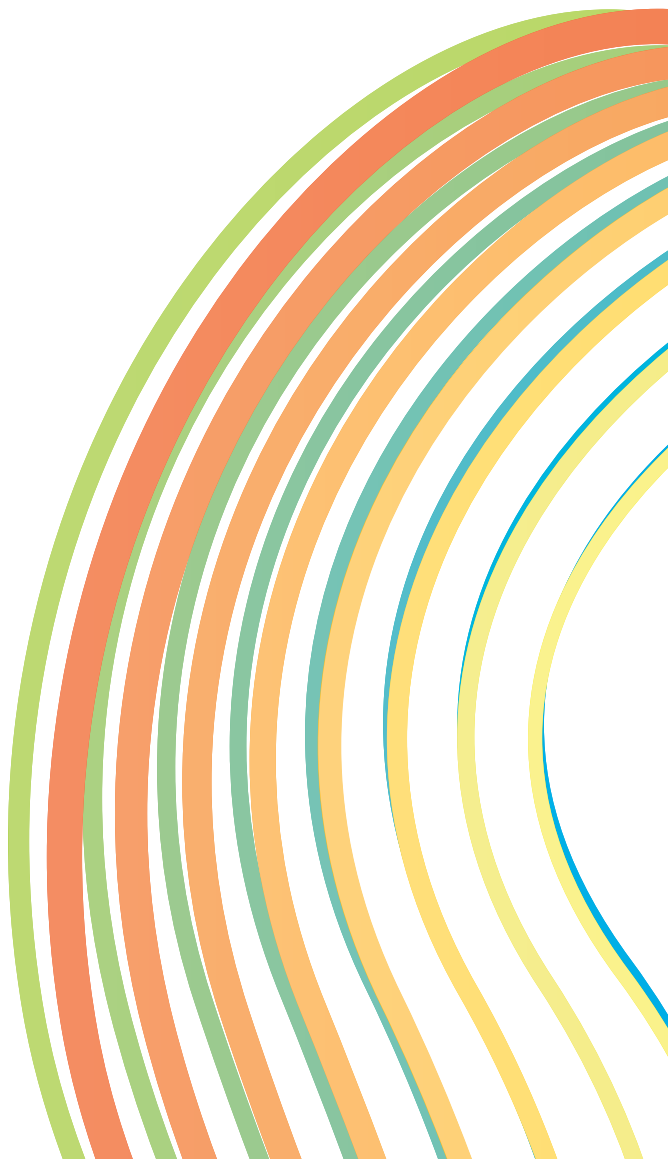
For all membership enquires, publication orders and information on local support groups.

Tel: 0845 123 2380 (Mon-Fri: 9am-5pm)

Acknowledgements

This booklet was written by Leigh Fenton with advice and support from a number of carers of people with M.E.

Action for M.E. is very grateful to everyone who contributed their advice and experience. Thank you.



"I found it really helpful to arrange times when someone could look after my son so I could spend time alone with my daughter and concentrate on her." Debbie*, Cardiff

"Yes, I am my wife's carer – but actually we're in this together." Duncan*



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for as little as £1.25 a month**

