



Your legacy of hope for people with M.E.



Transforming the world of M.E.



Foreword

Myalgic Encephalomyelitis (M.E.) is a chronic fluctuating illness. It is commonly also known as Chronic Fatigue Syndrome (CFS or CFS/M.E.). Sometimes it is diagnosed as Post Viral Fatigue Syndrome (PVFS).

Symptoms vary but may include persistent exhaustion ('fatigue'), muscle and/or joint pain, sleep disturbance, 'flu-like symptoms such as headache, sore throat, painful lymph nodes, dizziness and/or nausea and problems with memory and concentration.

It is thought that around 250,000 people in the UK have the illness. Men, women and children of all ages and backgrounds can develop M.E. but it is most common in women aged 25-50.

The youngest child diagnosed was only two years old when they first became ill.

There is as yet no cure.

By remembering Action for M.E. in your will you will be helping us to support people with M.E. now while working to overcome M.E. in the future.

**"I can't imagine how I would have managed without Action for M.E. They have been an invaluable source of information and support – a lifeline."
Stella Burridge**

Contents

| | |
|-------------------------------------|-----------|
| Why make a will? | 4 |
| Your gift in action | 4 |
| De-mystifying the process | 6 |
| Three ways to leave a gift | 6 |
| <hr/> | |
| Basic guide to making a will | 7 |
| Estimate the value of your estate | 7 |
| Think about inheritance tax | 7 |
| Decide whom you want to benefit | 8 |
| Find a solicitor | 8 |
| Use the right words | 8 |
| Appoint your Executors | 9 |
| Get your will signed and witnessed | 9 |
| Keep it safe and up-to-date | 10 |
| <hr/> | |
| Your questions answered | 11 |

“As a charity, we depend on the gifts left to us by generous supporters in their wills. It would help and encourage us immensely to know that, many years into the future, we will have your gift to help us continue our work.”
 Clare Francis MBE, President

Why make a will?

Making a will is important. It is your gift to the people and causes that are important to you. It is a way to ensure your wishes are followed after you have died.

If you don't make a will the law decides who inherits your property. It is vital to make one if you want to take care of your loved ones and remember the causes that you feel strongly about.

Why give to us?

At Action for M.E., our vision is simple: we want to overcome M.E. – whether through prevention, more effective treatments or ultimately, by finding a cure for this little-understood illness.

One way you can help us achieve this dream is by leaving a gift to Action for M.E. in your will – however large or small.

Gifts in wills help us to fund biomedical research, like the UK's first biobank for M.E., so crucial to understanding the biology of the illness.

They also help us to provide the information and support services that are needed and valued by people with M.E., their families and carers.

Because charitable legacies are free from inheritance tax, it means that if you choose to give to us, every penny you give, we receive.

Your gift in action

- £100 could help provide 20 vital information packs for people newly diagnosed with M.E.
- £1,000 could allow us to maintain our telephone helplines
- £10,000 could help fund new biomedical research projects.



I want to make a difference

Action for M.E. member Pamela Weston was a clarinet soloist. When she died aged 87, thanks to a generous legacy in her will, Miss Weston enabled us to continue our work, not least our campaigning for more research into M.E.

"I've had a wonderful, happy life and been very successful and I've been able to give something back," Miss Weston told us in a letter. "That's what's important."

More recently, Gill Jackson has also decided to leave a gift to Action for M.E. in her will.

"I want my possessions disposed of or inherited by people I choose and not the government," she explains. "By telling people what I want, it stops any confusion or even disagreements at a time when people may be emotionally affected by my death.

"Action for M.E. has done wonderful work and has made enormous strides at national government level as well as being at the forefront of dispelling the myth that we are all malingerers or 'yuppies' with flu.

"The work of Action for M.E. needs to go on, not only to improve people's lives but to find a cure, which I know will happen.

"I want my donation to go towards anything that helps. I would encourage others to leave a gift to Action for M.E. in their will. Even the smallest amount can make a difference to the work being done."

"Action for M.E. helped me realise that I am not alone, and has given me hope of a cure one day."

Gillian Waters

"M.E. is a very lonely illness and it helped to know that there were thousands of others going through the same thing. I could speak to people from Action for M.E. and knew they believed me and understood what I was going through."

Stacy Hart

De-mystifying the process

Our basic guide to making a will is on p7 but before we start, let's de-mystify some of the technical jargon.

A legacy or bequest is a gift left in a will. A beneficiary is a person or organisation who will benefit.

Executors are the people or organisations you appoint to handle your affairs according to your will.

Your estate is everything you own (minus anything you owe) at time of death. If someone dies without making a will they are said to have died 'intestate.'

Three ways to leave a gift

When deciding what to leave to whom, it is worth knowing that you can leave a gift in three ways – you can leave a share of your estate (known as a residuary bequest), a fixed sum of money (pecuniary bequest) or a specific item of value.

Leaving a share of your estate

After you have taken care of your family and friends, this is a good way to leave a gift to Action for M.E. This is called a residuary bequest – ie., what is left when all other gifts have been paid. This has a number of advantages. It is easy to include in a new will, or to add to an existing will, without needing to alter any specific sums that you have left to loved ones.

Leaving a fixed sum of money

You may wish to leave Action for M.E. a stated sum of money. This is called a pecuniary bequest. Since the value of money changes over the years, you may need to alter your will periodically to keep up with inflation.

Leaving a specific item of value

You may wish Action for M.E. to have a specific item after your death, which may be sold to help people with M.E. This might be property such as a house, shares, an antique or jewellery.



Basic guide to making a will

When it comes to planning your will, it's really important that you spend time thinking through the different aspects involved. You should think about who you would like to remember in your will, any directions for your funeral (such as donations to charity in lieu of flowers) and who you would like to care for your children or pets if you have any.

Making a will involves:

- estimating the value of your estate
- thinking about inheritance tax
- deciding whom you want to benefit
- finding a solicitor
- using the right words
- appointing your executors
- getting your will signed and witnessed
- keeping your will safe and up to date.

Estimate the value of your estate

Often people have more to leave than they think. Start by making a list of all your assets – house, car, personal possessions, savings, shares and insurance policies – and then deduct what you owe (mortgages, loans or credit card debts).

Think about inheritance tax

Are your possessions worth more than the inheritance tax threshold? If so, your estate may be liable to inheritance tax. This is 40% – unless you leave at least 10% of your estate to charity in which case (from April 2012) it will be at a reduced rate of 36%.

Further information may be found on HM Revenue & Customs website www.hmrc.gov.uk.

Decide whom you want to benefit

List all the people – family, friends or carers – you would like to leave something to. You may also have pets for which you wish to make provision.

After you have provided for those closest to you, you could consider leaving a donation to a cause or causes close to your heart. You could leave a residuary gift (a % of your estate), a pecuniary gift (a specific sum) or a specific item, for instance jewellery. Leaving a gift in your will to a charity reduces the inheritance tax burden for relatives and the gift is completely tax free.

Whatever you can provide helps the causes you care about to continue their charitable activities. You can give as little as £1 or 1% or as much as you are able. And every little counts – we care about every penny.

Find a solicitor

Using a solicitor ensures your will is valid and avoids any potential legal complications in the future.

A simple will shouldn't cost more than £100. You can ask friends or family to **recommend a solicitor**.

Use the right words

If you decide to leave a gift to Action for M.E., it is important that the correct wording is used in your will.

If you would like to leave a percentage of your estate:

"I give to Action for M.E., charity registered in England no 1036419, in Scotland no SC040452, of **42 Temple Street, Keynsham BS31 1EH** the residue (or ____% share of the residue) of my estate absolutely and I direct that 1) the proceeds may be used for the general purposes of Action for M.E. and 2) a receipt signed by a person for the time being authorised by the Board of Action for M.E. shall be good and sufficient discharge to my executors."

Or if you would like to give a fixed sum:

"I give to Action for M.E., charity registered in England no 1036419, in Scotland no SC040452, of **42 Temple Street, Keynsham BS31 1EH** the sum of £____ and I direct that 1) the proceeds may be used for the general purposes of Action for M.E. and 2) a receipt signed by a person for the time being authorised by the Board of Action for M.E. shall be good and sufficient discharge to my executors."

If you would like to leave a valuable item:

"I give to Action for M.E., charity registered in England no 1036419, in Scotland no SC040452, of **42 Temple Street, Keynsham BS31 1EH**

the following valuable item _____ and I direct that 1) the proceeds may be used for the general purposes of Action for M.E. and 2) a receipt signed by a person for the time being authorised by the Board of Action for M.E. shall be good and sufficient discharge to my executors."

Appoint your Executors

You can appoint up to four executors to carry out your wishes, including family members, friends and/or a professional person.

Get your will signed and witnessed

When your will is drawn up or changed, it will need to be signed by you in the presence of two witnesses. These cannot be people who will benefit from your will, or their spouses.



Keep your will safe and up to date

Your solicitor or bank will usually keep your will for you, although they may charge a small fee. Make sure your executors know where to find it.

But don't write a will then forget about it. Life changes. You may marry, get divorced, have children, or your preferences for giving may just change. If you don't keep your will up-to-date, it may not reflect your wishes at the time of your death. It's important to review your will regularly to ensure new circumstances are taken into account.

If you only need to make minor changes, making an amendment (called a codicil) is relatively inexpensive and very easy to do. If you would like to leave a gift to Action for M.E. you can leave any percentage of your estate from 1% all the way up to 100%. Every penny counts.

Please let us know

We would really appreciate it if you could inform us of any gift you choose to leave us. We understand that circumstances may change and we genuinely hope that we will not receive this kind of gift for many years. However, by letting us know, we can thank you for your very important contribution.

Call our **Director of Fundraising** on **0117 927 9551** if you would like more information on how your gift may be used or if you would like to discuss leaving a gift to Action for M.E. in more detail.

“Over the 17 years I have suffered with M.E., Action for M.E. has been a great source of strength, support and continues to be an invaluable contact. Just knowing you're all there fighting our battles and accomplishing major milestones on our behalf, with your outstanding victory in achieving recognition for this illness, has made a massive difference to my life.”

Louise Poulton



Your questions answered

Q Why should I use a solicitor to write my will?

A Using a solicitor is by far the best way to make sure your wishes are followed. The costs are minimal and it will give you peace of mind that your will is legally binding. See p 8.

Q Do I have to name an actual charity, or can I just leave money 'to help people with M.E.' or 'for medical research'?

A It's best to be specific – that's the only way to be sure your wishes are completely clear. If you would like to confirm any of our charity's details, please contact our Director of Fundraising on 0117 927 9551 or via email, simon@actionforme.org.uk

Q Do I need to tell Action for M.E. that I've included them in my will?

A It is not essential but we would be delighted if you chose to. Simply phone or write to our Director of Fundraising Any information that you give will be treated in strictest confidence.

Q What will it cost me?

A It doesn't need to cost anything extra if you are already revising your will. When your solicitor is next updating your will simply ask them to include a donation to your favourite cause. A new will on average costs £100.

Q Do I have to leave a lot?

A It's up to you. Every penny counts and we would be very grateful for any amount you are able to afford. Your donation will make a real difference to our work.

Q I want to include Action for M.E. in my will – what should I do next?

A Simply tell your solicitor you want to include Action for M.E. in your will and what you want to leave. They will do what is necessary.

On behalf of Action for M.E. – thank you very much.

"As a charity, we depend on the gifts left to us by generous supporters in their wills. It would help and encourage us immensely to know that, many years into the future, we will have your gift to help us continue our work."
Clare Francis MBE, President



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Registered charity

Registered charity in England and Wales no. 1036419

Registered in Scotland no. SC040452

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for as little as £2 a month**

