



ME Newsletter

www.bayme.org

August 2010

New Trustee Board: Welcome to the new Trustee board! Amy Stone has taken on the role of chair, Carole Bayne has taken on the role of Treasurer, Adrian Cunningham remains as Secretary, Lindsay Maskell remains as a Trustee and Lindsay Robertson and Elisabeth English both join the Trustees board. We're very grateful for them for taking on these roles and ensuring that the group continues to flourish.

New Co-ordinator: After a year as Co-ordinator I have decided to leave, due to a change in priorities. This last year has been both exciting and challenging and I am very glad to have had the opportunity to have worked with the group. I've met some wonderful people along the way and have really appreciated the work that Trustees and volunteers do within the group. I'm still intending to stay involved, but hope to have a bit of time out too!

The good news is that Sir John Fisher have continued our funding for another year, so the Trustees have been able to appoint a new Co-ordinator, Joanne Farmer, who starts on 1st September. We wish her well!

More courses and workshops: We are continuing to run courses and workshops as the last ones were an overwhelming success. The Assertiveness course in Lancaster was oversubscribed and participants gave enthusiastic feedback both about Viv's teaching and the skills that they have learnt. If you are interested in gaining assertiveness skills, this course is being repeated in Kendal this time, starting at the end of October (More details on page 4). A big **Thank You** to Viv Calver who has provided her time, energy and skills for free. Thank you Viv!

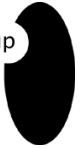
Development Group: A Development Group has been set up for anyone who is interested in becoming more involved in the group, giving ideas and discussing the direction and development of the group. If you are curious and think this may be for you, just come along. Details on page 3.

Friends of Morecambe Bay ME Group: The group is setting up a "Friends" to help support our activities. More details on page 6.

I hope you enjoy the newsletter and hope to see you at some of the events and workshops!

Alice

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Socials

Everyone is welcome at meetings and socials. It is a good way to meet up and share experiences with others who understand how you feel. Feel free to bring friend or family member along with you.

Barrow and Ulverston

Wednesday 15th September - 1pm at the World Peace café, Ulverston 1pm at the World Peace café, 5 Cavendish Street (off Queen Street), Ulverston. www.worldpeacecafe.org/ A beautiful café with lovely vegetarian food, coffee and teas. More details - Hazel 01229 586381

Wednesday November 17th - 1pm World Peace café (as above).

Currently we have no one to host meetings or socials in **Barrow**. Please get in touch if you would like to host or have suggestions for meetings or workshops. Email info@bayme.org or phone 01524 888214

Lancaster

The socials are in The Gregson, 33 Moorgate, Lancaster. <http://www.gregson.co.uk>. Quiet venue. Serves meals, snacks and a wide selection of hot and cold drinks. Free parking on the streets. Contact Christine for more details: 01524 62433 (after 11am please) or 07837 237 931 (brief calls on mobile or text please). If you would like to share lifts please phone Christine.

Thur 9th Sept - 2.30pm in The Gregson

Thur 14th Oct - 2.30pm in The Gregson

Thur 11th Nov - 2.30pm in The Gregson

Kendal

Friday 17th September – 12.30pm in the Warehouse Cafe, Brewery Arts Centre, Kendal. Come and relax in large comfy sofas. The café provides teas, coffee, soup, sandwiches and crepes. Just come for tea or stay and have lunch! For more details phone Alice on 015395 61444

Friday 19th November– 12.30pm in the Warehouse Café (as above)



Meetings and Workshops

Development Group Meeting - Friday 24th Sept 2pm Lancaster Friends Meeting House, Meeting House Lane, Lancaster, LA1 1TX Tea and coffee provided

Are you interested in contributing ideas to the group? Would you like to provide practical help through hosting meetings, assisting with fundraising or helping with organising activities? The Development Group has been set up so that members can come along, meet others, discuss what they want in the group and provide practical help if they wish. There is no commitment necessary. Just try it out, dip your toe in and see if this suits you!

It is intended for the group to be sociable and fun as well as an opportunity to talk about the group. Why not come along!

Kendal

Yoga

Monday 11th October 1.30 - 2.30 in the Detached Room

Castle Street Centre <http://www.castlestreetcentre.com/id1.html> (Close to Kendal Station and free parking at the centre) with Deyna Hirst <http://www.theyogaconsultancy.co.uk>

Yoga is concerned with harmonising the mind, body and breath. This will be a lovely, gentle, affirming class with an invitation to do no more than lie and breathe if that is what is right for you. Simply connecting and breathing deeply with awareness can have huge health benefits. Co-ordinating the breath with gentle movement can open the body and allow energy to flow more freely. Using visualisation and relaxation can invoke a feeling of well being and lightness of spirit.

You will be invited to experience these aspects of yoga according to how you feel, in a class that is friendly, supportive and gentle.

Please bring a mat or blanket and wear loose, comfortable clothing. There will be a short break in the middle of the session.

To book please email Jo at info@bayme.org or phone **01524 888214**



Lancaster

Saturday 2nd October - 2pm Yoga workshop (2-3pm) with Jess Abrahams. The Friends Meeting House, Meeting House Lane, Lancaster

This workshop will be a very gentle and adaptable form of yoga and participants can always choose how much they do. Movements can be done sitting and you can take time out at any point. Please wear comfortable clothing, bring something warm to wear during the relaxation and bring a mat or rug to lie on

Afterwards there will be time to chat and have a cup of tea.

To book please email Jo at info@bayme.org or phone 01524 888214

Saturday 6th November – 2pm Food ideas and sharing. Please bring along a dish to share. This will provide an opportunity to swap recipe ideas and healthy fast food options. The Friends Meeting House

Saturday 11th December – Christmas Party!! Come and celebrate! Meet old friends and make new ones. *More details in the next newsletter.*

Courses

Kendal: Assertiveness Course

Following the highly successful assertiveness skills course that was run in Lancaster, we are now running the same course in Kendal. Participants from the last course found it very practical and useful:

“I liked that the sessions were well prepared, with excellent, relevant hand-outs. It has been worth the energy it took for me to attend.”

“I found it useful talking to fellow sufferers and brainstorming problems.”

“It’s been very useful having a structure/resource to draw on. Knowing others are in the same boat who would cheer me on to use the tools has been very helpful”

Introduction to assertiveness skills for 5 weeks

Dates: Saturdays 30th October, 6th 13th and 27th November and 4th December from 1.30 – 3pm
at Castle Street Centre, <http://www.castlestreetcentre.com/id1.html> (Close to Kendal Station and free parking at the centre)

Do you find it hard to explain what having ME is like for you? Do you often fit in with what other people want because you find it hard to say what you need?

A number of members have been discussing the need to develop more assertiveness skills, to help them to manage their ME better. Viv Calver has lots of experience in helping people to be more assertive and she has agreed to run an introductory course which will be specially designed for our group!



The course will cover such topics as:

- What is meant by assertiveness?
- When are we unassertive?
- Barriers to behaving assertively
- Verbal and non-verbal skills in being assertive

The sessions will provide participants with opportunities to identify and discuss those aspects of communication which they personally find difficult, and to consider strategies for dealing with them assertively.

There will be a short refreshment break in the middle of the session and scope to rest when you need to during the session.

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Viv Calver has lived locally for over 30 years, and was employed as a health promotion specialist in the NHS before becoming a free-lance trainer. She worked throughout the North of England, providing courses for health authorities, social services departments and the University of Leeds. Viv has been retired for several years but acknowledges that she often misses the stimulus of running courses and the interaction with participants. She has been tempted out of retirement to run these introductory sessions exploring assertiveness skills for members of the Morecambe Bay ME Group.

To book a place or to try out the first session as a taster to see if this course suits you please email Jo at [info@bayme.org](mailto:info@bayme.org) or phone **01524 888214**

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## Future Courses

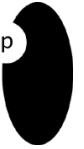
### Transactional Analysis

Viv Calver explains:

“Earlier this year I ran an introductory course on assertiveness for a group of very enthusiastic and responsive participants. I found this so enjoyable that I decided to offer some sessions on another related topic which can help people to develop their communication skills. This is a system called Transactional Analysis - TA for short – which provides a simple framework for analysing how you interact with others, and how to respond when communication goes wrong. For me it has been an extremely helpful tool which I still use regularly. Of all the courses I used to run when I worked as a free-lance trainer, this was my favourite!”

The details of the course have still to be worked out, but it will probably be early next year, in the Friends’ Meeting House in Lancaster, and will run weekly for four or five 1 ½ hour sessions. For those who attended the assertiveness course this will provide a useful addition, but it is also a stand alone course suitable for others.

***Watch out for more information in the next news letter!***



## Morecambe Bay ME Group News

Welcome to our new Co-ordinator Joanne Farmer

“I’m really looking forward to continuing, and building on, all the work that Alice has been doing for the last 12 months. It seems like a time when the group is ready to move forward and take on new challenges. I have a background as a radiographer and also as an advocacy volunteer and later advocacy worker with organisations across the North West. I have also been involved with voluntary groups and charities in the local area as a volunteer, trustee and employee at various times over the last 25 years.

On a personal note I live in Lancaster with my husband Ben and our two children age 7 and 4

I hope I have a lot to bring to the organisation and look forward to getting to know many of you over the coming months”

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### **Benefit Visiting Service: Do you want help with applying for benefits?**

Would you like help with applying for Disability Living Allowance or Employment Support Allowance? Are you facing a benefit renewal and want some assistance? The volunteer benefit visitors can assist you in completing the necessary forms.

To book an appointment or if you just want to have a chat about applying for benefits please phone **Jo on 01524 888214** or email at **info@bayme.org**.

It is a good idea to contact us as soon as possible so any potential claim or renewal is not delayed.

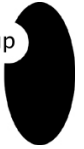
### **Friends of Morecambe Bay ME Group**

We are setting up a “Friends of Morecambe Bay ME Group” in order to support the activities we run and help with providing a better service to our members as well as publicising it more widely to members of the public.

The “Friends” will hopefully contribute ideas as well as practical skills to ensuring the continuation and development of the group. You may have family or friends that may like to become a “Friend”. There is no membership fee and no specific commitments, but we hope that the “Friends” will be able to assist both the Co-ordinator and volunteers in current activities as well as contributing to future activities. Some ideas.... Help with fundraising, providing skills and training for members of the group, helping with publicising the group, public speaking about the group’s activities.

We are hoping that the “Friends” will have more energy than most of our members and will be a boost to the role of this group in assisting those with ME.

If you have any ideas or know of someone who would like to become a friend please contact Joanne at [info@bayme.org](mailto:info@bayme.org) or phone 01524 888214



## **One Moment at a Time: Coping with M.E./CFS using mindfulness** by Hazel White

I have had M.E. for over 4 years. For the first few years it was severe and I was housebound, sometimes bedbound. I was so ill that I could do very little activity, sometimes no more than 5 minutes of standing, walking, reading, or cooking a few times a day, and very little socialising. Much of the time I stayed positive, feeling sure I would recover soon. But there were so many times when frustration, anger, and despair would over-power me and I'd end up feeling that I just couldn't cope with another day. Around 3 years ago I read a book about mindfulness and coping with illness by Jon Kabat-Zinn. More recently I attended a course run by Breathworks. Mindfulness totally transformed the way I dealt with having M.E. and gave me the ability to find some calm and happiness in my life, despite the difficult situation I was facing. I believe it has enormous potential to help M.E. sufferers make sense of their experience, feel more in control, and find some meaning and contentment in their life. That's got to be good for your health, as well as the people around you!

### **What is mindfulness**

Mindfulness is a way of living more fully in the present moment with a non-judgmental, non-reactive attitude. This means developing an awareness of how your mind works, learning not to put so much pressure on yourself, being less self-critical, and developing a new perspective of your situation. It's about not being driven by thoughts of the past or desires for some ideal future we think we need in order to be happy. Instead it is about developing the ability to let go and really accept and embrace what we have now, the present moment in which we find ourselves with all its difficulties, as well as its pleasures that can so easily be overlooked when we are feeling ill, in pain, and stressed. Developing the ability to be more in touch with our breath, body, and senses allows us to still our mind and really be in the present, so that we are not constantly lost in thought and worries and instead can live richer, calmer and ultimately healthier lives.

### **Mindfulness and medicine**

Mindfulness was first brought into mainstream medicine in the US by Dr Jon Kabat-Zinn around 30 years ago. He created an 8 week course called 'Mindfulness Based Stress Reduction; How to cope with stress, pain, and illness using mindfulness meditation' (detailed in his book *Full Catastrophe Living*), which is now being taught all over the world. More recently in the UK Vidyamala Burch set up an organisation called Breathworks, teaching the course 'Living Well with Pain and Illness'. Within the medical profession there is now a growing awareness of the power of mindfulness to help people cope with a variety of illnesses. There are a number of M.E. clinics around the UK incorporating mindfulness into patient programmes.

### **Mindfulness meditation**

Meditation is the practice through which mindfulness is developed. Mindfulness meditation is not about visualizing something or forcing a blissful state, although this can arise naturally and it's not about religion. Rather it's about working with what you're experiencing in the moment, whether its pain or frustration, and learning to change the way you respond to these, so that physical suffering does not lead to further emotional suffering. It's ideal for M.E. sufferers as it can be used as an effective way to rest and can help to reduce the mental noise that brain fog often creates. Before I started meditating I really struggled to find a way to calm my over-exhausted, wired brain and rest properly. During meditation you focus your awareness onto an object such as your breathing or the sensations in your body (I like to focus on the feeling of the breath coming in and out of my whole body, or my belly rising and falling as if I'm riding the waves of my breath). You are also taught gentle yoga. When you find that your mind has wandered off into thought, which it will naturally do, you see that this is happening and let go of the



thought, bringing your awareness back onto your breath or body. You do this over and over, kindly and patiently.

It's not that all thinking is bad, it's just that too much thought is not really helpful or useful. Many negative thoughts, especially when we are ill or stressed, spontaneously spring from feelings of insecurity, frustration, pain, fear, or anxiety. They may simply be the result of an exhausted brain. We do not always choose to have them, but are driven by them often unawares in a kind of automatic pilot. However we can choose to change the way we respond to them so that we are not just dragged off helplessly into a downward spiral of difficult emotions like rage, depression, and hopelessness, when we can start to feel like we are not coping.

With practice you learn how to release yourself from thoughts as they come up, accept difficult emotions and painful sensations in the body, so that you develop the ability to have some control over what's going on in your mind, and subsequently how you feel, not just during the meditation practice, but in your everyday life. Through meditating regularly you are essentially training yourself to be able to cope better. I found that these changes started happening all by themselves, just through me essentially resting and doing nothing!

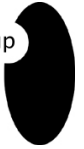
#### **Aspects of M.E. that mindfulness can help with**

- Adapting to having to just 'be' when you can't 'do' as M.E. severely restricts the activity we can manage;
- Living in the moment, taking each day as it comes, appreciating the good things in your life. This is important when we don't know how our health may be from one day to the next as we are living with a condition that can fluctuate massively and where there is an uncertain and often difficult recovery process;
- Calming an over-exhausted and wired mind;
- Coping with pain and physical symptoms. Changing the way you relate and respond to these can lead to acceptance, reducing additional emotional suffering;
- Pacing yourself more effectively as you develop a greater respect and awareness of your body;
- Coping with difficult emotional states like frustration, despair and depression;
- Coping with fear and anxiety, especially when the activity we do can impact our health so directly;
- Coping with flare-ups, relapses, and the unpredictability of M.E.

#### **Mindfulness is something we can 'do' even if we can't 'do' anything!**

However ill you are, even if you are trapped in bed for most of the day hardly able to stand or read a sentence, mindfulness is something that you can 'do'. Meditation takes very little energy. Mindfulness is all about working on ourselves and finding ways to help ourselves feel as happy as possible despite what life throws at us. We may not be able to choose the conditions in which we have to live, but we can choose how we feel about them and respond to them, so that we are not so out of control and helpless, and do not suffer so much. Happiness really is a state of mind that we can work to develop, whatever is going on in our lives, no matter how bad it seems, and no matter how ill you are. You can choose to undertake now what could be the most important work of your life.

*"We must learn to reawaken and keep ourselves awake. It is something to be able to paint a picture or carve a statue; but it is far more glorious to carve and paint the very atmosphere and medium through which we look. To effect the quality of the day, that is the highest art."* Thoreau, Walden.



### Want to find out more?

In this Newsletter there are details about the next *'Living Well with Pain and Illness'* course run by Steve Johnson, an accredited Breathworks trainer. I highly recommend it. I'm planning to train to teach the course and will be helping out. The length of the sessions may be a concern, but for much of the time you are lying down being guided through meditations. You can lie down whenever you need to and watch the yoga rather than do it if you need to. It's very flexible and relaxed. If you cannot make all the sessions Steve or I can meet up with you on an individual basis to offer advice and guidance.

If you'd like to read more about mindfulness I recommend the following books:

- 1) Full Catastrophe Living; How to cope with stress, pain and illness using mindfulness meditation. By Jon Kabat-Zinn.
- 2) Living Well with Pain and Illness; The mindful way to free yourself from suffering. By Vidyamala Burch. *There is a copy of this book in the Morecambe Bay ME group library.*

Both books have accompanying sets of CDs with guided meditations to learn with.

I am in the process of writing a booklet about my experiences which covers all the aspects above. If you would like a copy, or for any other information, you can email me: [h.a.white@btinternet.com](mailto:h.a.white@btinternet.com)

## Mindfulness and ME

"The course gave me my life back! "  
(course participant with CFS/ME)

### Living Well with Pain and Illness

Now available in a flexible format to meet your needs. Options include traditional 8 week group programme, individual coaching or a combination of delivery methods

**Next programmes start in September.**

Limited funding may be available for those on reduced income

**For more details contact:**

Tao Mountain - Mindfulness Cumbria™, Ford Park House  
Ford Park, Ulverston, Cumbria, LA12 7JP

T: 07976 356484; E: [steve@taomountain.co.uk](mailto:steve@taomountain.co.uk)

W: [www.taomountain.co.uk](http://www.taomountain.co.uk)

(Tao Mountain is an accredited provider of Breathworks 'Living Well' Programmes)



**DANCING MACHINE  
BY JUDITH COYLE**

Dancing Machine - Part Two

Our six weeks of dance classes at Ludus in Lancaster are now over. We had a good healthy turnout and I think I am right in saying that we all left each class feeling very uplifted and excited about what we had achieved.

Thanks to Helen Gould for her great teaching. It was so nice to hear how much she has enjoyed teaching us. Helen and Ludus would like to put on further dance sessions, possibly starting in mid-late summer. Watch out for further news on this.

The one hour class flies by. We begin with some stretching exercises, move onto some walking/dancing moves then comes ballet at the barre. The highlight for us all, though, has been learning two routines from the musical Chicago! To see pictures from one of the sessions please follow these links.

- <http://amiscaryforyou-michaeljackson.blogspot.com/2010/05/at-barre.html>
- <http://amiscaryforyou-michaeljackson.blogspot.com/2010/05/all-that-jazz.html>
- <http://amiscaryforyou-michaeljackson.blogspot.com/2010/05/all-that-jazz-ii.html>

Judith Coyle

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[www.severeme.info](http://www.severeme.info) is the home for SevereME/CFS: A Guide to Living by Emily Collingridge. With more than twelve years experience of severe ME herself, Emily's big hope in writing it was to make the lives of those affected by severe ME easier.

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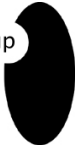
**FAITH, HOPE AND LOVE**

Hi, my name is Liz and I was wondering if people are interested in forming a network of support and encouragement. I am a ~Christian and have been so grateful to friends for keeping me optimistic.

I celebrate the fact that we are a multicultural society and wish the group to be totally inclusive. Faith or no faith, we all still need *hope* and *love*.

There are days when we are isolated, feeling low and this would be quick, hsort help if we cannot tak for more than a few minutes. Perhaps we could operate a phone a prayer (poem or literature) system or post words of hope to each other.

If you are interested please phone Liz on 01524 421803 between 1 and 2pm and 3.15 and 4pm Monday to Friday.



## Library



To borrow a book contact Emma on 07919505588 or email her at [badkielj@aol.com](mailto:badkielj@aol.com).

If you have books you have finished reading and would like to donate to the library, please email us or contact Emma.

|                                                                                        |                  |
|----------------------------------------------------------------------------------------|------------------|
| Living with ME                                                                         | Dr C Shepherd    |
| Better recovery from viral illnesses                                                   | Dr Darrel Ho-Yen |
| ME and you - A survivor's guide to post-viral fatigue syndrome                         | Steve Wilkinson  |
| Fatigue: the secrets of getting your energy back                                       | Xandria Williams |
| From fatigued to fantastic                                                             | Dr J Teitelbaum  |
| International conference on ME/CFS biomedical research, May 2008 (4 DVDs)              | ME Research UK   |
| Chronic Fatigue Syndrome: a natural way to treat ME                                    | Prof Basant Puri |
| An Introduction to the Lightning Process                                               | Phil Parker      |
| ME, CFS and Fibromyalgia: the Reverse Therapy approach                                 | John Eaton       |
| Setting the Pace: a guide to pacing for people with CFS /ME Booklet and DVD            |                  |
| Living Well with Pain and Illness:<br>The mindful way to free yourself from suffering. | Vidyamala Burch. |
| The Highly Sensitive Person                                                            | Elaine N. Aron   |

## Useful Contacts

New to the group, want to ask a question or simply need someone to chat to? Try calling our **Local Contacts**.

| Name              | Area Covered              | Contact Details                                       |
|-------------------|---------------------------|-------------------------------------------------------|
| Lindsay Maskell   | Lancaster/ Carnforth Area | 01524 727614 (evenings before 9pm)                    |
| Hilary Devereux   | Lancaster Rurals          | 015242 22104 (Daytime between 10 - 4)                 |
| Sarah Blackler    | Lancaster Area            | 01524 33553 (before 8pm)                              |
| Rina Roberts      | Morecambe Area            | 01524 845554                                          |
| Elisabeth English | South Lakes Area          | 015395 63567                                          |
| Amy Stone         | South Lakes Area          | 01524 381677 (between 4 – 8pm Only)                   |
| Alice Fleming     | South Lakes Area          | 015395 61444 (before 8pm)                             |
| Walter Jinks      | Barrow Peninsula          | 01229 463181<br>(after 6pm – if no answer, ring back) |
| Moyra Marshall    | Barrow Peninsula          | 01229 869705                                          |



## Useful Websites

**Action for ME:** [www.afme.org.uk](http://www.afme.org.uk) (0845 123 2380)

**Young people's Action for ME:** [www.a4me.org.uk](http://www.a4me.org.uk)

**ME Association:** [www.meassociation.org.uk](http://www.meassociation.org.uk) (0844 5765326)

**Association of Young People with ME:** [www.ayme.org.uk](http://www.ayme.org.uk) (08451 232389)

**TYMES Trust** (The Young ME Sufferer): [www.tymestrust.org](http://www.tymestrust.org) (01245 401080)

**25% ME Group** (For severely affected) [www.25megroup.org](http://www.25megroup.org) (01292 318611)

**Morecambe Bay PALS** (Patients' Advice and Liaison Service) 01539 795497

**Lancaster Advocacy** (One-to-one support in dealing with health & social services) 01524 841845

**One Voice** (Disability info and advice) 01524 34411

**Coping with Self Care** (Advice and advocacy in South Lakeland) 0845 6031529

**M.E Research UK** (National charity funding biomedical research into M.E) [www.meresearch.org.uk](http://www.meresearch.org.uk)

**Independent Complaints Advocacy Services** (North West NHS complaints) 0845 120 3735

### Information about the Group

#### Morecambe Bay ME Group

Morecambe Bay ME Group is an association of people with ME, carers and others who are interested, who come together to provide mutual support and companionship, keep members updated with research and treatments available, give information about benefits and campaign for better NHS services around Morecambe Bay

Membership is open to anyone and costs £12 for waged, £6 for unwaged (less £2 in either case if receiving newsletter by email). For a free copy of the newsletter please email or phone us.

**Co-ordinator: Joanne Farmer** *tel no 01524 888214*      **Email:** [info@bayme.org](mailto:info@bayme.org)

**Email group:** You can subscribe to an email 'round robin' which provides regular updates and publishes members' responses to issues. Email [baymeroundrobin@googlemail.com](mailto:baymeroundrobin@googlemail.com) to join this group

**Trustees** – Amy Stone (Chair), Carole Bayne (Treasurer), Adrian Cunningham (Secretary), Lindsay Maskell, Elisabeth English, Lindsay Robertson

**Morecambe Bay ME Group**, *Caroline Green Cottage, Oxenholme Lane, Natland, Kendal LA9 7QH*

**Reg. Charity No. 1084277**

#### Please note

The therapies/techniques/treatments are described for information only. Inclusion in this newsletter should not be taken as a recommendation.

The views and opinions expressed in articles are those of the contributors and are not necessarily those of the group.