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**[www.mesupportgroup.co.uk](http://www.mesupportgroup.co.uk)**

The Bury/Bolton ME/CFS Support Group was founded in September 1990  
and is managed by a committee of six members:

Pam Turner, Margaret Benn, Ann Richards, Maria Sale, Sheila Myerscough & Kim Finney.

**Support Group Posts & Contact Information:**

Group Contact / Welfare & Benefits Advice:	Pam Turner	
Treasurer & Parents' Contact:	Kim Finney	01204 882826
Minutes Secretary:	Margaret Benn	0161 761 2723
Bolton CVS Contact:	Ann Richards	01204 521769
Meetings Secretary:	Maria Sale	01204 575613
Medical Sub-Group, Group Rep & Carers' Contact:	Yvonne Leech	0161 764 7822
Bury Socials:	Sheila Myerscough	0161 7970026 (after 12noon)
Web Master:	Caroline Higson	01204 525955 <b>caroline@mesupportgroup.co.uk</b>
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Link Up Co-ordinator:	Stephen Walker	01204 842395 <b>stewalker@postmaster.co.uk</b>
Librarian:	Carole Senior	01942 810320
Door at Meetings:	Sue Forshaw	01204 883506
Roving Reporter:	Andrew Levy	0161 798 6183 <b>andmk1@googlemail.com</b>

**DISCLAIMER:**

The observations expressed in our newsletter may not necessarily represent the views  
of the Committee or the Bury/Bolton ME/CFS Support Group.

All products and treatments featured are for information only.

## **Editor's Note**

Thankyou for all of the appreciative comments we have received regarding our new style newsletter. We welcome your views, whether positive or negative and wouldn't want to get complacent, so please do tell us what you want and we will do our best.

Please carry on sending anything you would like to share with the rest of the group, whether it is a whole page, or just a few lines, it all counts! Please send your contributions to: Dave@mesupportgroup.co.uk, or if you are unable to email, post to Pam Turner (7 Burghley Drive, Radcliffe, M26 3XY). Or alternatively, if you have an idea, but you prefer not to write about it yourself, then please contact Andrew on 0161 7986183 or andmk1@gmail.com and he will discuss it with you and write it up on your behalf.

## **Researchers find virus in blood cells of CFS patients**

Researchers at the Whittemore Peterson Institute in Reno, USA have identified genetic material (DNA) from a mouse virus - murine leukaemia virus-related virus (XMRV) - in 68 out of 101 CFS patients (67%) compared to 8 out of 218 (3.7%) of healthy people.

Further blood tests showed that more than 95% of CFS patients have antibodies to XMRV, indicating they had been infected with the virus, which may then have lain dormant in their DNA.

Dr Judy Mikovits, research director, Whittemore Peterson Institute, is testing a further 500 blood samples collated from patients diagnosed with CFS in London.

Although the sample is small, the results are very promising.

Sir Peter Spencer, CEO of Action for M.E., the UK's biggest M.E. charity, says:

"It is still early days so we are trying not to get too excited but this news is bound to raise high hopes among a large patient group that has been ignored for far too long.

"If the researchers can go on to prove a definitive cause and effect between this retrovirus and M.E., it will make an enormous difference to 250,000 British men, women and children who have M.E. in this country.

"Action for M.E. has long been calling on the UK Government to invest more in research into the causes of this horrible illness. Once we know the cause, researchers can start working on more effective treatments, preventive measures and ultimately a cure for M.E."

**Thanks to Action For ME**

## Dates For Your Diary

**Longsight Meetings:** Our main meetings, often with guest speakers, are held at Longsight Methodist Church, Longsight Lane. Harwood, Bolton, BL2 3HX, on the third Thursday of each month from 7.30pm until 9pm (except in April, August and December). Entrance is £1, tea, coffee, water, biscuits, etc provided.

**Thursday 19<sup>th</sup> November 2009:** The pre Christmas social with “Bring & Share” buffet supper.

Please note there will be no meeting in December. The next meeting will be 15<sup>th</sup> January, details to be confirmed.

**Radcliffe Socials:** Our Social Group meets informally on the first Monday of each month, our next will be on **Monday 7<sup>th</sup> December** at **4pm**, at **The Sparking Clog, Radcliffe Moor Road, Radcliffe, M26 3WY**. It has plenty of parking, good accessibility, comfortable seating, is relatively quiet and serves very tempting chips that we just can't resist. For anyone who does fancy a snack, these start at just £1.50, with main courses from £3.50. For more information please email [dave@mesupportgroup.co.uk](mailto:dave@mesupportgroup.co.uk) or phone 05601 335037.

**Bury Socials:** Are continuing on the first Thursday of every month, the next meeting will be **Thursday 3rd December, 3pm** at **The Automatic, next to the Met theatre** (it is across the street from Yates, not the Met Café next to Yates), **Derby Hall, Market Street, Bury, BL9 0BW**. [http://themet.biz/location/find\\_the\\_met.pdf](http://themet.biz/location/find_the_met.pdf). If you need any more information, please phone Sheila on 0161 7970026 after 12noon.

**Yoga Classes:** Are **3:15pm-4:15pm on Tuesdays** at the **Jubilee Centre, Darley Street (off Eskrick St), Bolton, BL1 3DX**. Designed to cater for the average ME sufferer, classes are free and yoga mats are provided. Please wear loose, comfortable clothing. Contact Olivia on 01706 829488, or [olivia@oliviayoga.co.uk](mailto:olivia@oliviayoga.co.uk) for more information.

PLEASE DO NOT WEAR STRONGLY SCENTED TOILETRIES WHEN YOU ATTEND OUR MEETINGS, AS SOME MEMBERS ARE VERY SENSITIVE TO THESE PRODUCTS, THANKYOU.

Those of you who live in Bury, might be interested in the “Age of Opportunities” programme focussing on the health and well-being of people aged 50+, including a wide range of activities and initiatives. For more info see the [bury.gov.uk](http://bury.gov.uk) website, or phone 0161 2536587.

Bury District Citizens Advice Bureau has been funded this year as part of the “Age of Opportunities” programme, particularly focussing on providing a take-up campaign for those people over 50 who might not be getting all of the benefits they are entitled to. For more info, contact Julie Cuddy, based at Prestwich CAB on 0161 7981611.

Manchester Disability Benefits Centre is closing in November. New claims are to be sent to Preston and renewals to Blackpool. The benefits helpline number is unchanged: 08457 123466.

Many of us suffer from light sensitivity, particularly under the ‘wrong’ sort of lights. We recently heard from a lady with ME/CFS who has been prescribed green tinted glasses to help her with this. Blue tinted glasses can help with other conditions such as MS or dyslexia. So it might be worth asking your optician about, or perhaps experimenting with the yellow anti-glare glasses, which are usually sold for driving. We would be very interested to hear about your experiences – but please, no jokes about rose-tinted glasses!

# **Bolton/Bury ME Support Group Meeting October 2009:**

## **Gail Sumner**

Gail Sumner, of the Back to Health Physiotherapy practice, came to talk to the group on 14 October. Gail is a chartered and state registered physiotherapist, and has had experience and qualifications in many other health and nutritional fields. She contracted ME about eight years ago, and has made an almost full recovery. At the worst stage of her illness, she could not even take a shower. So, seeing her speaking to us that evening was proof positive that ME can be addressed successfully. Gail's strength and determination to conquer the disease was clear throughout the entire talk. This determination was increased after Gail's meetings with people who had recovered from serious illnesses. She thought, 'if they can do it, so can I'.

Gail felt that ME was difficult to understand because of the many different stresses which were causing trauma to the person's body. These stresses could range from additives in food to pollution in the air. As a result, Gail felt that treatment had to be multifaceted and that patients should not rely on one type of treatment alone. This was reinforced by a meeting with four people who were very much better after contracting ME. All of these people spoke about 5 to 6 things that they had done to recover. Gail then went on to describe some of the areas that she felt would be of use to a recovering ME patient.

**The Perrin technique** - Gail is a practitioner of this technique, which removes toxic build up from the lymphatic system and central nervous system. The drainage techniques would be applied to the head chest and back and supplemented by regular doses of Vitamins C and B complex, milk thistle and Veg EPA.

**Nutrition** - This is a very specialized subject in itself, although problems with ME patients focus on a poor digestive system. There are problems with not absorbing nutrients properly digesting food properly and toxic build up. The digestive system is also linked to the immune system and getting that right can lead to improving a person's ability to fight disease. Gail made a number of recommendations including going organic, avoiding any food with chemicals or pesticides and reducing acid forming foods, such as red meat, which can inflame the digestive tract. Gail felt that wheat and yeast could also be harmful as well as foods which contained trans fats. Gail also focused on specific additives in foods especially, monosodium glutamate, often used in Chinese cooking, and Aspartame, found in soft drinks. Finally, the foods high in sugar should be avoided as they create a peak in energy just after they've been consumed. The effects of caffeine in coffee and tea will also have the same effect and need to be avoided as ME patients need a balanced release of energy from their food and drink.

Gail has been very strict on her own diet, and follows the latest research on issues such as the impacts of processed foods and chemical additives. The issue of dental fillings was brought up during the talk, and Gail said that she felt that amalgam fillings were damaging because of their mercury content. Gail herself has had these fillings removed. On the subject of mercury, Gail also mentioned predatory fish such as tuna. Fish like tuna would be contaminated with mercury and therefore should be avoided.

**Biochemistry** - This is a very specialized field also the use of vitamin C and antioxidants should be encouraged to repair the damage caused by free radicals. Supplements such as Veg EPA, milk thistle, magnesium, zinc, copper and coenzyme Q. 10 are also beneficial. Their effect is to combat cell stress and damage and make them more effective at producing energy. Dr. McLaren Howard's research for example, showed a build up of calcium in the membrane around the cells. The caused damage, and the calcium would have to be removed with doses of magnesium. Patients in Bolton

were advised to speak to Dr. Wright, as he could prescribe the right treatment to remove the calcium.

**Immune system** - Gail was aware of the recent discovery of the XMRV virus which was found in 67% of a sample of ME patients. What was more important however, was that 95% of the sample possessed antibodies to deal with the infection. At the moment this research is in its early stages, and the scientists believe that the transmission of the virus similar to that of HIV. The next question they are looking to answer is how the virus takes root. They will want to know if the body becomes weaker first and then become susceptible to a latent virus. On the other hand the virus may just infect the person at the time they caught it.

**Hormone imbalance** - This was because the hypothalamus was not working properly. Hydrocortisone is just one solution, as it improves the efficiency of the adrenal glands. Gail also mentioned natural therapies that would perform the same task.

**Mechanical work** - Making sure that your joints and muscles are stretched and moved are important. Yoga, tai chi and the Alexander Technique are all examples of disciplines which could help.

Gail also looked at herself and how she reacted under stress. Having ME is in itself stressful, and your personality can make it worse because you can't switch off and rest properly. Gail described one trait of a typical ME patient as being someone who willingly helped others. They would do this selflessly and without caring for themselves. In Gail's case she had to learn how to say no and stop giving too much of herself to too many people.

**Sleep hygiene** - Gail said that ME patients do not get enough deep sleep, called the delta level. If this level of sleep does not occur, then the body will not repair and recover properly.

Overall, Gail said that all of these things together would significantly help a person suffering from ME. A good diet would help improve digestion and the immune system. Good sleep, making sure the body is moving, detoxifying and managing the body's biochemistry were all important factors to make a long-lasting recovery. To help you with your diet, she recommended a book called the Gut and Psychology Syndrome by Dr. Natasha Campbell McBride.

Moving on to psychology, she recommended many different treatments such as Breathworks, Emotional Freedom Technique and the Lightning Process. She said that Dr. Myhill's website was a "treasure trove" of positive information. She also recommended trying to switch off properly using the quote "we are all human beings not human doings". Gail also used pacing as an example of being too aware. At one stage, she knew how many steps it took to get to any particular destination. This was clearly too much, and she was too involved in performing everyday tasks. She needed to detach itself a little yet still pace herself correctly.

In conclusion she recommended that we try to remove stresses from all aspects of our lives and create a better environment for ourselves. It's all part of a recovery "jigsaw", and we should be open, try new things and look inwardly as well. After all, the person that gets you better is you.

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## **Thought For The Day**

Half an ounce of help is worth a ton of sympathy.

## **Family, friends and ME – helping them, to help you**

If you suffer from CFS/ME, then you'll know that there's also a severe impact on your family, friends and carers. It really helps if they fully understand and accept what you're feeling. This can provide you with valuable and much-needed support and maybe even help you to recover. But what if your family and friends don't accept your condition and mistakenly believe the bad press that CFS/ME often receives?

For those who doubt what you're experiencing, it's time for you to swing into action in order to set the record straight. To do this you'll need to make sure that your story is clear and is based on the facts. What makes it difficult is that CFS/ME is not something that can be easily described or medically defined. Therefore, you need to explain it in simpler terms to keep it on that person's level. Where you can, avoid detailed medical terms as this can be confusing. Instead you could rely on more realistic examples such as making an analogy to a different illness or feeling. What is clear is that you're not just feeling very tired, as many other people feel very tired too. When I explain my condition, I ask, "Do you know what it's like when you have the flu? [*They always say yes.*] Well, my symptoms are like having the flu day in and day out month after month." if you need some help with simple explanation of CFS/ME then try your GP or use a website such as, <http://www.nhs.uk/Conditions/Chronic-fatigue-syndrome>, which has a short video explaining the symptoms of CFS. The video has a greater impact, as it was recorded by a doctor who had CFS/ME himself.

Once your family and friends understand what the illness is all about, you then need to clean their understanding about how you need to be treated. You could get them involved in your care, but starting in a small way. This could be as simple as coming round for a cup of tea and a chat. By doing this, they can get closer to you, and may start to understand what you're facing. If you can be clearer about what you can and can't do then this will also help them to understand the boundaries you're living with.

Often with CFS/ME you will shut yourself away and deny family and friends contact due to your symptoms. However, if you are working to a recovery plan, do your best to include them in it as this will help you get the acceptance which is so beneficial for your wellbeing.

People who care for people with CFS/ME will also need support in a variety of ways. From basic information to financial assistance, support is available; but you need to know where to get it. The Bolton & Bury ME support group has many contacts to help you get the right assistance to your friends, family and carers. So please check the newsletters for these details. However, if your friends and family just need some clear advice they can ring the CFS/ME helpline on 0845 123 2390 (open on Tuesday, Wednesday and Friday from 10am to 1:30am). This line is run by the NHS and a charity called Action for ME and applies to anyone living in Greater Manchester and the surrounding areas.

If you have any experiences with getting your friends and family "on-side" then please let us know by contacting: [andmkl@gmail.com](mailto:andmkl@gmail.com) or ringing Andrew on 0161-798-6183.

### **UNDERSTANDING SEVERE M.E. INFORMATION PACK LAUNCHED** **Essential reading for Family & Friends of Severe M.E. Patients**

As you know, M.E. is a cruel and disabling illness which wrecks thousands of lives, none more so than those who suffer the most extreme version of the illness, Severe M.E.

Few people understand or appreciate the true impact of this illness, and for the millions of relatives and friends of patients, it can be a terrifying time. In 'Understanding Severe M.E.', 44 year old, Catherine Saunders draws upon her own inspirational recovery from Severe M.E. to explain the harsh reality of the illness.

In this immensely positive, hopeful and easily accessible information pack, Catherine addresses the many questions, worries and fears that family and friends have about what is happening to the patient. She sign-posts the way to expert sources of information and treatments. Most importantly, she suggests hundreds of ways in which they can ease the burden for the patient and their carer, both practically and emotionally.

Priced at £10 each (+£1.95 postage & packing), with 25% of profits going to ME/CFS charities and research. To order copies, email : [understandingsevereme@hotmail.co.uk](mailto:understandingsevereme@hotmail.co.uk) or visit : [www.understandingsevereme.blogspot.com](http://www.understandingsevereme.blogspot.com).

**Benefits & Work Guides:** Our group is a member of [www.benefitsandwork.co.uk](http://www.benefitsandwork.co.uk), allowing us to access their fantastic guides to a range of benefits and disability related issues. The guides are created by a welfare rights expert and a barrister, drawing on their own in-depth knowledge plus use of the Freedom of Information Act. They are essential reading for anyone filling in a benefits application or renewal form, attending a medical, or faced with an appeal. The group's subscription allows us to email or post these guides to our own members, so please look through the list below and if you need anything phone Dave on 05601 335037 or email [dave@mesupportroup.co.uk](mailto:dave@mesupportroup.co.uk).

**Please note that some of these guides are very lengthy (up to 88 pages) and so it is rather expensive for us to print and post them. After each guide listed below is the number of pages in brackets, to give you a rough idea what it costs us to print and post them to you, here are a few figures:**

**10 pages - £1.00**

**20 pages - £1.80**

**40 pages - £2.70**

**60 pages - £3.50**

**100 pages - £5.50**

**200 pages - £11.00**

**If possible please help us to keep costs down by providing an email address we can send them to, if you do not have internet access yourself, perhaps you have a friend or relative who could help you out. Or alternatively, if you go to one of our meetings, social groups or yoga classes, you could pick them up from there and then return to us to be used again. We don't want anyone to miss out and will do our best to accommodate your needs, but perhaps if you do need us to post any of the longer guides to you (or several of the smaller ones), and you can afford to make a contribution towards the costs, it would be very much appreciated.**

### **DLA & AA**

The best possible Attendance Allowance claims on physical health grounds (44)

The best possible Disability Living Allowance claims for adults on physical health grounds (61)

The best possible Disability Living Allowance claims for adults on mental health grounds (53)

The best possible Disability Living Allowance claims for children on physical health grounds (65)

The best possible Disability Living Allowance claims for children on mental health grounds (58)

70 questions you are likely to be asked at your DLA medical (5)

The best possible way to challenge a DLA or AA medical report (28)

The best possible support for clients with DLA and AA appeals (41)

Appealing against a DLA decision (16)

Giving persuasive information about how far you can walk (13)

Challenging the claim a bottle or commode will replace the need for help (8)

DLA renewal claims (6)

Changes of circumstances for people claiming DLA (8)

Letter claimant to decision maker requesting reconsideration because of additional evidence (3)

### **Incapacity for Work**

The best possible incapacity for work claims on mental health grounds (43)

The best possible incapacity for work claims on physical health grounds (48)

Exempt but sent a questionnaire (7)

60 questions you're likely to be asked at your incapacity medical (3)

### **ESA**

Understanding Employment and Support Allowance (43)

ESA claims for mental health and learning difficulties (88)

ESA claims on physical health grounds (65)

ESA appeals (35)

Permitted Work (6)

Getting the best from Work Focused Interviews (11)

### **Other**

If I do any work can I continue to claim my...? (4)

Caution, it may not count as voluntary work (5)

Am I covered by the Disability Discrimination Act? (9)

Which benefits can I claim? (9)

Reasonable adjustments: Employers and Jobseekers (8)

Work and benefits for people with long term health conditions (7)

## **SOME CONTACTS YOU MAY FIND USEFUL**

**Benefits Agency Information Officer:** Bolton - 01204 367000 Bury - 0161 762 2000  
**Bolton Primary Care Trust:** 01204 907724  
**Bury Primary Care Trust:** 0161 762 3100  
**Citizen's Advice Bureau:** Bury - 0161 761 5355 Bolton - 01204 900200 (/213 Housebound)  
**Disabled Living:** 0161 832 3678  
**DIAL** Disability Information and Advice Line: equipment/gadgets and where to get them: 0161 703 8887  
**Bolton Community Voluntary Services:** 01204 546010 **Carers Support (Bolton):** 01204 363056  
**Bury Council for Voluntary Services:** 0161 764 2161  
**Social Services:** Bolton 01204 337841  
Bury (town hall) – 0161 253 5000 (ask for adult social care team)  
**Bury Carer Services:** 0161 253 6008 and **Bury Carer Assessment:** 0161 253 7190.  
**Basic Neurocare Centre (inc Assisted Gym):** 554 Eccles New Road, Salford, M5 2AL: 0161 707 6441  
**Ring & Ride:** Bolton - 01204 388500 Bury - 0161 764 1999  
**Welfare Rights Advice Line:** 01204 380460  
**Benefits Helpline:** 0800 882200. **Completing Forms:** 0800 44 11 44  
**Equality Human Rights Commission (was Disability Rights Commission):** 0845 604 6610  
**JOB CENTRE PLUS:** [http://www.jobcentreplus.gov.uk/JCP/Customers/Disabled\\_People\\_and\\_Carers/index.html](http://www.jobcentreplus.gov.uk/JCP/Customers/Disabled_People_and_Carers/index.html)  
**ACCESS to WORK:** [http://www.jobcentreplus.gov.uk/JCP/Employers/advisoryservices/diversity/Dev\\_015798.xml.html](http://www.jobcentreplus.gov.uk/JCP/Employers/advisoryservices/diversity/Dev_015798.xml.html)  
**General government guidance on entitlements:** <http://www.direct.gov.uk/DisabledPeople>  
**SHOPMOBILITY:** Bolton – 01204 392946 Bury – 0161 7649966  
Manchester Arndale - 0161 839 4060 Trafford Centre: 0161 749 1728  
Bolton Market Place - Wheelchair Service: 01204 361100  
**ACTION FOR ME:** 3rd floor, Canningford House, 38 Victoria Street, Bristol. BS1 6BY.  
Tel: 0845 1232380 (or 0117 9279551), e-mail [admin@afme.org.uk](mailto:admin@afme.org.uk) for general enquiries  
Welfare Rights Helpline - 01749 330136 9am to 1pm Mon Tues Thurs 9am to 12.30 Fri  
Telephone support - 0845 1232314 (11am to 1pm Mon to Fri) - advice and information for anyone affected by ME (including non-members). [www.afme.org.uk](http://www.afme.org.uk) or for young people with ME [www.a4me.org.uk](http://www.a4me.org.uk)  
**ME ASSOCIATION,** 7 Apollo Office Court, Radclive Road, Gawcott, Bucks., MK18 4DF. 01280 818968.  
Information Line: 0870 444 1836 (10am to 12noon, 2pm-4pm & 7pm to 9pm – every day) [www.meassociation.org.uk/](http://www.meassociation.org.uk/)  
**BRAME:** (Blue Ribbon for the Awareness of ME) 30, Winner Avenue, Winterton on Sea, Great Yarmouth, Norfolk. NR29 4BA. Tel/Fax - 01493 393717. The BRAME campaign was launched to create a greater awareness and understanding that ME is a very real and debilitating illness. [www.brame.org](http://www.brame.org)  
**CHRONIC FATIGUE SYNDROME RESEARCH FOUNDATION:**  
2 The Briars, Sarrat, Rickmansworth, Herts. WD3 6AU. 01923 268641. [www.cfsrf.com](http://www.cfsrf.com)  
**M.E. Research UK:** The Gateway, North Methven Street, Perth, PH1 5PP. 01738 451234 [www.mereseach.org.uk/](http://www.mereseach.org.uk/)  
**NATIONAL ME SUPPORT CENTRE:** Disabled Services Centre, Harold Wood Hospital, Romford, RM3 9AR.  
01708 378050 <http://www.nmec.org.uk>  
**The 25% ME GROUP:** Simon Lawrence, 4, Douglas Court, Beach Road, Barassie, Troon, Ayrshire, KA10 6SQ ME Group for the Severely Affected ME sufferer. [www.25megroup.org](http://www.25megroup.org)  
**CHROME:** (Case History Research on ME), 3 Britannia Road, London SW6 2HJ. 020 7736 3511 This charity was set up to identify as many severely affected ME sufferers as possible in the UK and monitor the course of their illness over 10 years. The study will supplement medical research into the condition.  
**TYMES TRUST** (The Young ME Sufferers Trust): P.O. Box 4347, Stock, Ingatestone, CM4 9TE, Advice line 0845 003 9002 (Mon-Fri 11-1 or 5pm-7pm). [www.tymestrust.org](http://www.tymestrust.org)  
**AYME:** Association for Young People with ME, Box 605, Milton Keynes MK2 2X. 08451 232389. [www.ayme.org.uk](http://www.ayme.org.uk)  
**INDEPENDENT COMPLAINTS ADVOCACY SERVICE (ICAS):** help with NHS complaints: 0845 120 3735  
**COMMUNITY LEGAL ADVICE:** 0845 3454345 [www.communitylegaladvice.org.uk](http://www.communitylegaladvice.org.uk)  
[www.writetothem.com](http://www.writetothem.com) - type in your postcode to find out who is your MP/MEP/councillor & how to contact them.  
**The Pensions Advisory Service (TPAS):** 0845 6012923 [www.pensionsadvisoryservice.org.uk](http://www.pensionsadvisoryservice.org.uk)  
**The Pensions Ombudsman:** 020 7630 2200 [www.pensions-ombudsman.org.uk/](http://www.pensions-ombudsman.org.uk/)