



MP urged to probe power crises

Carer Marjorie Tierney is living in fear of more power cuts which could threaten the life of her severely disabled husband who depends entirely on electricity for his every day needs.

Former dentist Michael Tierney is paralysed by motor neurone disease and relies on a large amount of equipment to be able to survive at his South Oxfordshire home.

This winter the couple faced a frightening ordeal during repeated power loss and fear the situation will only get worse with more extreme weather patterns forecast in the future.

Now Mrs Tierney, of Whitchurch Hill, near Reading, is campaigning for a national hotline to be set up empowered with resources to help them and other vulnerable families in times of power crises.

The 76-year-old gran has called on Henley MP John Howell to put pressure on energy minister Michael Fallon after "meaningless" assurances from him were followed by power cuts in November and February.

Her plight, along with other couples in the area, has prompted the branch to call on the MND Association to investigate and back this campaign. It says it is essential that the issue is taken up at a national level to make sure vulnerable people living with MND get power at all times.

Mrs Tierney says although they are registered with Scottish and Southern Energy as a priority home with medical equipment and assured they would get an immediate response the demands on the service were so great during the

February power cuts that they were badly let down.

She said: "It was a horrible, horrible, feeling and we were absolutely desperate. If it hadn't been for the friend of one of Michael's carers who worked for the SSE and arrived with a generator I don't know what would have happened."



In her appeal to John Howell the former social worker made an impassioned plea for him to take their plight seriously and not to let them down.

"We are talking about life and death situations and a shortage of equipment, inadequate personnel or pressure of work are simply not acceptable excuses," she wrote.

"We should not have to wait until the next hurricanes and floods bring a further crisis – we need to be prepared. We do not need to have to live in dread

of the winter or any other extreme weather event - we know now that these will continue, they can no longer be regarded as unusual or unexpected."

Mr Tierney, aged 76, has been battling with motor neurone disease for five years. The devastating neurological condition has gradually robbed him of the ability to do any everyday task for himself. At Christmas he lost the last bit

of movement in his limbs on the tip of his index finger which meant he could no longer use his ipad. Unable to speak, he now communicates using an electronic Eyegaze device which he controls by blinking.

Mrs Tierney told her MP: "There are no plateaus or temporary improvements. He cannot move at all and is a dead weight. He cannot speak, eat or drink. He needs 24 hour care, provided by myself and professional carers, who get him up in the morning and put him to bed at night. I do all the rest of his care.

"We have a great deal of equipment in the house, all totally reliant on electricity to operate.

His bed, mattress, two hoists – one upstairs, one downstairs – his wheelchair, armchair, lift, shower, feeding pump, a cough assist machine, a communication computer are all completely useless without electric power. "At present, his breathing is good. Inevitably, a time will come when this will not be the case and when a respirator will have to be used in addition to all his other electrical equipment. How can I convey to you and to Mr. Fallon what this means?"

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Mrs Tierney has also written to SSE which, she said, tried to help initially but during the last cuts in February was floundering with staff helping out in other areas of the country. SSE has since given her the direct telephone line to its Reading depot and pledged to send her a pack of battery operated lighting.

This, she maintains, is not enough to alleviate their stress and concerns for the future.

“We need to have access to a hotline to a resource which is empowered and required by law to respond rapidly and efficiently to such vulnerable homes and they must have sufficient resources, e.g. an adequate supply of efficient generators, to be able to deal with the crisis,” she added.

John Kell, policy manager of the MND Association, has pledged to write to Ofgem and the sector's trade body, Energy UK, asking them to look at this issue specifically and improve energy companies' systems and responses. The Association's Chief Executive Sally Light is also being asked to write to the minister drawing attention to the issues he overlooked in his reply to Mrs Tierney.

Association Visitor Joanna Knott said: “All people living with MND should contact their power supply company and ensure that they are on the register of vulnerable people who would be at risk in the event of a power cut. Ideally, they should have a direct number they can ring which would connect them to a real person with the ability to help.”

The branch knows of another case in a rural part of West Berkshire where a man suffering from advanced MND had been left without power while his wife struggled to cope with the crisis.

Publicity officer Jane Gilbert said: “This very worrying issue needs to be taken up at a national level so that vulnerable people get the support they deserve. Mrs Tierney expresses so well the stress and exhaustion it engenders for her and other carers like her.”

Jane Gilbert

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'THE NEWS'
from the MND Association ONLINE

Walk to d'feet



Jenko & The Bear will be walking along the 87 mile Kennet & Avon Canal this summer, to raise awareness (and funds) for the MND Association. They will walk from Sunday 17th August until Thursday 21st August. Anyone wishing to join them can contact us for start times, and lunch breaks. Although the boys walk at quite a fast pace, it would be nice if people set out with them, and then did a section at their own speed. The more people we can get out in MNDA T shirts the better!

Paul (Jenko) will be doing a 20 mile practice walk, along The Ridgeway, on Saturday 10th May. He is also walking into Reading Town centre twice a week, in preparation.

Ross (The Bear) will do no training, but still finish as fresh as a daisy. We are expecting Paul's brother Alec, who is living with MND, to be there to see them set off on Sunday, and to welcome them home on Thursday. Hope some of you can join us. Our email is rlp.jenkins@tiscali.co.uk

Lin Jenkins

Meredith's mission for her dad

Working mum Meredith Miller fitted in runs at the unearthly hour of 5.15am to train for the Mizuno Reading Half Marathon.

The 38-year-old tax consultant from Ellesmere Close, Caversham, had a cause close to her heart to spur her on – she was determined to take on her first big run for her “amazing” dad Bill Potts who is suffering from motor neurone disease.

Mum-of-two Meredith completed the 13.1 mile course in 2:08:49 raising more than £2,000 for the MND Association, the charity that supports Bill, a 71-year-old former US marine who lives in Tilehurst.

She said: “My amazing Dad was recently diagnosed with this awful disease and it would mean so much if I could raise a bit of money for this very worthy cause and help to make the lives of people with this horrible condition a little bit better!”

Her dad's health deteriorated just before Christmas and she praised the brilliant support her parents have received from the charity's Reading and West Berkshire branch.

Meredith, who works for accountancy firm Grant Thornton at Winnersh, took up running again with her neighbour, mother-of-three Judy King and they decided to enter the challenge in March together. While Meredith pounded the streets husband Jon was at home asleep with their daughter, Bethia, aged six, and four-year-old Euan.

Despite her nerves about the day the devoted daughter's weeks of training paid off and she was delighted to finish in under her hoped-for time.

She said: “I saw another girl running for MND and we gave each other a thumbs up -she definitely finished before me!”

“It is a great cause and I find, the more I mention it, the more I meet people who have been affected by the disease in one way or another.”

Bill was not feeling well enough to turn up on the day but Meredith went straight from the finish to visit her dad to prove that her mission had been accomplished.



Meredith Miller with husband Jon and children Bethia and Euan



Meredith with dad Bill after the run

To make a pledge for Meredith visit:
<http://uk.virginmoneygiving.com/MeredithMiller>

Jane Gilbert

WANTED

It was nice to see some of you at the recent Drop In at Theale. Can I just remind everyone that I am in urgent need of stuffing for my knitted dolls. If you have any old cushions, pillows, duvets etc I would love to hear from you. I also always welcome any craft items that you no longer need. Equally, if you are sorting out any cupboards, lofts etc I always need new stock to take to Car Boot Sales, which I attend throughout the year.

On the subject of my knitted dolls -

As ex Olympic Games Makers we often get invited to other events. My friend Sheila, and I, recently attended The Clash of the Titans, part of the Sports Relief weekend. Many of us wore our uniforms, many others wished they had!

Beside me sat a complete eccentric - not only in his full GM uniform, but complete with jesters hat and bells! He would not rest until he got presenter Gabby Logan to wave to him! We got into conversation and ended up discussing MND. It turns out his dad died of it. I told him about my fund raising, and how I am knitting mascot dolls for the Commonwealth Games. He is going to be a volunteer “Clyde Sider” so he asked me to post him one of my dolls, which I duly did. When his mum saw it, and heard about my fund raising, she asked for one as well. I will be attending the Games, and hope to meet up with him. I will also be making some World Cup mascot dolls - so watch this space.

Lin Jenkins

Nurse Anne ran for Angela

Nurse Anne Crean, pictured right, ran the Reading Half marathon in memory of an inspirational Berkshire teacher who died from motor neurone disease.

Mum-of-four Mrs Crean raised about £1,000 for the branch which supported her close friend Angela Fung who lost her battle to the devastating condition in December 2012.

The 52-year-old, who works as a practice nurse at Emmer Green Surgery, said: "Angela was a great friend of mine. We first met at St Anne's School in Caversham where my four sons were at school with her boys.

"I went to Lourdes with her and two other friends in 2010.

"The Reading and West Berkshire branch of the Motor Neurone Disease Association was a great support to Angela, her husband Daniel, and their four boys throughout her struggle."

Mrs Fung, from Caversham Park Village, taught French at St Anne's School where a Rockin' for Angela



concert was held following her death, aged 53. It has since become an annual event. (see story on Caversham Rock 'n' Ale Festival)

Her friends have supported the branch in a variety of amazing ways including Mrs Crean's sponsored run which came after her eldest son, 24-year-old Ciaran,

bought her entry into this year's Mizuno Reading Half Marathon as a Christmas present.

She said after the event: "Yesterday was amazing and I must say I really enjoyed it.

"He assured me I could do it if I had a goal," said Mrs Crean of Peppard Road, Reading. "My usual distance is 5k at Reading Park Run on a Saturday morning so I have been busy training and upping my distance each week in preparation."

After completing the challenge in March she admitted she had actually enjoyed it saying: "The weather was perfect and the atmosphere and support all the way round the course was fantastic."

To sponsor her visit:

<http://www.justgiving.com/annecrean>

Jane Gilbert

Choir's cathedral tribute to Sean

A prestigious choir will be singing their hearts out as a tribute to popular former maths lecturer Sean Murphy who lost his battle with MND in February.

Sean's wife Dr Kay Murphy had organised the May 17th concert by The Oxford Collutorium with him on behalf of the Friends of Christ Church Cathedral. Now it will be held in his memory with a retiring collection for research work at the Oxford MND Care and Research Centre.

More than 350 people attended the funeral of much-loved 72-year-old Sean at Douai Abbey, Woolhampton, near Reading, on March 3rd and donations of £2793 have since been given to the Association.

A graduate of University College Cork, Sean lectured in maths at universities in Dublin, Reading, and East London before retiring in 2006 from Queen Mary's College Basingstoke. A lover of poetry and music he enjoyed listening to The Oxford Collutorium, a choir of 10-15 singers led by its director, Dr Will Orr, a consultant cardiologist at the Royal Berkshire hospital.

Dr Murphy, a retired consultant rheumatologist, said Sean had been diagnosed with MND in 2012.

She said: "He was very keen for me to organise this concert and was very fond of Will, the director."

The choir will sing a programme of music by both Tudor and contemporary composers at 8pm interspersed with poetry and readings. Wine and soft drinks will be served in the interval.

For tickets, costing £15 for guests, £13 for Friends of Christ Church Cathedral, email: kayseanmurphy@yahoo.com.

Jane Gilbert

No 'pumping iron' here!

A new specialist centre has opened at 7 Clerewater Place, Lower Way, Thatcham RG19 3RF, close to West Berkshire Hospital. Its aim is to help people with disabilities keep fit by providing exercise therapy, using equipment that provides repeated movement, gently and quietly.

The specialist power-assisted equipment works so that no effort is required as it incorporates motors to assist the user in achieving the range of movement required. It will exercise and stretch all the major muscle groups in the body, stimulating them and improving circulation. If they so wish, the user can add his or her contribution to the exercise (i.e. adding strength in the same direction as the motor, not resisting it.)

Types of equipment include cycling machines, 'upright exercisers (rather like those in conventional gyms, except they are equipped with motors), a 'toning table' (which provides gentle mobility exercises in a lying position) and a vibration platform and table.

With space for wheelchairs, the staff at the centre will be able to help adults who have almost any type of disabling condition, following an assessment which ensures that the exercise therapy plan will be safe and tailored to each individual.

Initially, the centre comprises one main facility, a gym equipped with power-assisted exercise equipment. However plans are being made to add a Hydrotherapy pool at some time in the future.

The centre was developed by a not for profit charitable organisation and will charge the lowest rates compatible with providing an excellent service for as many people as possible.

To contact the centre for an appointment or more information, please phone 01635 864561 or e-mail info@westberkshiretherapycentre.org.uk

Val Pearson



Roland's birthday bundle

Meet Teddy Michael Gow who was the special delivery 65th birthday gift for his grandpa Roland Lewis.

Overjoyed Roland, who is living with MND, is pictured with his wife Jennifer Hay, the former branch vice chair, after their bundle of joy arrived in February.

Teddy timed his arrival perfectly for Roland's birthday and lives with his parents, Roland's daughter Mari and her husband Simon Gow, in Talfourd Avenue, Reading.

Roland and Jennifer are also pictured on Page 3 in the Association's invitation to its annual conference in September which arrived with the recent Spring issue of Thumb Print.

Jane Gilbert

Cash windfalls help branch appeal

Two generous donations have given a big boost to the branch's appeal for cash to buy key equipment which helps people with respiratory problems caused by MND.

The Berkshire Masonic Charity kindly gave branch chair Margaret Moss a £1,000 cheque towards the cost of buying several expensive cough assist machines after hearing of the appeal. Margaret is pictured presenting the cheque to branch treasurer Ed Gryglaszewski.

She thanked the freemasons for their latest gift and for their continued support to people living with MND.

Margaret also highlighted another generous donation of £1,500 from Waitrose HQ in Bracknell in memory of former employee Mrs Lynne Dowd who died of respiratory failure caused by MND. Margaret said it was felt the company would appreciate knowing that its donation would be used to help fund the cough assist machines.

Jane Gilbert

It is hoped that proceeds from the Caversham Rock 'n' Ale Festival on June 21 can also be channelled into this project.



ROCK AND REAL ALE IS BACK



Hundreds of people will be flocking to the second Rock 'n' Ale Festival in Caversham this Summer to enjoy beer and bands while raising funds for good causes including the MND Association.

The popular event, first inspired by the death of mum-of-four Mrs Angela Fung from MND in December 2012, was a major success, attracting 400 people last year.

Now her friends led by Reading businessman Mike Ryan have decided to make it an annual event. This year's festival will be held from 6.30pm until 11.30pm on Saturday, June 21, at St Anne's School playing fields in Washington Road, Caversham, where Mrs Fung had been a very popular modern languages teacher.

All the organisers, musicians and bands give their time free and the 2014 charities will be the Reading and West Berkshire branch of the MND Association and the Reading charity Culture Mix.

Reading steel band RASPO, which has performed at The Royal Albert Hall and the Notting Hill Carnival will open the

evening followed by The Bears of Brasnov. Six-piece covers band Rigsby and Down at Dino's, who will play a set of classic rock covers from the 1970s, complete the line-up.

There will also be a bar serving local ales, lagers and soft drinks, red and white wines and food will be provided by Graham's hog roast of Bucklebury. Look out for the balloons at the MND Association's tent where branch volunteers will be raising our profile!

This year's event has been sponsored by The Reading Post, the Parish of Our lady and St Anne's, HIBU Plc, Jelf Group, Conservatree Print and Design and UKLS Studios.

Tickets cost £10 for adults and £5 for under 16s and are available in early May from www.rocknale.co.uk or call 0118 958 4498 (office hours only).

Follow the build up to the event on facebook at www.facebook.com/rocknale

Jane Gilbert

AGM was a puzzler



This year's branch Annual General Meeting was followed by a fun quiz night in aid of the MND Association.

Quizmaster Tony Wainwright came up with a host of brain teasers for the 42 supporters who attended the eggstra special evening on April 12th at Englefield Social Club, near Theale.

The winning team of eight, Rent a Crip, ably led by quiz veteran Alec Jenkins, went home with a clutch of Easter egg for their cerebral challenge.

Our picture shows: Alec (seated) with, from left, Joanna Knott, Fiona Turner, Janet Lloyd, Phil Jenkins, Netta Thorne, Chris Jenkins, and Richard Turner.

Earlier, those who attended the AGM, heard that financially it had been another good year for the branch even though receipts of £45,000 were £5,000 down on the previous year.

Vice chair Phillip Adams presented the treasurer's report in the absence of Ed Gryglaszewski saying that fundraising was up by 50 per cent while care related costs were slightly down due to the effective team of Association visitors who ensure costs are met by statutory services if possible.

"We are still supporting our patients," he said. "This disease has got to be fought. Please keep fundraising."

Our thanks go to the quizmaster and his wife, Tony & Olwyn Wainright, who so generously gave of their time with some really tricky questions to get the brain cells working. Our thanks also go to the Englefield Social Club, who so kindly allowed us to use the club house for the event.

Jane Gilbert

... And from the chair

It's my duty and pleasure to report to you that the Branch is as strong as ever thanks to the work of our stalwart committee and is strong, active and generous - with a reputation for asking questions, challenging and doing when we see what seem to us to be unequal, impractical edicts and also a reputation for generous donations from supporters and as a result, healthy finances.

And of course this is because of the prime concern and aim of the Branch is the care and support of those people living with MND in our patch. This is mainly carried out by the Association Visitors (AVs) who give so much time and concern to help make the MND journey smoother - from phone calls and visits to Drop-ins, liaising with health and social care professionals and services - it can be and often is a demanding role since AVs must also meet regularly and report back on what's going on.

Starting Carer's Support meetings during the year we then found NHS funds for Respite for Carers, up to £300 pp. This encouraged carers to take some respite, be it a day out, a gardener, chiropractor or hairdresser.

We must pay tribute to the six AVs who 'look after' about thirty people living with MND who have asked for support. We are always on the lookout for new AVs so if you know someone who'd make an AV do ask them and let us know so we can tell them what's involved.

All our committee members contribute in many ways to the successful running of the branch, each in their own area working alongside the AVs these all help to achieve our aim: **the care and support of people living with MND.**

If you could help, we need someone to look after the Website and another to be Branch Liaison for linking with other organisations eg Memory Giving

I am proud to tell you that it has been a successful year and Team MND will work next year once again to achieve this and to continue our work for those with MND in the area.

Margaret Moss

If you would like to receive newsletters by email please contact Val Pearson:

Valerie.a.pearson@btinternet.com

Please also contact Val if you know of anyone else who would like to receive a copy of the newsletter by post or email

What's On?

CARER SUPPORT GROUP

Thursday 22nd May

The next Carer Support Group Meeting will be held in a meeting room at English Martyrs RC Church, 64, Liebenroad Road, Tilehurst RG30 2EB, from **2.30 – 4pm** on **Thursday, 22nd May, 2014.**

Judy Davies, the Chaplain at Duchess of Kent House, will be joining us to discuss end of life issues. Anyone involved in the care of someone living with Motor Neurone Disease, is most welcome.

If there are difficulties in arranging care to enable you to come to the meeting, please ring Joanna Knott (0118 984 4495) to discuss.

DROP IN / Tea Party

Monday 30th June

Sue Ryder Hospice, Nettlebed

Includes a hand-massage therapist and a talk about the hospice

MND Association

Stall at Fawley Hill Show

Fawley, Henley-on-Thames RG9 6JA

May 17th / 18th

2014 World Cup Rock Party

Max Hunt, leader of West Berkshire-based "Yes" tribute band "Fragile", is getting fans rocking again for MND funds in support of the band's founder member Tom Dawe who is living with the disease. Earlier this year Max, from Newbury, whose mother Pamela died from MND, staged an impressive Fragile gig in Hungerford to raise £700 in funds for the branch. This time the band is performing in Tom's home town and looks like it will be quite a party for both rock and football fans.



The party, which will include live screening of England v Italy is on **Saturday 14th June** (doors open 2.30, live bands from 3pm) at **The Holbrook Club, N Heath Lane, Horsham RH12.**

Bands include Spoof Led Zeppelin, Fragile featuring Claire Hamill plus Hardtail (Classic Rock Covers) and The Jawbreakers (Surf Rock, Jump Jive and more).

Tickets cost £18 in advance, £20 on the door and £10 for under 16s and can be purchased by calling 01403 751150.

Friends of Christ Church Cathedral CONCERT

To be sung by THE OXFORD COLLUTORIUM

Saturday 17th May at 8.00 pm

North Transept, Christ Church Cathedral

Director: Dr Will Orr

TICKETS: Friends of Christ Church Cathedral £13 per person - Guests £15.00pp.

White wine or soft drink during the interval.

Tickets can be obtained by contacting Kathryn Murphy on 01635 201254 or by email kayseanmurphy@yahoo.com.

THERE WILL BE A RETIRING COLLECTION IN AID OF THE MOTOR NEURONE RESEARCH UNIT AT THE JOHN RADCLIFFE HOSPITAL.

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