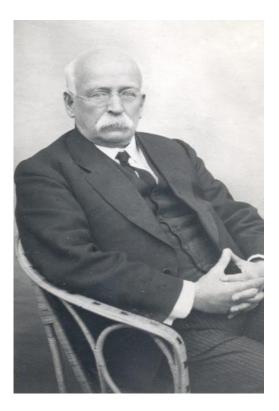


North and East Herts Branch Newsletter

March 2023



Sir Ebenezer Howard OBE - 29 January 1850 - 1 May 1928

Founder of the garden city movement, known for his publication *To-Morrow: A Peaceful Path to Real Reform* (1898)

The first garden city was Letchworth Garden City, commenced in 1903

The second true garden city was Welwyn Garden City in 1920

The National Office Helpline is 0808 8026262 Motor Neurone Disease Association – Registered Charity No. 294354 Branch Patron: Dr Viv Lucas

A Message from the Chair

I have just started a new book, titled *Microjoys, Finding Hope When Life Is Not Okay*, by Cyndie Spiegel.

The world is a difficult place right now: a pandemic, a cost of living crisis, a war in Europe, the rise of the far right, police brutality and intolerance and violence towards everyone who is not like "us". However, even when times are hard, noticing tiny moments of joy such as a robin in a hedgerow can be uplifting for us.

The book's basic premise is that we all deserve joy, even when life is terrible. This doesn't mean constant rewards through treat culture – buy yourself a new jumper! – but seeing the joys that are right in front of us at any moment. As examples, the robin in the bush, my first cup of coffee today and my cat purring on my lap – or the other examples below.



Even when, or especially when, the odds seem stacked against you. When life really seems to be putting you through it. And to know that these things, *these microjoys*, will not fix what is wrong but might help the load seem lighter.

There is no recipe for *microjoys* – no prescribed number per day, no money to be spent and no way in which they must be experienced. They are deeply personal. They do not need to be understood by anyone else, or captured for social media. They do not need to be beautiful or fashionable. *There are a myriad of small daily pleasures that cost nothing and can lift our mood.*

"It is about honing the ability to access joy, despite all else. I didn't get that dream job, I couldn't bring my mum back, I couldn't change my diagnosis, it is not going to change what is. The shitty things have happened. You've lost loved ones, you've lost your job. Those things don't change," she says. "But in building these reserves of joy so that when you need it, is there for you. *It is the lens that you see the world through".* Indeed.

By the end of the experiment, I felt truly changed. It reminded me how much of life is right in front of us and how those things we take for granted as just another spin around the sun, just another day, are actually the pieces of a blissful puzzle. Life is both so cruel and a constant miracle. My life was no different, the circumstances the same, but I was different. I am different.

So, if you take a minute to think about what microjoys you have, what would come to mind?

I have many, many each day – the gift is taking a few seconds to acknowledge each one and smile.

Finance Report – January and February 2023

We have continued to receive some very generous donations during January and February including £385 from the CUI Club in Old Stevenage, £533 from a Christmas raffle at Scarlett Hair Design in Baldock, £730 raised by Letchworth RUFC including £50 raised by the Under 14's Team, £652.50 in memoriam donation and £150 from the NHDC branch of Unison. We have also received £1,623.15 from a Ball held in Cheshunt and £2,450.80 from fundraising events at Welwyn Golf Club, both these amounts were part of larger donations shared between us, South Herts Branch and National Office.

We have been able to fund a number of items including 4 Riser recliner chairs, help with moving costs, a suction machine and a grant for a carer's well-deserved birthday treat.

Heather

Branch Meetings

Friday 27th January - Zoom

For the winter months we have returned to using Zoom for meetings to save journeys in miserable weather. So, the last Friday in January saw us gathering round our screens for our monthly chat.

It was lovely to welcome Justine Cox, our new Area Support Co-ordinator (ASC) to her first Branch meeting and for her to get to know some of our members.

As usual it was not long before the subject of toilets came up and Vernon was able to tell us about his new wet room, which is now completed. He did have some problems with a faulty closomat, but this has been rectified now.

We must have all been feeling hungry by the end of the meeting as we discussed our favourite eating places and especially which ones were wheelchair accessible. Despite all the regulations regarding disability access, some places still seem to overlook details when they are refurbished, such as forgetting to provide ramps where there are internal steps. Richard made us all laugh as he told us of a new restaurant his son had told him about, which had a wheelchair accessible toilet. Apparently, it was easy to get too, you just went down the spiral staircase! It's always good that we find humour in some of these situations.

Lindsey

Friday 24th February - Zoom

We met on Zoom again at the end of February for our regular catch up. It was lovely to see both new and familiar faces at the meeting.

With Spring around the corner, it wasn't surprising that our thoughts turned to holidays and getting out and about. This ranged from issues with wheelchairs, such as Vernon having a tyre blow out, to house modifications for Rick so that he will be able

to go out in his new wheelchair. The meetings provide an opportunity to ask questions and share knowledge. We discussed hiring wheelchair accessible vehicles and using trains and taxis. We also spoke about both travel and wheelchair insurance. I'm not sure whether it says something about our wheelchair users but after hearing about tyre blow outs, hats with built in lights for night-time rides, it was reassuring to learn that the wheelchair insurance does cover you for damage to property or people. Lindsey

Our thoughts turn to Holidays

Disabled Holidays.com - 0161 2600224

DisabledHolidays.com (originally called The Disabled Holiday Directory) was launched in 2001 by a bright lady called Sian (Welsh for Jane and pronounced Shahn). Sian has suffered with Peroneal Muscular Atrophy (CMT) since childhood. Her own difficulties over the years looking through countless brochures at tempting cottages, guest houses, hotels and caravans, but not finding any information that would enable HER with HER disability to decide whether it would be suitable for HER holiday, led to a sense of hopeless frustration.

After many years' experience working in the holiday industry, a personal ultimate frustration over lack of detail led Sian to wonder whether she could do something about it and help the 9 million plus of us suffering from some sort of impairment.

After much research, Sian was able to launch the Disabled Holiday Directory website. Still working from home, but ably supported by her husband John and her PA Peter, she helped people find the holidays they really wanted

DisabledHolidays.com is proud to partner with Goodtogoinsurance.com, a specialist travel insurance provider covering travellers of any age with and without medical conditions. Cover is available for all types of medical conditions, up to high levels of severity, including heart conditions, cancer, diabetes, arthritis, dementia and many more.

Goodtogoinsurance.com - 0330 024 9906

Goodtogoinsurance.com is trading name of Ancile Insurance Group limited who are authorised and regulated by the Financial Conduct Authority, No.471641 No age limits on single trip or annual multi-trip policies, £10m Medical and Repatriation expenses cover available for those on a waiting list for treatment or investigation. A host of additional cover options including many Sports and Activities

AllClear Travel Insurance – 0800 8488608

Travel with confidence with their Travel Insurance for pre-existing conditions. They cover over 1300 different medical conditions. Comprehensive cover for medical emergencies while abroad.

Many thanks to Vernon for names and address of accessible_hotels he has stayed at:

Rothay Garden Hotel	The Hare and Hounds	The Victoria
Grasmere, Cumbria	Westonbirt, Nr Tetbury	Holkham, Norfolk

Room 4

Room 51

Many thanks to Alan who visited this hotel several years ago.

Maison des Landes, on the island of Jersey, combines the relaxing atmosphere of a modern hotel with the very latest facilities for people with disabilities and their carers. Each of the 23 rooms is different, which means that they can select the accommodation that will best suit your needs. Whether that's inter-connecting rooms or specific facilities, they tailor your experience so that you can relax without worry.

Jersey is renowned for its good food, and Maison des Landes is no exception. Start the day with continental or cooked breakfast, enjoy freshly prepared light lunches, or even a cream tea while enjoying the view. In the evening the chef serves a delicious meal, with a choice of dishes in each course. They also have a fully licensed bar for those who enjoy socialising.

Living Well with Isabel Hospice

Building Compassionate Communities. They recognise the huge effect that keeping connected and feeling supported has on our wellbeing. Their Compassionate Communities programme offers a range of opportunities including Compassionate Neighbours, cafés and social meet ups, as well as activity groups and workshops.

Living Well with Isabel service is held in various locations across our community in Welwyn Garden City, Bishops Stortford and Waltham Cross. You can refer yourself to any of these sessions, without the need to come through your GP or any other medical professional. For further information, to discuss your needs, or to attend any of the groups or activities, please email to livingwell@isabelhospice.org.uk, or call 01707 382500 (option 3) or 07593 137359. Further details regarding Isabel Hospice can be found on the website: <u>https://www.isabelhospice.org.uk/what-we-do/living-well-with-isabel</u>.

Address: Living Well with Isabel Community Hub, Douglas Tilbe House, Hall Grove, Welwyn Garden City, Hertfordshire AL7 4PH

website: www.isabelhospice.org.uk tel: 01707 382500 61 Bridge Road East, Welwyn Garden City, Hertfordshire, AL7 1JR

Garden House Hospice

Garden House Hospice Care provides specialist palliative care for patients, families and carers facing life limiting illnesses, to enable them to have the best possible quality of life by providing care and support in the setting of their choice, without discrimination.

Their committed and passionate team offer physical, emotional and spiritual care to hundreds of people each year living in North Hertfordshire, Stevenage and surrounding towns and villages in Central Bedfordshire and Cambridgeshire. Their wide range of free services are tailored with you in mind, focussing on your wellbeing, supporting you to live pain-free and manage the symptoms of your diagnosis, so you can live well until the end of your days.

Rehab and Wellbeing – Hospice at Home – Family Support – Inpatient Unit – 24 Hour Advice Line – Care Home Support – Community Hubs

Garden House Hospice Care Gillison Close L G C Herts SG6 1QU – 01462 679540

Palliative Care Advise Line – 24 hours a day – 01462 416794

The helpline is for patients, carers and healthcare professionals.

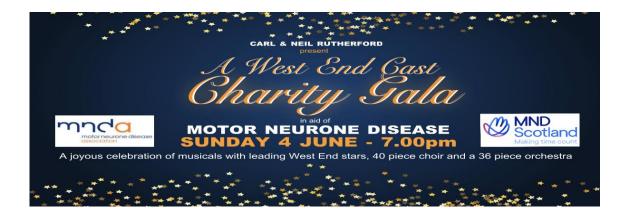
It gives direct access to nurses with experience in palliative care who can offer advice and support or guide you to other appropriate agencies. If medical advice is needed, the nurses can speak to their team of doctors. You do not need to be referred to their services to be able to use this advice line.

Fundraising

Due to the postal service introducing the new bar-coded stamps, it has left the value of stamps plummeting in value, leaving charities no choice but to discontinue collecting after 30th April 2023. Many thanks to everybody for all the stamps you have sent in, supporting the branch.

If you have not already booked your tickets for the Gala please go to the Gordon Craig Theatre website – <u>www.gordon-craig.co.uk</u> or call 01438363200

Additionally, there will be a beautiful moment of remembrance within the performance. If you wish to remember someone who had Motor Neurone Disease, please send a digital jpeg photograph and their name to <u>neil@neilrutherford.com</u> and they will be remembered in the performance.



Saturday 8th July

The Herts County Walk – Stanborough Lakes – Welwyn Garden City

Future Meetings and Events for your Diary

Daytime Group - Zoom - 3rd Tuesday of every month Tuesday 21st March 11am For more information contact - <u>Liz.Cooper@mndassociation.org</u>

March Branch Meeting - Face to Face - The Three Horseshoes Monday 27th March 11am

Evening Carers Group - Zoom - Carers only - Last Wednesday of each month. Wednesday 29th March - 6.30 For more information contact - justine.cox@mndassociation.org

South East Carers Coffee & Chat - Zoom - Carers only - First Tuesday of each month Tuesday 4th April 11am ID Code - 829 5957 3420 Password 670598 For more information contact - <u>lisa.burnard@mndassociation.org</u>

Daytime Group - Zoom - 3rd Tuesday of every month Tuesday 18th April 11am For more information contact - <u>Liz.Cooper@mndassociation.org</u>

April Branch Meeting - Face to Face - The Three Horseshoes Monday 24th April 11am

Evening Carers Group - Zoom - Carers only - Last Wednesday of each month Wednesday 26th April - 6.30 For more information contact - justine.cox@mndassociation.org

South East Carers Coffee & Chat - Zoom - Carers only - First Tuesday of each month Tuesday 2nd May 11am ID Code - 829 5957 3420 Password 670598 For more information contact - <u>lisa.burnard@mndassociation.org</u>

Face to Face Meetings will now be held on the last Monday of the month at 11am at the Three Horseshoes Zoom meetings will still take place on the last Friday of the month at 11am. The Three Horseshoes Hooks Cross Watton at Stone Hertfordshire SG14 3RY 01920 830391