



# Herefordshire Disability United Network News

Summer 2017

Dementia



We welcome articles from individuals and organisations to promote their stories or interests.  
Please contact the Editor..... details on the back page.

## Editorial:

Dementia is something we hear about so frequently and it seems we all know someone with the condition. This is why adopting “dementia friendly” community ideas is a necessity for society.

Many of you will be aware of the “Leominster Meeting Place”, where people with dementia can express themselves, enjoy activities and simply be part of society. The project has been so successful that a similar idea is being considered in Ross on Wye.

On 9th June a group of like minded people met at Alton Street Surgery, Ross, to hear from the Alzheimer’s Society and the Dementia Action Alliance (DAA) on how such a scheme could begin. Around 25 people attended, from all walks of life, and there was a great buzz of enthusiasm to see such a scheme rolled out.

Where do you start? Who wants to be involved, how much time and money will it cost? We were guided through the basics. The Alzheimer’s Society are happy to run hour long courses demonstrating what is necessary, to understand how to include people with dementia in everyday life, why they do certain things and how to make them feel at ease.

There are Dementia champions, and Befriending opportunities, or just becoming a volunteer. But the DAA work on local action plans, bringing together all aspects of the community not just social care. This could be shops, libraries, or community centres, which provide that extra service, financial institutions such as banks, and education establishments, all doing their bit to guarantee understanding of dementia is universally accepted.

So what transpired at Alton Street Surgery is that four volunteers decided to step forward to form a Steering Group. HDU is one of them, along with Ross Age Concern, Walford Community Centre, and a volunteer with the Alzheimer’s Society. We will meet and discuss our ideas for a simplistic action plan, as suggested by the DAA. We will sign up with them and then look at what small steps we can take to get a local DAA established. Once we have a foundation on which to begin, the 25 interested parties from 9th June, and any others we meet along the way, will be encouraged to meet up, and begin our strategy working together.

We would like to see training sessions, and community involvement. Small groups already operating in the Ross area will be encouraged to share good practice, and hopefully regular activities will emerge, all for people living with dementia at the heart of everything we do.

If you think you are interested please let me know. We need to hear from those with dementia and their families/ carers too.

Contact details are:

**Email: [sylvia.nicholls@btinternet.com](mailto:sylvia.nicholls@btinternet.com) or  
Ring 07817 473 813 our dedicated line.**

**The Editor**

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A date for your  
diary

Thursday

9th November

Shire Hall,

Hereford

Technology

Event

10.30—3.30

Check our website for  
details

[www.herefordshire  
disabilityunited.org.uk](http://www.herefordshire<br/>disabilityunited.org.uk)

Herefordshire Disability United (HDU) is an organisation that has developed to voice the concerns of disabled people, and to provide a platform where disability issues can be raised and policies developed.

HDU is run by people with disabilities for people with disabilities. It was started in January 2011, and has grown to be an acknowledged organisation representing service users, and their families fighting for a better future and understanding.

HDU take part in consultations to highlight issues that affect persons with disabilities.

Our networking is effective with representation via public sector officialdom, providers and the third sector, local and national businesses to improve their practices and policies.

We are a democratic, non sectarian, non party political organisation, stimulating discussion to improve outcomes for disabled people.

### Editorial or advertising queries:

Contact the editor on 07817 473813 or email : [info@hdu.org.uk](mailto:info@hdu.org.uk)

### Contact:

**Herefordshire Disability United** welcomes any feedback on Network News, or any of the services it provides.

### Disclaimer:

The views expressed in Network News are not necessarily those of Herefordshire Disability United.

## The reality of dementia



My Mother in Law, Sybil, aged 91 this June has Dementia. She lives in a care home specifically catering for those with this condition in Ipswich, her home town. Let me take you back through the journey to this point.

Sybil had been in good health until 1999 when she suffered a minor stroke. Despite weakness on her left side, she recovered 95%. Life progressed well without issues until 2011 when she collapsed with an Abdominal Aortic Aneurysm, (also known as a Triple A) whilst staying with us. Despite the trauma and an emergency op at Shrewsbury Hospital (we were in Ludlow when it happened) Sybil recovered

well. In fact within 9 weeks she was living independently again in her bungalow in Ipswich. A very strong woman.

However it was during the following year we noticed a distinct change. She repeated news over the phone, talked more about the past, and for the first time forgot our wedding anniversary. Amazingly in October 2012 when her youngest son Roy (my husband) suddenly passed away, she coped with the journey to see him one last time in Gloucester hospital, and then for the funeral two weeks later.

Sybil and I have always been close, and we enjoy a good giggle together. I would still go and stay with her, but noticed a specific deterioration in everyday tasks. After discussions with her other son Lawrence (who lives in Surrey) I put in place some care, weekdays to ensure support with shopping and cooking a meal. I'd already brought in a gardener in 2011, as that was her pride and joy. She found it strange at first, and her dementia caused us to query was this the right thing. Sybil would complain carers were putting things in the wrong place, but we couldn't be sure if it was Sybil misplacing items herself. We progressed however, adding Saturday to the care too. On a Sunday Sybil would go to church with a friend in the car, and then each week be invited out to a homemade Sunday lunch with different friends from the church.

Winter 2012/13 became more of an issue when her ability to reach the loo in time brought new problems. Sybil also went out to the local shops at odd times. The parade of shops within ten minutes walk (20 for her) had all she needed. Sometimes on return she would get lost, but because of the community in her suburbs, she would be "returned home" by some kind soul. The "panic button" alert Sybil wore round her neck was used more and more. Neighbours or Sybil's sister (also in her 80's) would ring me, and her niece too. All people whom responders contacted if Sybil had a fall or was unwell. Everyone was kind but we needed to address the issue of living independently, as Sybil insisted she wanted to. During 2014 we put Sybil's name down on the waiting list of two care homes, and trusted fate to take a hand.

## Enjoying life with the right care

Christmas 2015 when my grandchildren were back in the UK from Houston for the festive season, we all met up at Lawrence's home to share the occasion. Sybil didn't recognise her great-grand children, but was happy with the huge group assembled together. They certainly were pleased to see her again, remembering better times.

In March 2016 a vacancy became available at Norwood Care Home in Ipswich, situated next to Christchurch Park, a huge green space in the centre of town. Sybil knew the home as her cousin had reside here for 10 years. She agreed it was time to move, and I went across and helped her pack. She enjoyed the process, deciding what would be kept and moved with her. This included furniture too.

Lawrence came and did the physical move of property into a ground floor room which overlooks the park. It was when I then set about sorting Sybil's bungalow for sale and discovered the depth of "neglect" Sybil had lived through. Not one item of clothing was clean, and stains on her carpet and furniture told the true story. Sybil's decision to be independent at all costs was being unraveled.

Norwood Care Home is brilliant, with around 30 clients. My first visit a month later showed how Sybil had settled. We went for a walk in the park next door and enjoyed ice cream together whilst watching the wild life and children at play. Two weeks later though, the staff found Sybil sitting on her bed in agony. Somehow she had broken her hip, but struggled back onto the bed. An op followed but this marked a sharp decline. Sybil's memory had lapsed terrifically. Although the hip healed well, Sybil has forgotten how to walk, now uses a wheelchair and is hoisted into chairs/ bed etc. Sybil has become doubly incontinent and sleeps a great deal too.

The care home though ensure clients are taken to the daily activity room, and there is not a central TV room where residents are left without thought.

For meals two dining rooms accommodate the clients, split between the more able, and those who need extra help. The able have a cafeteria style room where they pick their delights. The less able eat in another room. When all are seated, staff offer choice of meals, not just by asking what they want, but by showing the meals platted already. This is for all courses. Best of all, is when the chef comes from the kitchen and pours a sherry for each client who would like one before their dinner.



Sybil is thriving. When I visit she thinks I'm her cousin, but welcomes me with a bright smile and a kiss. We still go into the park for walks but I push the wheelchair. So whilst Sybil can no longer read a book or paint beautiful water colour pictures, she is still enjoying life and is incredibly happy.

The Editor

## I am a Dementia Survivor



(This article nearly did not make it to print as I am constantly being interrupted by my husband. He can no longer “take a hint” and leave me in peace when I am working on the computer and wants to know what I am doing all the time even though I may have told him the same thing a few minutes before. It’s no good getting cross although I have just had to tell him firmly to leave me alone for a while and I now feel guilty for having hurt his feelings although he will soon forget.)

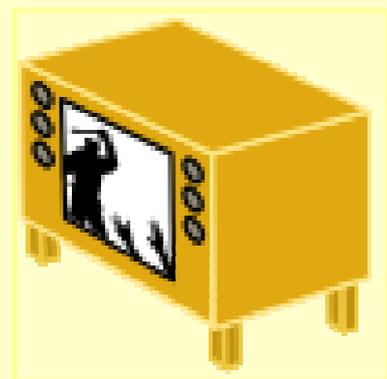
There are many kinds of dementia, but I think the most cruel kind is that which leaves the person aware of their condition, and that there is no cure, and they can only get worse. Fortunately, they are only aware of this part of the time and for us the word “Dementia” has to be avoided as he can’t come to terms with the diagnosis.

Neither can he come to terms with not being able to drive anymore. He thinks he is capable of cooking and I have more than once come home to find a saucepan on the stove glowing red with it’s contents splattered over the kitchen wall. Also he recently put the electric kettle on the gas hob!

I am what is known as an “informal carer” so in other words I look after, am responsible for, someone (my husband) all the hours that he is awake. I therefore call myself a Dementia Survivor as it is a real battle to get through each day.

Dementia is insidious, little by little it steals away not only a person’s memory but also their character. From being a gregarious person who liked to be outdoors with his dogs, and made decisions concerning his business, every day he is now a man “old before his time”, who can only decide what he wants to eat or what mindless TV channel to watch.

He does not want to go outside the house even to walk around the garden anymore. He rarely smiles and does not laugh at anything other than what is on TV. That is very sad.



I have lost my partner, he has regressed into a second childhood, but whereas you can tell a child not to do something you can’t tell a man who still thinks he should be the boss.

He can’t help me to make any decisions now although I do discuss things with him, but he is obsessed with money so I try to avoid that subject.

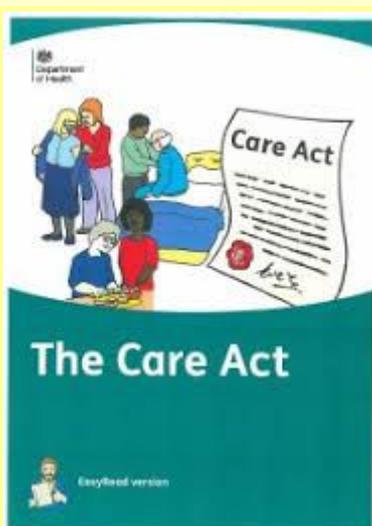
## But life is very hard

I have no time anymore to listen quietly to music or to paint out in my summerhouse. He comes to find me and demands that I come in to keep him company, so in I go and then he just goes back to watching TV.

I can get out in the garden for a couple of hours so long as I frequently go past the window on my scooter for him to see me.

As I need to use a wheelchair all the time indoors I have a Direct Payment from Social Care for my own needs. I used to have sufficient hours for my personal assistants to also help me to help my husband, but the recent cuts in the social care budget have left me traumatised.

I have lost count of the number of times one of the 3 social workers now assigned to us has visited in the last couple of months. My needs have to be separated out from my husband's needs, but of course as his needs are mostly met by me I need help to do so, but that can't be considered.



My Carer's Assessment has given me a little time away from home each week so long as I pay the mileage, but no help whatsoever to be a carer at home. I have been worried sick, literally, about how we will cope, my mental state is very fragile and I hardly sleep. I think it would be laughable that my husband only qualifies for half an hour per day of help but who's laughing?

Seems the only obligation Social Care now has, is to see you are washed, dressed and fed but nothing beyond that in the home. I do get help to access the community and shop for food as well, so long as I pay mileage to my personal assistants.

My daughter is coming to live with us as she is well aware that we could not cope on the number of hours allocated. I never wanted to be so reliant on her but can see no alternative.

We need to build on upstairs to provide accommodation for her and her son and in order to do this have released some money from a pension my husband has. However, guess what!!! That is now counted as capital so my husband does not even get his half hour per day from Social Care, and we must pay for it ourselves as well as the cleaning etc., etc.

I hope that I continue to be a Dementia Survivor but it's awfully hard just now!

**Written by Barbara Millman, Vice Chair of HDU**

## Young Dementia



### Young Dementia Herefordshire

Active, Out & About, Adjusting to Life with Early Onset Dementia

The original concept of the group was to be able to go "out and about" and show that dementia doesn't mean you can't do the things you enjoy.

The first group meeting was the idea of Helen Purkiss OT and Isabel Kirmes OT who were looking after a gentleman who was diagnosed with Alzheimers in his late 50's. He was an ex army brigadier general who had been very active playing golf, riding bikes etc and wanted to meet like minded people living with early onset dementia and socialise.

May 2013 the group was formed and originally was known as "Out and About". The first meeting was attended by about 8 people who were either diagnosed with a form of dementia or their carers and the two OT ladies.

The name change came fairly quickly and we have since been known as "Young Dementia Herefordshire". We were having monthly group meetings at The Friends Meeting House, King Street, Hereford but since September 2016 have been meeting the last Thursday of the month at The Courtyard, Edgar Street, Hereford.

Financial sponsorship has come from Harley Davidson Motorcycles in Gloucester, Rotary Club of the Marches, Cargill, Asda and several private donations.

Our aim is to show that being diagnosed with dementia does not mean you have to give up and to continue to enjoy life and to help each other and exchange experiences.

Contact details are:

Phil Morris, email: [morrisgoon@aol.com](mailto:morrisgoon@aol.com)

Mobile number: 07922 042 434.

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Also check out the Courtyard Theatre Hereford, which is heavily involved with promoting events for all people with dementia. Their website is:

<http://www.courtyard.org.uk/search/dementia>



# Herefordshire Carers Support



**Herefordshire Carers Support** run courses over a period of five weeks which are planned to cover “Understanding Dementia and Living Well”.

## Are you an unpaid Carer looking after someone with Dementia?

Knowing that the person you care for has Dementia/ Alzheimer’s is difficult enough to say the least, and Herefordshire Carers Support believe that by providing Carers with as much information and preparation as possible, it will enable them to give the best possible care. It is also a huge relief for the Carers to meet others in a similar position, and know that support is available.

### Week 1. Introductions

To begin, in this first session we take the time to introduce ourselves and explain our caring roles; take at how we feel we are coping, discuss types of Dementia and look at some statistics.

### Week 2. Information

In this second session, we explain how Dementia can affect the brain, memory and impair our ability to function or understand the world as we once did. Discussions around how this relates to our own circumstances, changes in the person we care for and look at things from their perspective as well as discussion around coping strategies.

### Week 3. The carer For

This week we look at any legal aspects which may be necessary for us to consider, focus on local support services with the introduction of local service providers and a range of information available for the continued wellbeing of both the Carer and Cared for.

### Week 4. The Carer

As Carers, we need to consider ourselves and during this session we will talk about planning for our own needs as a Carer so we will look at support options that we may wish to consider; emergency and longer term contingency planning; formal assessments, benefits and counselling services.

## Courses we offer to Carers

### Week 5. Recap and Evaluation

During week 5 we re-cap on the previous 4 weeks; discuss how we are feeling; consider next steps to take and the support needed along the way for both the Carer and Carer for.

Evaluation– How was it for you/ what could we do better? Not forgetting some photos.

In order that you get the most out of this provision, **you will need to attend each of the five sessions.** For more information or to book a place please contact:

**Herefordshire Carers Support on 01432 356068  
or email: [help@herefordshirecarerssupport.org](mailto:help@herefordshirecarerssupport.org)**

## Tomorrow's World

The University of Pennsylvania which is researching machine learning for patients with dementia have discovered some interesting facts. They've used it to analyse brain signals and stimulation to boost memory.

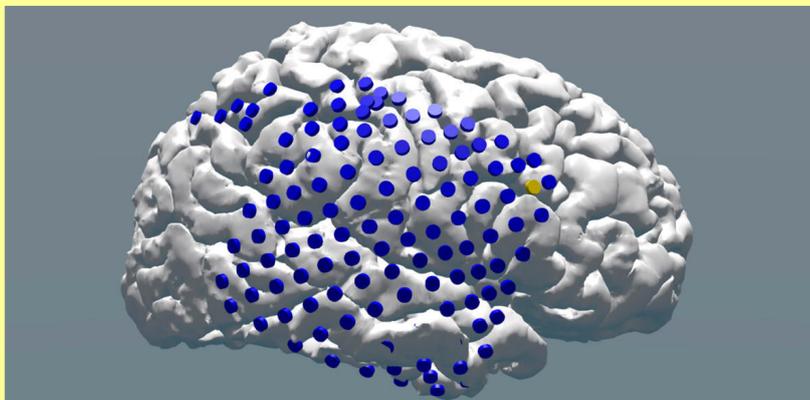
A team of researchers led by Psychologist Michael Kahana ran a four year project investigating memory loss and electrical stimulation.

To get to this point, the "Penn Team" first had to understand and decode signalling patterns that correspond to highs and lows of memory function.

During this process, the Penn Team recorded electrical activity from electrodes implanted in the patients' brains as part of routine clinical care. These recordings identified the biomarkers of successful memory function, activity patterns that occur when the brain effectively creates new memories.

"We found that, when electrical stimulation arrives during periods of effective memory, memory worsens," Kahana said. "But when the electrical stimulation arrives at times of poor function, memory is significantly improved."

Kahana likens it to traffic patterns in the brain: Stimulating the brain during a backup restores the normal flow of traffic.



Check out this website where these details have been taken:

<https://news.upenn.edu/news/penn-researchers-show-brain-stimulation->

## Creative ageing at the Courtyard



A huge part of our Creative Ageing participation programme is working with artists, care homes, and community groups to deliver high quality arts experiences for older people.

We specialise in how creativity in all its many forms can aid communication with people who are not able to engage in a way they once were. Working with leading figures in the sphere of arts and dementia we offer a

wide range of low cost training opportunities here at The Courtyard.

Take a look at our current training programmes which include Dance training, poetry projects, and regular free dementia friends sessions.

On **Wednesdays 11th July & 15th August, 2.00 pm** at the Courtyard, Hereford they will be running Dementia Friends information sessions last about 45-60 minutes and are **FREE** to attend, **BUT** you are advised to book.

The Courtyard are committed to making Hereford more dementia friendly and so we are now offering monthly Dementia Friends information sessions here at The Courtyard.

### **WHAT ARE DEMENTIA FRIENDS?**

Anyone can be a dementia friend. Being a dementia friend isn't about volunteering or fundraising (though you can if you want) it is about understanding a little more about dementia, and the little ways you can help.

ALSO on **Monday 17th September from 10.00—1.00 pm; Cost £10**

### **COLOUR ME PURPLE: ADAPTING CREATIVE ARTS FOR OLDER PEOPLE**

Training sessions with Jeanette McCulloch, for care staff, activity leaders and arts practitioners. A great big 'Goodie Bag', packed full of useful skills and ideas galore... accessible and affordable ways of running art sessions with Older People.

Mark special times of the year with decorative garlands. A simple card wreath can be decorated throughout the seasons, using fabric, crepe paper, tinsel... Jeanette will provide information on how art activities can be adapted for older people in a variety of settings.

To book : [boxoffice@courtyard.org.uk](mailto:boxoffice@courtyard.org.uk)

Or ring **Box Office – 01432 340555**

## Financial Help

We understand that estate planning can be difficult and worrying to think about. However, it is important to organise your affairs and have full control over what happens to your assets, or those of someone you care for.

A Will is perhaps the most important document you will execute. If you die without making a Will it is left to the law to determine who inherits your property and who will administer your estate.

Having the right components in your Will brings peace of mind ensuring that loved ones are provided for in the manner you want. You may also wish to consider tax issues and whether any other lifetime planning is appropriate for your circumstances.



We are supporting the Midlands Air Ambulance charity's Free Will Writing Service, which is available for those aged 55 and over. Remembering Midlands Air Ambulance in your Will helps save lives in the future. Our legal representative, Zoe Smith, will be attending the Dementia Awareness Day on the 21st June and she will be happy to discuss this or any other matter with you.

A Lasting Power of Attorney is a critical document to prepare to ensure that your legal, financial and health affairs are dealt with in the proper manner. If a situation arises where you become incapable of dealing with your own affairs, either mentally or physically, an attorney will need to be appointed to administer your affairs. If you leave this until you become incapable of making your own decisions, the process through the Court of Protection is far more complex and expensive.

Solicitors are not allowed to discuss the financial implications of a Lasting Power of Attorney, funding of care or the protection of assets but we are in partnership with St James's Place Wealth Management. They offer face-to-face wealth management advice tailored to meet your own specific circumstances. A representative will be joining Zoe at the event on the 21st June where they will also be available for questions.

For any further information please do not hesitate to contact us:

**Ring 01432 278179**

**Website: [kidwellssolicitors.co.uk](http://kidwellssolicitors.co.uk)**



## The Alzheimer's Society

The Alzheimer's Society is committed to generating different ways to support people affected by Dementia, whether as part of Dementia Awareness week, or throughout the year. Do have a look at the facts and figures, and if possible online at the links seen below.

### Turning Up the Volume –Unheard Voices of people with dementia

[https://www.alzheimers.org.uk/downloads/file/3545turning\\_up\\_the\\_volume\\_unheard\\_voices\\_of\\_people\\_with\\_dementia-49k](https://www.alzheimers.org.uk/downloads/file/3545turning_up_the_volume_unheard_voices_of_people_with_dementia-49k)



This State of the Nation project has been our largest ever consultation with people affected by dementia about their day-to-day life.

We spoke to three groups of people: people living with dementia, carers of people with dementia and the general public. We engaged with nearly 4,000 people.

We worked with our research agency, Ipsos MORI, to develop four research strands for the project:

1. An online quantitative survey of 2,356 people from the general public
  2. In-depth interviews lasting 60 to 90 minutes with 32 people living with dementia
  3. An online survey of 500 carers of people living with dementia
  4. A short face-to-face survey with 966 people with dementia who use our services.
- Our amazing volunteers helped us carry out the survey across our services in England, Wales and Northern Ireland.

#### Locally:

Our **Service User Review Panel** is now up and running. A small group of people with dementia meet on the last Tuesday of the month at 178 Widemarsh Street to review and influence resources and topics that affect people living with dementia nationally and locally.

#### Dementia Awareness Week

Nationally did you see our United Against Dementia adverts on ITV and Channel 4? Locally many people joined us in 'Uniting Against Dementia in Herefordshire' creating a map of individual pledges which has been at the Courtyard since 'Remember Me' day and is now on display in our office entrance. Many people around the county supported the week in many ways. From Dementia Friends sessions to sponsored walks, tea dances to information stands - Thank you to everyone involved. The campaign has communicated how now, more than ever, people must put aside their differences and come together to tackle dementia – because dementia will affect us all.

## What's going on in your locality?

### Innovation Fund supporting 12 month project in Herefordshire Learning Disability and Dementia Project

#### **The Courtyard Hereford:**

Initial Information Meeting at the Courtyard Theatre 30<sup>th</sup> June 10.30 – 13.00

Please ring 01432 371137 for more information.

Also see page 12 of this publication for activities specifically devoted to Dementia.

#### **Kington:**

Please help us to get the word out that there is currently a Memory Café **or** Singing for the Brain at the Burton Hotel on 2<sup>nd</sup> Tuesday of each month. We need more attendees to continue offer this.

#### **Leominster:**

We also have spaces at Leominster Memory Café and Leominster and Ledbury Singing for the Brain.

#### **Ross on Wye:**

A recent meeting on 9th June was held at Alton Street Surgery to see what interest there is in Ross to how a local Dementia Action Alliance might work, also consider if that is something to take forward / how we might support that.

If you would like to make contact with the Services Manager in Hereford, details are:

**Alzheimer's Society**  
**Unit 6, 178 Widemarsh Street, Hereford, HR4 9HN**  
**T: 01432 371137**  
**M: 07834619545**  
**Email: [ginnie.jaques@alzheimers.org.uk](mailto:ginnie.jaques@alzheimers.org.uk)**



**Here for everyone affected by dementia**  
Get in touch today to find out how we can support you  
**01432371137**  
**[herefordshire@alzheimers.org.uk](mailto:herefordshire@alzheimers.org.uk)**

The banner features a photograph of a man with a white beard and glasses sitting in a wheelchair, with another man standing behind him with his hands on the man's shoulders. The Alzheimer's Society logo is visible in the bottom right corner of the banner.

## Befriending.....

Through completing the RSPH (Royal Society for Public Health) course in Understanding Dementia, plus a Dementia Befriending course alongside, I soon realised that Dementia is so much more than just memory loss that accompanies the ageing process. Because everything we do is controlled by the brain – including speaking, swallowing and breathing - brain failure is terminal.

Although there is currently no cure, there **is** hope, partly through medical research and partly through helping people to live well with Dementia. As well as a much better understanding of the medical and social aspects of Dementia, the course taught me some invaluable approaches that I would take forward with me to my befriending experience:-

\* **Validation:** Dementia forces sufferers to live in their brain's version of reality – they can't change their behaviour so you have to change yours. Step into their reality, If they say things that you know are inaccurate or impossible, it is pointless and upsetting on both sides to argue the point, whereas going with them will more likely make them feel safe and happy.

\* **Emotional Memory Retention:** Sufferers can usually hold onto feelings, not facts and can continue to feel happy long after the visit or experience they may have forgotten. It is more important to have a conversation that makes them feel good than it is to have one that is completely accurate.

But what I could never have imagined or learnt was what a deeply personal and emotional human experience my visits would be for me too. Here is just one example which still makes me reflect on love, life and the power of human contact.

The visits were with people in fairly advanced stage of Dementia, living in care, typically not able to recognise family, incontinent and unable to get around on their own. Patients and befrienders were loosely matched. The e.mail came out for Patrick (not his real name) with Irish roots (tick), catholic (tick) sense of humour (tick) loves music/poetry (tick) – this one was for me!

The first time I visited Patrick I 'rescued' him from the after lunch game of bingo in the main room and we went off to his room sharing a giggle about his lucky escape and that set the tone for our easy rapport. There were clues around the room to help the conversation flow; a picture of his 80<sup>th</sup> birthday and his wedding photo, though sadly he had no recollection of the event or the fact that he had a wife. Although in his wheelchair, he was obviously a tall, smart man, nicely spoken and still with an Irish glint in his eye – all these things that help you to look at the person, rather than the disease. As I left he held his arms out for a hug and I told him honestly that I had enjoyed our time together and would visit again next week.

On the second visit the nursing staff said the visit had made him happy, but when I got to the room it was of course like meeting for the first time.

## A personal experience

So I introduced myself and we started over again, but now I was able to inject little things into the conversation that he had told me last time to help us along. And so the visits went on, still as enjoyable as the first and we laughed a lot together too, especially when he couldn't remember a word and substituted a particularly ridiculous one. He talked about his apprenticeship years with the military and in detail about the planes he worked on and flew in. Also his school years and especially his arduous walk to school across fields. Of course, I had no way of knowing how much of it was true memory, but I decided to keep a diary with the idea of giving it to his family – he'd told me of his sons and daughters. He talked about meeting his first love and when he said her name I recognised this to be his wife, but he didn't make the connection. He had some lovely ways of pursuing and courting her, and I put it all in the diary when I got home, just in case.

You are in a unique position as a befriender, because you are one-step-removed: you don't get upset when they can't remember your name; you don't get cross at them for repeating the same thing. You can just enjoy the moment with them instead of trying to put them right and hoping upon hope that they will improve.

One day when Patrick was talking about his Irish home, he talked of the light that came in through his bedroom window and how he never wanted it to fade.....and then, this lovely man, who couldn't even remember what he'd eaten for breakfast, went on to recite all three verses of a poem he'd learnt as a child. That was such a special moment. Having scribbled down what I could remember of the poem, I looked it up when I got home and wrote it out in full in the diary. The irony.....it was entitled 'I remember, I remember'.

I wrote a copy out and left it on his bedside too, in case visitors or the nursing staff wanted to ask him about it. He and I certainly read it together on many subsequent visits.

Patrick was becoming more visibly tired now and on one day when I didn't want him to feel he had to stay awake because I was there, I asked him if we should put some music on. He pointed to the drawer and there on the top lay Mary Black, Cut By Wire, one of my all time favourites. I put the CD on and we just spent the visit holding hands and listening along to the music.

Soon after that Patrick was put on End of Life Care. I still visited weekly, sometimes more now and although the time was mostly spent holding hands with the music playing, it felt just as worthwhile as when we'd chatted the visits away. Even on the evening before he died I sat at his bedside just holding his hand and humming to the music.

At the funeral I did give the diary to his daughter. She said Patrick had told her how he enjoyed my visits – I'm not sure if that was true, but nice of her to say I do think I made a positive difference to his days though and I do know that befriending made a profound difference to mine.

Gill Davis

## Twiddlemuffs... what are they?

About a year ago, I came across Twiddlemuffs on the internet and they ticked all my creative boxes. Easy to make, colourful, worthwhile and possibly a good fundraising idea. It was whilst visiting my mum in a local nursing home, I started making Twiddlemuffs for the residents there with dementia. They have been a great success and feedback from family members and staff has made it all worthwhile.

After a few initial contacts, I had cards printed and set about to 'spread Twiddlemuffs around Herefordshire'. I now give talks to local WI's, Church and Craft groups and also display and demonstrate the Twiddlemuffs regularly at our local Hobbycraft store. Last year, I ran a workshop at The Courtyard as part of their Creative Ageing project and, to date, I have made and distributed around fifty muffs and raised £200.00 for the Alzheimer's' Society.

Margaret Light, an American lady, is the founder of Twiddle© and created the prototype activity/comfort aid for her grandmother, Lily in 1997. Throughout her life, Lily had created beautiful knitted sweaters and delicate embroidery. As she aged, her eyesight began to fade and those wonderful hands became idle. The Twiddle gave Lily's inquisitive hands something to keep them active, engaged and warm.

So what is a Twiddlemuff ? They are knitted creations with interesting bits and bobs attached inside and out.



## Get creative and indulge for dementia

Research has found that Twiddlemuffs provide a source of visual, tactile and sensory stimulation for people with dementia and other memory conditions. They minimise agitation, increase flexibility of the fingers and sooth fidgety hands, as well as being a great comfort and keeping hands warm. They are valued by NHS hospital trusts and care homes in this country and, indeed, worldwide.

Finally, there are many therapeutic benefits to be gained from knitting and indeed other arts and crafts. Being able to think creatively is important to wellbeing. It can reduce stress levels and help with pain relief. (reference: Knit for Health and Wellness by Betsan Corkhill)

If you require any further information, would like to have a go at knitting a Twiddlemuff or would like me to come along to talk to your group, please email me on: [maggiesan@live.co.uk](mailto:maggiesan@live.co.uk) or contact the Editor for my details.



I will be taking part in the HDU event on Dementia at Hinton Community Centre  
21 June 2017 – look forward to seeing you there

Maggie Sanderson

## Useful Contacts

### **NHS Herefordshire**

#### **Patient Advice and Liaison Service (PALS)**

The County Hospital, Hereford

Mon-Fri 8.30-4.30

Office Tel No: 01432 372986

Mobile Tel No: 07825 681801

Email:

[makingexperiencescount@wvt.nhs.uk](mailto:makingexperiencescount@wvt.nhs.uk)

### **Equality and Human Rights Commission**

Freepost RRLL-GHUX-CTRX, Arndale House,

Arndale Centre, Manchester, M4 3AQ

Tel: 0808 800 0082 Website:

[www.equalityhumanrights.com](http://www.equalityhumanrights.com)

### **RADAR, now at Disability Rights UK**

12 City Forum, 250 City Road, London, EC1V 8AF

Tel: 020 7250 3222 Minicom: 020 7250 4119

Email: [enquiries@disabilityrightsuk.org](mailto:enquiries@disabilityrightsuk.org)

**NHS Direct** Tel: 111 (free service)

### **Wye Valley NHS Trust**

The County Hospital

Union Walk

Hereford

HR1 2ER

Tel: 01432 355444

### **Wye Valley NHS Trust**

#### **Community Health**

Vaughan Building

Ruckhall Lane

Belmont

Hereford

HR2 9RP

Tel: 01432 344 344

### **Herefordshire Council and NHS Herefordshire**

Social Services Adult Duty Desk

Office hours 9am - 5pm

**Office Tel No:** 01432 260101

Out of hours: 0330 1239309 adults

01905 768020 children

**Next HDU event details will be signposted on our website**

**[www.herefordshiredisabilityunited.org.uk](http://www.herefordshiredisabilityunited.org.uk)**

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c/o 39 Lea Villa Residential Park, Lea, nr Ross-on-Wye, Herefordshire, HR9 7GP.

Tel: 07817 473813 Email: [info@hdu.org.uk](mailto:info@hdu.org.uk)

Website: [www.herefordshiredisabilityunited.org.uk](http://www.herefordshiredisabilityunited.org.uk)

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