



# Herefordshire Disability United Network news

Autumn 2016



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

## Editorial:

It is very poignant that this issue which covers Care Provider changes, also features a tribute to three of our regular attendees at HDU meetings, David Price and Anthea Penfold and Sue Rennie.

David, who sadly passed away suddenly in May had a condition most people have never heard of, Neurofibromatosis type 1, and his wife Christine has written an article for us on pages 4/5. The photo which accompanies it is a beautiful reminder of them as a couple, who coped with the tragedy which disability brings.

I have written a tribute to Anthea, one of the original HDU committee, who died suddenly in August from a stroke. Just before Anthea's funeral when I had contacted her sister Linda by email, Linda reminded me of the following details.

"In spite of her physical problems, Anthea maintained lively interests, and loved seeing friends, going out on trips (e.g. having lunch at a garden centre or folk museum / going on a couple of outings to Wisley RHS Centre), and attending concerts and the theatre...particularly when her nephews (musicians / an actor-musician) were performing not far from her home.

I do remember Anthea telling me about one of the concerts she attended, smiling broadly, remembering just how proud she felt when watching her nephews perform.

One can easily dismiss the notion that disabled people can lead full and enjoyable lives. Certainly both Anthea and David made valid contributions to their own families and communities, as well as that of other disabled people.

Sue Rennie, chaired Hereford Stroke Club for many years only easing off last year when her husband became ill. Sue was very keen to encourage carers of stroke patients to engage with each other and join in social events to ease their lives.

A recent Making it Real Board meeting which was held at the Aspire hub, Canal Road in Hereford brought together members of Hereford Council and adults with learning disabilities. This unlikely partnership was to iron out what "Easy Read" language and pictures could be incorporated into the WISH website which Hereford Council oversees.

Terminology means different things to different people. When asked if they knew what Assessments are, a shudder of fear was felt, as those adults, consider that mass of paperwork with dread and worry. If they saw "assessment" they probably wouldn't read any further! So somehow by listening to their concerns, a new simplistic type of language is needed in order that such knowledge about essential services and activities actually does reach all audiences.

It's also not just the language which requires thought, but keeping text to a minimum constantly. Work in progress I believe!

The Editor

## HDU newsletter contents and information

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Be prepared

for 2017 and  
changes

Next HDU event  
in March with  
our AGM

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.

## In Memory of David Price

My husband, David, was very courageous in accepting and dealing with his increasing limitations as a wheelchair user.

David had Neurofibromatosis type 1, a hereditary condition which causes multiple benign tumours or neurofibromas on the skin, brain, spine and internal organs. (The location of the tumours will determine how the individual is affected.)

David had the neurofibromas on his skin and spinal cord, which led to difficulties with mobility and continence. He was first diagnosed at the age of 13, and a gradual decline ensued, so that in his twenties he was using a walking stick and then later in his thirties he was using a wheelchair.

As well as his mobility problems, David also experienced cramp, muscle spasms, chronic pain, frustration and depression, eventually leading to quadriplegia, so that he needed all care and support.

His condition deteriorated, but it was so gradual, it was not noticeable on a day-to-day basis. It was only when someone once remarked to me: 'I remember when David could hold a cup', that it made me realise the changes that had occurred over time.

A series of adjustments had to be made, not just physically, as in adaptations to the house and the increasing use of disability equipment, but also emotionally too.

In his early years, David was able to play the violin, learn to drive, paint the most wonderful pictures and walk the dog several miles. His illness robbed him of all of these things and he often felt frustrated. But he remained positive and channelled his energy into things which he knew he could make a difference in.

David always championed the cause of the physically disabled and for years he was involved in the Group for Improved Living for the Disabled, the Hereford Access for All group, and more latterly, the Making It Real Board, where his contributions were valued.

Not one to feel sorry for himself, David always wanted to learn more. He regularly attended a music group, went to WEA classes and was interested in local history and wildlife. He had a huge impact on everyone he met and was known for his cheerful disposition and sense of humour.

Most people who knew David remained good friends. They admired and respected him and listened to his ideas.

In addition to being David's wife, I was also his main carer. I was fit and strong and able to cope with the physical demands that his illness made.

## Written by his wife, Christine



I organised the rotas for his PAs, acted as a second PA for moving and handling, and frequently looked after him on my own at times when he didn't have a PA. For me, the work was relentless, tiring and often lonely, as few people really understood what was involved in David's everyday routine.

Respite care away from home didn't work in our situation, so I organised 24 hour care on 2 occasions, so that I could have a short break away with our daughter, Rachel. Herefordshire Carers Support was available for support, but I personally did not find this support very helpful. Whenever I attended any meetings arranged by HCS, I felt that I was giving more information and support than I was receiving.

The most significant aspect that helped me to cope emotionally with David's condition was our shared Christian faith. We had a good support network of friends at our local church, where practical help was available as well as spiritual. My favourite Bible verse is: 'I can do all things through Christ who strengthens me', which has certainly been true for me over the years, as God has given me the strength to cope with each day.

Sadly, David died in May 2016, but I am proud to have been his wife, carer and friend for so many years, and to have done my best to enable him to maintain his independence and dignity at home.

## A stay in hospital when you can't see!



I had been lined up for a simple hernia op for a while now, and was pleased when a letter arrived with the date arranged. Most people who know me understand I accept my failing sight and make jokes about the situation, but underneath it all going to unknown places without my guide dog isn't something I relish.

After the regular pre-op tests I felt mental attuned to what was planned. A simple day op, and hopefully a smooth recovery returning to my regular swim and Zumba classes, as well as long solo walks with Pickles, my guide dog.

For all my appointments I was accompanied by Rob my husband, and Pickles. Hospitals are notoriously bad for long winding corridors, and plenty of signs, all of which I cannot make out, so navigating on my own was unwise. The day dawned for my op and both Rob and Pickles were there by my side to begin with.

That's when the first issue arose. Unbeknown to me the area where we arrived was for females only. However we wandered in oblivious to other ladies in their dressing gowns, where the notice "No males beyond this point" remained unseen by us. It took half an hour for staff to realise, when we were suddenly ushered into a small private office.

That's when the wait started to worry me, being isolated from others in a similar position where we could have chatted amongst ourselves about the impending op. I was ready from 7.20 am but sat there until 10.45 am, getting more and more anxious.

What people don't understand is, that whilst others can "watch comings and goings, read a book or magazine, these options are not available to me. Time drags when you are nervous, and that day felt like a week.

A surgeon/ anaesthetist appeared, not speaking to me the patient but blurting out, "Has she signed the consent form?" His attitude of superiority blanked any consideration for me the patient. It wasn't me he wanted to address, just anyone to get a signature! Not a good start to feeling comfortable, and demonstrating no one had mentioned my sight loss.

Luckily my operation went well, after which I went to recover in a ward until later that day, in order to check I was suitably fit to go home. This time I had a nurse to help me dress, until Rob and Pickles arrived to take me home.

The story does not end there, rather like the recovery and continued need for NHS input. So disjointed, demonstrating the lack of patient care in Hereford Hospital.

## NHS please take note.

I was advised the District Nurse would visit me everyday to check the dressing on the drain from my wound. By 5.00 pm on my first day home, no visit had materialised. Rob rang Hereford Hospital to check arrangements, being told, ring Ross Community Hospital. This he did and discovered no one had been informed about me. How ridiculous! The next surprise was when a district nurse appeared at **9.30 PM**.

One might imagine a routine would be set up for my daily visit, but no, that didn't happen. It was considered that as a patient you would always be there for them....just as in hospital so they could turn up without warning. If this is community nursing and how community ideas are to be run in the future, **they will fail**.

Again, no one knew how long the drain would/ should remain in situ, but it soon became clear the weight of the drain was excessive and needed completely changing. Surprise, surprise, no one knew how to do it, or where to get a new drain. Surely this isn't the way to run the NHS?

I couldn't go anywhere, make any arrangements or even take a walk with my guide dog. Luckily (if that's what you can call it) I needed to attend A&E when a rash appeared. Hooray, the drain was changed by the emergency doctor service, 12 days before the drain was eventually removed.

Freedom at last, but what a disaster. You can truly understand that patient care is put at risk. Forget the fact that I have sight issues, if this is the way local services work, I'm obviously living in the wrong place. I'd hate to find out that these are issues nationwide.

I will be sending this account to Hereford Hospital Board, The Wye Valley Trust, Ross Community Hospital, Jeremy Hunt, and any other organisation which supposedly oversees patient care.

If you too, have similar stories then please air them. Just because you are better now, and don't want to upset the overstretched nursing staff, hiding the facts is not going to help anyone.

Wellbeing and Preventative care are paramount to better mental health. Depression can easily set in after operations, when adjusting to restrictions and disability/ lack of usual mobility. So much pressure on already overstretched services. Let's get things right and help save money too. **Becky Bettington**

## Counselling – a solution to modern day stresses

### What is counselling?

It is being in a safe place, with a trusted, qualified, person to whom you can talk openly and honestly about your innermost concerns and know that you will not be judged nor expected to be someone you are not.

Counselling is not about becoming dependent upon someone else to change your life, it is about discovering yourself and what gives meaning to your life. Your counsellor can help you find ways of feeling confident about the future, whatever it might hold.

### Why might I want it?

Sometimes life can be challenging: work, relationships, money, bereavement, job security, abuse, homelessness, addictions and anxiety (to name just a few issues) all cause stress.

At these times, you may not be able to discuss how you feel with those closest to you. Talking with a qualified counsellor enables you to look at different ways of coping, helps you to understand yourself and can provide support while you make the changes you want or need in your life.

### When is it open?

Marches Counselling Service (MCS) offers flexible appointments to fit around modern life, including evenings and weekends.

### What is MCS?

MCS is a registered charity that opened in 2010 and provides a BACP (British Association for Counselling & Psychotherapy) accredited service to adults living in Herefordshire.

### Who will I see?

The first step is a discussion with one of our Assessors after which you both agree the best way forward. The second step is deciding the right time and day to meet your counsellor on a regular basis.

### How much does it cost?

The initial meeting is up to 90minutes and costs £45 for individuals and £55 for couples. Clients are asked to pay as much as they can afford for the on-going sessions.

### How do I book?

MCS welcomes referrals from GP surgeries and employers as well as direct enquiries. You can either send an email to [marches.referrals@gmail.com](mailto:marches.referrals@gmail.com) or call on 01432 279906. The office is staffed Monday – Friday from 10am until 1pm. Outside those hours there is a confidential telephone answer machine, so please do leave a message, someone will call you back.

**Continued** 

## Marches Counselling Services



### Where is MCS?

The main offices are in St Owen Street, although other counselling rooms in Hereford and around the county are used if needed.

### What else?

Herefordshire Council recognises that modern life can affect us all, even if we are volunteering. So MCS has received funding to deliver a series of creative workshops, specifically for volunteers, in Hereford. Details can be found on our website:

[www.marchescounselling.org](http://www.marchescounselling.org)

### What next?

Herefordshire is the 3<sup>rd</sup> most rural county in the country, so we are planning to extend our service to offer support in rural locations as well as in Hereford itself. This is a major project and will need time to get established. In the meantime, we continue to offer face to face support on days and times to suit you, our clients.

## Sue Rennie



**I must apologise for the grainy picture of Sue, but hope that it will remind you of the quiet, unassuming person who did so much for Hereford Stroke Club until her untimely death in September.**

**Ironically having supported her husband David through diagnosis of prostate cancer in 2015 and it's intrusive treatment, it was whilst on their first holiday in August when Sue suffered a stroke.**

**During her MIR scan after the TIA, cancer of the brain was discovered, and Sue spent the last few weeks in a hospice.**

**Sue gave her life so freely for others who were coping after strokes, and also took a keen interest in Autism, as her son although reasonably independent was diagnosed with Aspergers.**

**Our thoughts are with her family at this sad time.**

**The Editor**

## Anthea Penfold



It is with sadness that we advise of the death of Anthea Penfold aged 75 years on 8th August from a stroke. Anthea Penfold was one of the original HDU committee members when we set up in 2011.

Anthea coped well with cerebral palsy but her condition deteriorated further after an accident on the deck of a “Tall ship” later in life, resulting in the need of a wheelchair. Her mind was very sharp, and with years of experience, she was able to speak with precision about many aspects of disability, and other aspects of life.

Anthea used an electric wheelchair, but sometimes lacked the dexterity for fine manoeuvres. We were used to that at our committee meetings, when we would hold our cuppas aloft until she had settled into a comfortable position around the table.

Anthea had been chair of trustees at SIL for a number of years, but resigned a couple of years ago when her unstable health often made it difficult to reach Leominster for the meetings. She believed in doing things to the full wherever possible.

Anthea’s resignation from the HDU committee in March 2015, was due to poor health, although she contributed via emails after this date as her knowledge was extensive and we valued her input.

After moving to Ross on Wye, Anthea fulfilled a life long ambition studying at the Open University, to achieve a degree which included the arts and Victorian history. Anthea’s love of books and poetry, She was very good at Scrabble too.

During 2015 further nerve deterioration to Anthea’s shoulders meant less independence as she could not longer control the wheelchair or use her computer. This brought frustration, and a great deal of remaining at home. She did utilise her PAs to type email messages for her, but this meant nothing was private anymore. Anthea had for a long period been a member of the Ross Baptist Church, but had not been able to attend so regularly later in life.

Anthea had four regular PAs, (who became her friends as well) as she needed 24/7 care, and this was funded by a Direct Payment and the Independent Living Fund (now defunct). Anthea’s greatest worry was that with funding cuts she would end up in a home and become institutionalised totally losing her independence.

Anthea was very grateful to her PAs hard work and loyalty, and at Christmas 2015 to ensure they all could spend time with their families over Christmas, she decided to take a respite break in suitable accommodation in the Bristol area. A true caring friend, employer and Christian to the end.

**The Editor**

## Post Polio Syndrome



Polio is a disease eradicated in the a huge percentage of the world, and whilst we accept immunisation against the disease is necessary, many do not understand polio, or the lasting effects on those who contract it.

Strangely enough until moving to Hereford in 2011, I had not personally known anyone else who had contracted the disease, which I had as a baby. In this category are the majority of GPs too, who are required to offer advice/ medicine to such patients but have no real experience in it's effects and treatment needs as patients age.

I have met several sufferers in this county in the last five years, all left with highly complicated effects, pain, disabilities and lives. Many who have had polio as a child, go on to develop the debilitating effects later in life, of Post Polio Syndrome, PPS.

The severity of weakness and disability after recovery from poliomyelitis tends to predict the relative risk of developing PPS. Individuals who had minimal symptoms from the original illness are more likely to experience only mild PPS symptoms. A person who was more acutely affected by the polio virus and who attained a greater recovery may experience a more severe case of PPS, with greater loss of muscle function and more severe fatigue.

Leg callipers are common in polio sufferers, and they often are the outward sign of those who have fallen victim to polio. The "iron lung" a familiar machine in the 1950's worked as a type of ventilator, increasing and decreasing the air pressure to expand and contract patient's lungs because their own were too weak. One person in North Carolina USA, lived for 61 years in one at home until 2009, but still graduated from high school with honours and held dinner parties too. She had help from two carers.

PPS symptoms include:

Swallowing and breathing problems, muscle loss, new or increasing weakness, joint pain, muscle fatigue and pain, cold intolerance, sleep disturbance and general fatigue.

It may be difficult to get a diagnosis of PPS because many healthcare professionals know very little about the condition, or even about Polio. Referral to a consultant neurologist ideally with knowledge about polio and PPS is the best way forward to get a diagnosis and advice.

The British Polio Fellowship has more information about Polio and PPS, and a list of healthcare professionals with an interest in PPS. Contact them at: 0800 0431935

Email: [info@britishpolio.org.uk](mailto:info@britishpolio.org.uk)

or by post:

The British Polio Fellowship, The Xchange, Wilmington Close, Watford, WD18 0FQ

**The Editor**

## A Cybathlon.....what's that?

On Saturday, 8 October 2016 a world premiere happened in the SWISS Arena in Kloten: ETH Zurich organised the very first Cybathlon!

A Cybathlon allows individuals who have lost their limbs or the power in them, to use advanced technology to compete side by side in six demanding disciplines. Athletes are known as Pilots in a Cybathlon, and only compete in one discipline.

You could watch the athletes as they tackled flights of stairs in the new wheel chairs and proved their speed and skill using the most up-to-date modern prostheses. The various races tested how the competitors cope with specific challenges and activities from everyday life.

There were races for athletes with powered arm and leg prostheses, for those wearing a robotic exoskeleton and for powered wheelchairs.

The regular cycling races were something different to that seen in the Paralympics

These cyclists have no use of their legs, but their muscles become powered by electric stimulation.

The effort to complete their course even after months of training leaves them mentally and physically exhausted.

Photo copyright; ETH Zurich Nicola Pitaro



Then there were computer games where paraplegics used brain waves to fight and run over obstacles. A unique brain-computer interface race was held where competitors known as pilots, played a computer game called "Brain runners"



Here the Pilot sat with a cap loaded with electrodes on his head. This was fastened to an amplifier which in turn was connected to a computer.

The computer recognises the brain waves, which enable movements of the brain runners in the race to race, overcoming the obstacles put in their paths. The computer processes the signals sending commands to the runners on the screen. Think of it as "Mario" with all actions completed by the brain signals of the seated operator on their computer.

It's not use just willing the "runner" to duck and dive out witting their opponents, but thinking out the tactics as well as running in the race. It's no wonder the Pilots are absolutely drained at the end.

## Assistive technology racing

The pilots participating in the Brain Computer Interface Race have complete or severe loss of motor function (i.e. paralysis) at the neck level due to a spinal cord injury (SCI), stroke, neurological disease, or another trauma.

Most teams will use electroencephalography (EEG) to detect brain signals; however, other methods, such as near infrared spectroscopy (NIRS), are allowed.

The gentleman below is competing in the Powered Arm Prosthesis race.



Photo copyright : <https://www.skyfish.com/p/cyathlon>

The intricacies of operating such tiny movements to open and close pegs is indeed taking technology to another level. It's not just a case of completing the movement each time, but racing against the clock and other competitors.

New arm prostheses are able to transfer the intended motion automatically from the user to the prosthesis (and can even transmit a sense of touch when handling objects). In addition, these new devices are less heavy and, therefore, more comfortable, making them much more suited to daily life.

In each race, four pilots will simultaneously compete on four parallel tracks to solve six tasks. During the race blue objects may only be manipulated with the prosthetic device. All other tasks will allow the use of both arms.

Cyathlon provides a platform for the development of novel assistive technologies that are useful for daily life. Through the organisation of the Cyathlon we want to remove barriers between people with disabilities, the public and technology developers.

**For more information check out this link** <http://www.cyathlon.ethz.ch>

## Care Provider contract changes

Following the 12 week consultation during the summer for changes to the “Home Care Market”, and Hereford Council’s planned contract with Care Providers, a new tender is being launched to bring in ideas formulated from feedback from both service users and the market concerned.

Following details are taken from a presentation recently aired and being discussed at our Open Meeting on 16th November. **Herefordshire** will be “split” into different areas to ensure Providers can manage both rural and town/city service users, with mileage issues considered to make it a fairer distribution.

“D” pathway – north/south split – 2 providers

“M” pathway – not part of the tender

“O” pathway – 5 zones – 10-13 providers

Incentivisation – recognised for longer term partnerships and delivery of outcomes – financial and non-financial

Data available from August this year is used as base to formulate the packages, demonstrates the complex needs and hours required for service users already in the system.

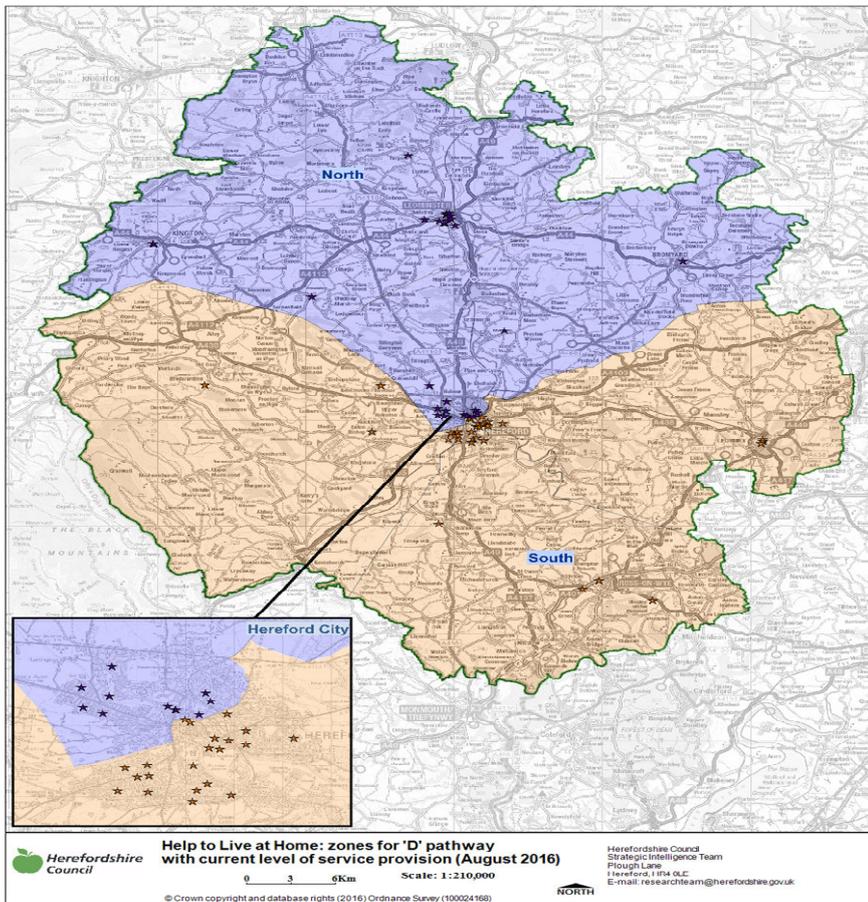
The cost of course is incredible, but only covers those who received care paid for by Hereford Council. It does not include those paying for their own care as their financial situation is above the mean tested amount.

### These costs cover the new D pathway

Zone	Clients	Hours		Costs (£)	
		Weekly	Annual	Weekly	Annual
Complex A & B	31	1,373	71,386	14,516	754,832
Complex C,D,E	31	1,053	54,746	11,754	611,229
<b>TOTAL</b>	<b>62</b>	<b>2,426</b>	<b>126,131</b>	<b>26,270</b>	<b>1,366,061</b>

# Different pathways

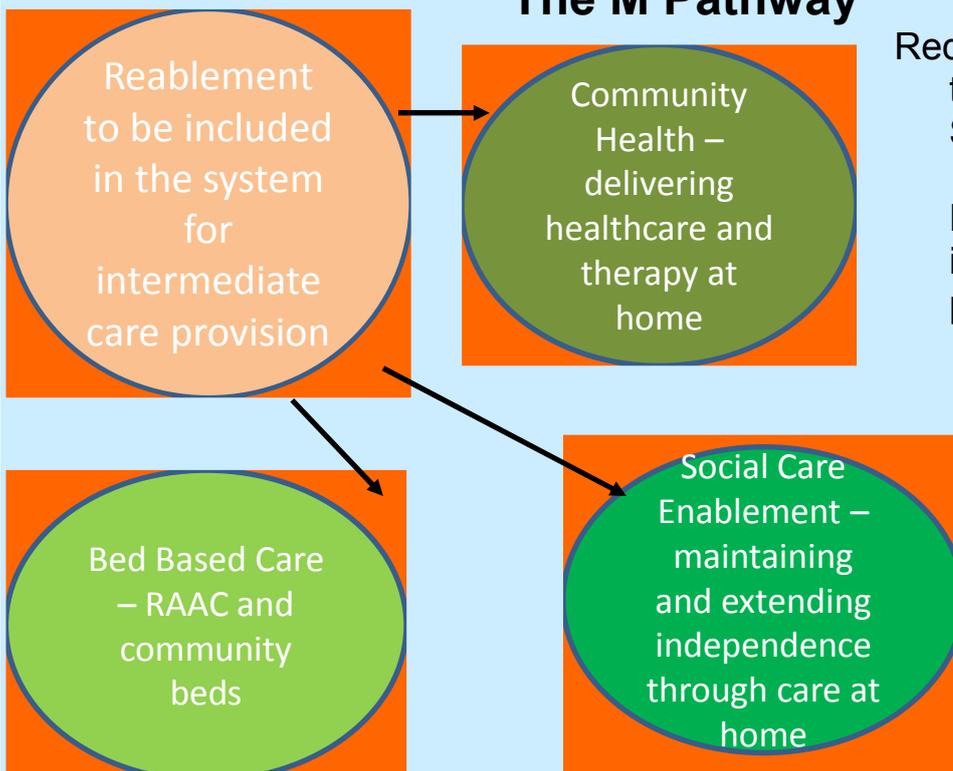
## D Pathway map with the “ north/ south divide” .



This service is re-commissioned as a stand alone “lot”, under the tender process.

- ◆ It includes 28 hour + packages, which are assessed on an individual basis, and determined to be either D or O Pathway case by case.
- ◆ This will contain all 24 hour packages
- ◆ The service will be split over a north/ south basis looking at broadly equitable hours per lot.
- ◆ There will be a minimum of 1 Provider per lot

## The M Pathway



Redesign of reablement through the Herefordshire Health and Social Care system.

Physical and Mental Health interventions and therapy provided by Health.

Enablement to develop confidence and practical skills to carry out essential daily activities of independent daily living provided by Social Care.

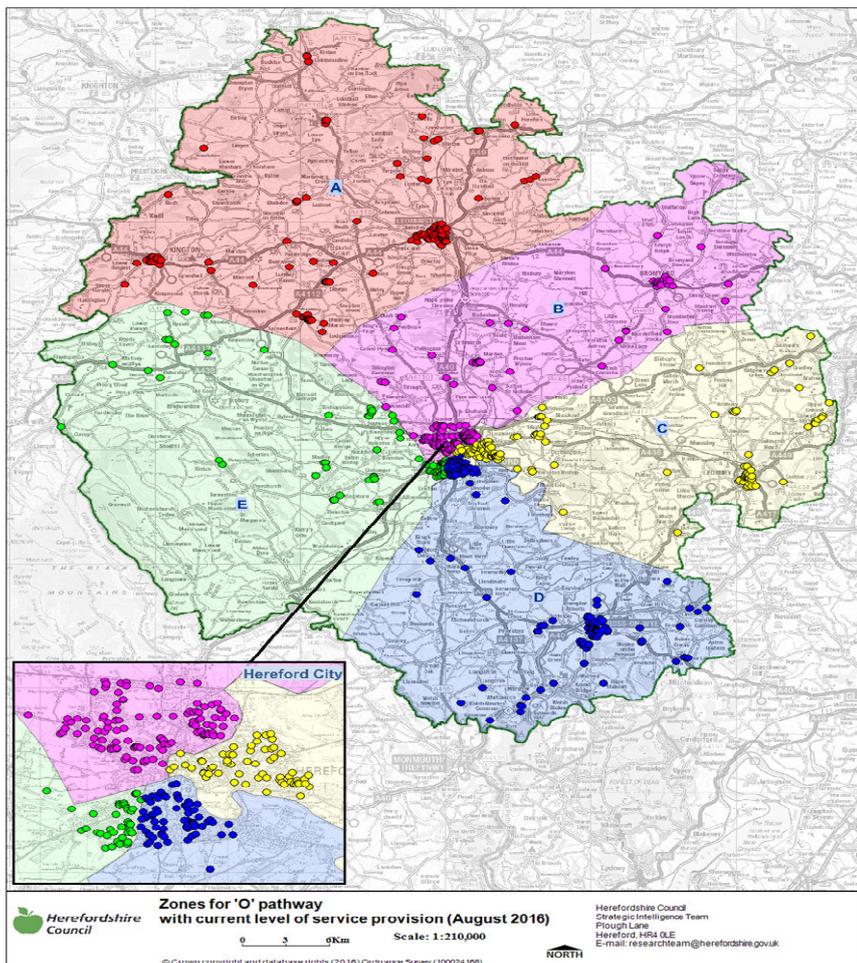
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# Home care pathways cont...

## The O Pathway

There was not a preferred map option or optimum number of zones, key feedback included.

- ◆ The majority supported a zonal model for the delivery of the 'O' pathway.
- ◆ Business viability for providers ranged from 700 – 2000+ hours per week.
- ◆ A key risk around zoning is the lack of recognition for protecting diversity of supply market and promoting maximum choice available.
- We need to understand the current picture, along with strengths and weaknesses across the county.
- ◆ Support for between 1 and 3 providers per lot.



Zone	Clients	Hours		Costs (£)	
		Weekly	Annual	Weekly	Annual
A	179	2,267	117,894	31,710	1,648,941
B	199	2,565	133,370	35,240	1,832,480
C	169	1,711	88,982	25,654	1,333,987
D	207	2,692	139,984	38,070	1,979,661
E	93	1,427	74,214	20,318	1,056,557
<b>TOTAL</b>	<b>847</b>	<b>10,662</b>	<b>554,445</b>	<b>150,993</b>	<b>7,851,626</b>

These figures show the split into 5 zones with 10 – 13 Providers across the county.

Editor's notes: The financial costs are still being worked out as we go to print. By this I mean what will form the basis of costs which providers must adhere to, to provide the service. Who knows whether the tender will go to the Provider offering the cheapest price or whether valued reputation for the best care will win!

## Recognising the value of Unpaid Family Carers

Herefordshire Carers Support, as an organisation which supports **unpaid carers**, feels that it is important to make the distinction between paid care workers and **unpaid Carers** and the clear difference between these two types of roles.



**Unpaid Carers** can be any age they provide help and support to very vulnerable people that helps to keep them out of our very busy hospitals, and as far as is possible helps to maintain their independence in their own home. Young unpaid Carers are children and young people who often take on practical and/or emotional caring responsibilities that would normally be expected of an adult.

But there is a price to be paid for this, and it is often the unpaid Carer who pays, with in many cases financial consequences and an impact on their own health and well-being.

Herefordshire carers Support routinely hears accounts from exhausted unpaid Carers about having to navigate a complex system to try and establish what they are entitled to and this supposes that people have already identified themselves as being unpaid Carers as opposed to “just being a family member” who carries additional responsibilities. With fewer resources to juggle, unpaid Carers more often than not sacrifice their own interests and sometimes their health in placing the needs of those they care for above their own.

Unpaid Carers just don't need sympathy, but genuine recognition of their vital role they have and an expectation from us all they shouldn't need to fight for resources to help them to maintain their caring roles.

If you are an unpaid Carer and not yet registered with Herefordshire Carers Support, please call us on **01432 356068**, to access advice, information and training, activities and events.

**Don't forget these important dates**

**Carers Rights Day Friday 25th November**



**Carers Christmas Party Wednesday 14th December**



**Email: [help@herefordshirecarerssupport.co.uk](mailto:help@herefordshirecarerssupport.co.uk)**

**Website: <http://www.herefordshirecarerssupport.org>**

## Dementia friendly charter



**The Alzheimers Society have develop a set of principals which they believe will ensure Personal Budgets work effectively and improve the lives of people affected by dementia. They want every local authority to sign up to these principals and demonstrate to more dementia friendly penal budgets.**

### Communication

- ◆ We co-produce relevant, easy-to-find information about personal budgets with people with dementia.
- ◆ We give people the opportunity to prepare for the personal budget assessment and support planning before the process begins.
- ◆ We always explain all the available methods for receiving a personal budget, so people can choose the one that best suits their needs.
- ◆ We will offer people affected by dementia real examples of how personal budgets could help people to live well with their condition.

### Process

- ◆ We always explain clearly and carefully how we decide on the amount of money that a person will receive.
- ◆ We will ensure that the process – from initial assessment to giving a person their personal budget – is timely and that any changes to packages are processed as simply and quickly as possible.
- ◆ We train all our care and support planning staff to have consistent person-centred, outcomes-driven conversations about how personal budgets could be spent.
- ◆ We always explain how a Direct Payments Support Service can help to manage a direct payment, and put people with dementia in touch with a fit-for-purpose, dementia-friendly provider if they want one.

### Understanding Dementia

- ◆ We collect robust data on the uptake and outcomes of personal budgets for people with dementia to help us continuously improve our services.
- ◆ We will work with people with dementia to ensure that our personal budget process meets their needs.
- ◆ We train all of our staff involved in care and support planning to understand dementia, personal budgets, fluctuating needs, person centred risk and mental capacity.

We have developed a wide range of dementia-friendly support in our area and we keep our staff continually informed about new services.

## Will Hereford Council sign up?

### Understanding Personalisation

- ◆ We train all of our staff involved in care and support planning in the personalisation agenda so we can ensure they are providing accurate and appropriate information.
- ◆ We audit and review our performance and provide opportunities to share best practice between teams.

**How can Herefordshire Council demonstrate their commitment to those with Dementia?**



**Receive a copy of the accompanying guide and adopt the dementia-friendly personal budgets charter.**

**Email: [stakeholderrelationsteam@alzheimers.org.uk](mailto:stakeholderrelationsteam@alzheimers.org.uk) to make your pledge.**

**The Alzheimers Society through their research identified the following areas that need addressing if personal budgets are to be more accessible to people with dementia and their carers:**

- ◆ **Communication**
- ◆ **Process**
- ◆ **Finance**
- ◆ **Understanding dementia**
- ◆ **Understanding the personalisation agenda**

**The Care Act 2014 gives people a legal right to access a personal budget to pay for their care and support**

## 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 and AGM**

### **March 2017**

### **Hinton Community Centre, Hereford**

### **Check out website for details**

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

**Network News is produced by Herefordshire Disability United,**

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

**HDU is registered with the Charity Commission. Charity number 1154349**