

**Herefordshire
Disability
United**



Network News

Stroke Issue May 2014

Do you need to be inspired? See page 16

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

Editorial: Acknowledging the use of technology in everyday life

I have for some time embraced the ever increasing variety of technology found in everyday life, knowing that to be a “user” is paramount in keeping in touch with reality. I am also aware that to many this can be a frightening experience as they don’t understand it, and are worried about things like security, the cost, or even how to start.

Firstly consider whether you need to know how the scientific aspect works; after all you probably use a TV, washing machine or even the old mode of radio without wondering what makes it tick. You plug in, switch on, turn the dial or click the remote and it does what you want it to (usually). The issue has arisen with the age gap for people who have never needed to use a computer in their employment years, and who now are expected to without tuition, or anyone in their household to be there as backup when “it won’t work”. Its no using telling you, “its simply a case of practice” or regular use, but slowly everyone will have no alternative in the next few years.



The government has announced that 10% of GP surgeries will soon offer online services, such as appointments, digital prescriptions and Skype check ups. Skype (for those new to the word) is a form of video phone format. You ring the number from your mobile phone/ laptop/ I-pad and hear /see the person too, as they can you. The £50 million trial scheme launches this month and is part of a wider move aimed to make it easier to see your GP.

In some hospitals robots can be found in the operating theatre, and certainly using digital technology has allowed surgeons to perfect their skills by using 3D images to detect tumours, and injuries when diagnosing conditions. In the mortuary 3D imaging allows post mortems to be carried out in some countries, so hands on experience may be lost. Who knows?

The mass of information at our fingertips on the Internet is almost infinite, and certainly has given us the opportunity to keep in touch. Gadgets are being developed for all sorts of medical reasons, and strokes survivors too have simplistic ones at their disposal. After all the Wii-Fit encourages sport and co-ordination, even if the user is using it from their wheelchair. I-pads have linguistic apps to aid speech development with exercises to follow, rather like a vocal coach. Communication aids like “Dragon Speak” is there to allow users the opportunity to “write” even if their hands are too weak to use.

One issue with all technology though is accessibility. We have seen many times in the past that PowerPoint presentations are written for one audience, usually the professional, and then re-used for Service Users. Here is our plea, remember that text size and font should be clear and large. Background colours suitable, slides simplistic in detail and content. PLEASE LISTEN TO THOSE WHO KNOW WHAT THEY NEED!



About

Herefordshire Disability United

Herefordshire Disability United 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.

Herefordshire Disability United (HDU) is an organisation run by people with disabilities for people with disabilities. It was started in January 2011 and its objectives are:

To promote the interests, welfare and social inclusion of disabled people living in Herefordshire by facilitating the following:

- Fostering understanding among policy-makers and practitioners of the needs and aspirations of disabled people.
- Taking part in consultations to make aware issues that affect persons with disabilities
- Raising awareness and debate on disability issues, stimulating the engagement of disabled people within that debate.
- Providing a platform where matters of concern to disabled people can be raised and policies developed.
- Making representations to public sector organisations, voluntary sector organisations, local and central government and local and national business to improve their policies and practices.
- Exchanging information with organisations providing services for disabled people, co-operating with but independent of such organisations.
- Providing information and sources of advice to disabled people.
- Combating discrimination on the grounds of disability by promoting equality of opportunity and a positive image of disabled people.
- Being a democratic, non sectarian, non party political organisation.

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A date for your diary!
25th June
2nd Autism Seminar
Hinton Community Centre,
10.30 am-2.30 pm

**What has progressed since
our first event on
27th November 2013?**

Editorial or advertising queries: Contact the editor on 07817 473813 or email 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.

Life after stroke



Strokes are a frightening experience, rather like a tornado, strike without warning and leave devastation behind. As ever those left with the aftermath try their best to cope, clear up and carry on...usually with some form of governmental help and financial support to get the families "on their feet again". Well that's where the analogy stops!!



To recover the survivor often needs round the clock attention, and their carers/families require so much more than just emotional support. For both parties have suffered a bereavement, the loss of that being, personality/ loved one, who one minute was full of life and fun and in a flash has changed forever. To put it in perspective, whilst you sit reading this article another person in the UK has just had a stroke.

After effects will vary according to severity and may be all or one of the following:

- ◆ Full or partial paralysis of either one or both sides of the body
- ◆ Loss of speech and communication
- ◆ Mental confusion
- ◆ Inability to swallow, eat or drink unaided
- ◆ Unable to sit, stand or walk momentarily or forever
- ◆ Blurred vision or loss of sight
- ◆ Inability to control bladder and bowel
 - ◆ Loss of employment...income...a regular life
 - ◆ Independence and choice



Basically the faster an ambulance is called and correct medical procedures followed the more successful the outcome. This is one reason by TIAs (Transient Ischaemic Attacks) should be taken seriously, being a forerunner to more serious episodes.

Strokes DO NOT discriminate, and although people associate strokes with being over 65, they can affect children or even babies.

For many a stay in hospital occurs, and once deemed to be ready for rehab the fight begins! Patients may have been medically stabilised, but the road to recovery is unknown. This is the most frustrating part, with so many areas needing "work on them" where do you start? The Physios and Occupational Therapists do a magnificent job, but a tired shocked body is limited to short bursts of energy, before a sleep is required. Initially the patient and family feel trapped and in a catch 22 situation. Without being able to swallow, one can't eat/ drink independently. Although tube fed and on a drip for rehydration, tiredness is impacting on any improvement. Meals which are a central aspect of the day with social interaction



What's the options?



Hillside Rehabilitation Centre in Hereford is a well equipped reablement unit to help get patients back on track, with twenty two single bedrooms built in 2003. Here you can develop and regain skills with the assistance of specifically trained OTs and Physios, along with speech therapists, and nursing staff all working for the same goal, for you to regain independence and return home. The staff are dedicated but very busy and there is the need for volunteers who can offer

one to one time with patients playing cards, games or just communicating in what ever way is possible. THIS IS A PLEA FOR VOLUNTEERS PLEASE!!!!

With all recovery there are unanswered questions, and the need for respite not only for the survivor but their loved ones too. Who to turn to, who can help and offer the right type of support, and when is such intervention right? From carers I have spoken to there is great appreciation for Hillside and the work they do. Staff are stretched and with the ever increasing tight budgets there is little expectation for extra cash. However carers say more is needed to enable them to gain insight into what to expect, and prepare, for the huge task they will undertake once patients are returned home. It is then they feel isolated, and out of control. **They need a Family Liaison Officer.**

There are of course Stroke Clubs in three localities in the county at Ross, Ledbury and Hereford itself, all run voluntarily. They run programmes of support with therapies, speakers, and social events so that everyone there is able to gain support and encouragement from each other. I wondered whether a "Drop In" centre would also be an option. Somewhere one could go for a coffee and a chat, a moan and a groan and relieve the tension caused by this new found anxiety. Perhaps feedback on this idea will be forthcoming at our event or afterwards using the email address or dedicated phone number of HDU, 07817 473813.



The Stroke Association does a wonderful job with leaflets and education for prevention of strokes, highlighting the right type of diet and exercise which everyone can participate in. They offer support too and strive to endorse the work of the local stroke clubs, (details on the next page).

The world of technology also supply answers with an array of gadgets and apps to aide recovery. Lingraphica (found under The Aphasia Company on the internet) have several apps to download onto I-pads etc which are speech generating devices to get communication going again. "Small Talk" oral motor exercises can be found on i-tunes, contains videos illustrating cheek, tongue, palate, lip, and jaw exercises that help strengthen the oral musculature. These can be heard in male or female voices. There are now 13 different apps for speech therapy for all types of communication difficulties after a stroke. These are all FREE. Try the link below.

<http://www.aphasia.com/products/apps/smalltalk>

Hereford Stroke Club

We are a small friendly group that offers support to people who have had strokes and to their families, friends and carers. We provide access to the many helpful and varied publications about all aspects of stroke produced by the Stroke Association and members receive their quarterly magazines and newsletters.

Activities are varied and offer a choice of evening and daytime activities with speakers and social events including pub-lunches, skittles matches, quizzes, garden visits and theatre trips. There are opportunities to share problems and advice can be given about other agencies that may be able to offer additional support.

- ◆ 12.06.14:* Remedial massage provided by the students from the RNCB
- ◆ 10.07.14:**Gentle exercise with Denise Nethercott
- ◆ 14.08.14: 1p.m. Lunch at the Three Horseshoes, Little Cowarne
- ◆ 11.09.14:**Cornish gems: an audiovisual presentation by Gordon Taylor
- ◆ 09.10.14: Pub Lunch and skittles 12 midday at the Walwyn Arms Much Marcle
- ◆ 13.11.14:**Quiz
- ◆ 11.12.14: 1p.m. Christmas Lunch
- ◆ 12.02.15:* Handbells Meryll Jennings and team

PLEASE NOTE:

Dates starred** will be at 7p.m. at Drybridge House Day Centre.

Dates starred* will be at 2p.m. at St. Martins Church Hall. Red Cross therapeutic massage will be available for members at some meetings.

Theatre trip to be arranged.

Communication Support:

Prime Time meets from 2 to 4p.m. on the first Thursday and the Yes You Can Group from 2 to 3.30p.m. on the third Friday most months at St Johns Methodist Church Hall (accessed from East Street).

For information contact Jill Clarke 01432 851805, Sylvie Nicholls 07817 473813 or Sue Rennie 01432 830754

Please give numbers for outings or lunches to one of the committee a week before events.

Contact details: Sue Rennie 01432 830754; Ann Goodwin 01432 343780;
Marian Hardisty 01432 269446; Esther Williams 01432 276113;
Ruth Wardle 01544 340065

Aphasia information

Aphasia is a language disorder which can occur after brain injury or a stroke. People with Aphasia may have difficulty with speaking, listening, reading and writing. Having Aphasia is traumatic and a life-changing experience for patients and relatives.

“How much language is the patient likely to recover?” and “How long will this take?” are two questions which immediately spring to mind. Of course there are no specific replies, as with each patient the answer is true to that individual alone.

Back in September 2012 HDU held an open meeting where strokes was one of the topics, after which we realised that Herefordshire does not have a specific aphasia support group. Consequently we launched the “Yes I Can Club” which meets on the third Friday of most months at St John’s Methodist Church, St Owen’s Church Hall, Hereford, from 2.00– 3.30pm. We have fun using various therapies to engage with stroke survivors who find the social aspect enjoyable. Sometimes this is music, seated exercise, games sessions or demonstrations of equipment. Carers come too.

The next meeting on 20th June will see Annamaria Berger describe and demonstrate “Conductive Enablement”, a series of individual exercises to improve life after a stroke, (see page the following page for an explanation in her words). Please feel free to join us.

Aphasia Software Finder

One charity which aids Aphasia support is the “Aphasia Software Finder”.

The charity is part of the Tavistock Trust founded in 1992 by Robin Tavistock the 14th Duke of Bedford (27th January 1940- 13th June 2003).

Robin suffered a brain haemorrhage in 1988, after which he had great difficulty in “finding the words” he needed or wanted to use. The Software finder has over twenty five years of experience in sourcing and finding software which will assist in helping those with Aphasia. Its website is:

<http://www.aphasiasoftwarefinder.org/information>

British Aphasiology Society

When speech is lost after a stroke the frustration for many can be frightening, as they can no longer control not only parts of their body physically, but also being able to communicate needs/ wants /emotions etc can compound the issue. There is huge research into the condition and one such institution in Newcastle is the home of the British Aphasiology Society. It has its own website, where you can discover their latest findings and read newsletters explaining various aspect of their work over the past few years.

The address is: <http://www.britishaphasiologysociety.org.uk>

Conductive Enablement

Would you like to increase your independence? Would you like to regain control?
Would you like to improve the use of your affected side? If YES, please read on...

Conductive Enablement offers group and individual therapy sessions through providing conductive education, a unique form of rehabilitation for people with neurological motor disorders like Stroke.

“Conductive education (CE) is a holistic and integrated pedagogical/educational system, which enables people with damage to the central nervous system to learn to overcome the challenges they face. CE is a process of experiences which leads the person to work with their motor disabilities, moving towards increased independence.” (Professional Conductors Association 2009).

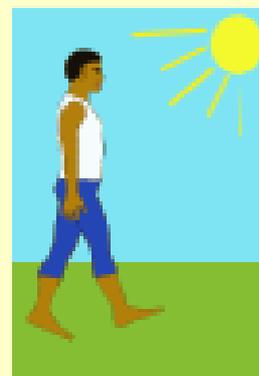
The practitioners of CE (conductors) believe that everybody is able to learn regardless of their age or condition if provided with the correct support and taught the right strategies. This form of therapy can help people to view themselves differently, in a positive way through carrying out meaningful activities. These will provide useful techniques to approach the difficulties and challenges that must be faced and will also teach to problem solve and to tackle those issues.

Session times vary between 1.5-2 hours depending on need/ size of the group. During this time, participants carry tasks out in lying, sitting and standing positions as well as walking. The tasks may vary but the format of the session remains the same; this enables continuity and ensures that greater learning takes place. The programme is not simply a series of exercises; it is designed to provide opportunities to learn how to perform a movement with the correct part of the body in a symmetrical way.

Some potential benefits for people with Stroke from attending sessions include:

- ◆ Improved ability to find centre of gravity
- ◆ Improved posture
- ◆ Improved symmetry
- ◆ Increased awareness of affected side
- ◆ Improved and active use of affected side
- ◆ Improved control and fluency of movements
- ◆ Increased range of movements
- ◆ Improved balance
- ◆ Improved ability to change position in a co-ordinated way
- ◆ Improved walking technique

Improved self-esteem and confidence



Holistic therapy as part of rehabilitation



A stroke participant's sister's story:

"In 2008 my brother had a stroke which left him paralysed on his right side and unable to speak more than a few words. His prognosis was bleak and we were offered minimal therapy to support him.

Six months later I took him to be assessed by a Conductive Education therapist. When we got back into the car after about an hour and a half of very comprehensive assessment, he grabbed my hand and said "Thank you, thank you, thank you." He knew immediately, as did I, just from the things that were assessed and the way in which the assessment was carried out, that this form of therapy was unlike anything he had been offered up until then and that it would make a difference. We have not been disappointed. There is a clear structure and continuity as things are monitored from one week to the next. The holistic approach of CE impacts not only on his physical abilities but also his speech and his cognitive function which, in turn, affects his overall state of mind.

Although we know that the damage done by the stroke is irreversible and that he will always be limited in his abilities, this mind/body approach combines all aspects of his being, seeing him, working with him and thereby strengthening him, **as a whole person**. When he misses a number of sessions (if he is on holiday for example) it is really noticeable how stiff he becomes and how his range of movement becomes more and more restricted. I have no doubt that without Conductive Therapy he would not have the range or extent of movement that he has."

Conductive Enablement also offers home visits and works with people with other neurological conditions such as Parkinson's, Head Injury and Cerebral palsy.

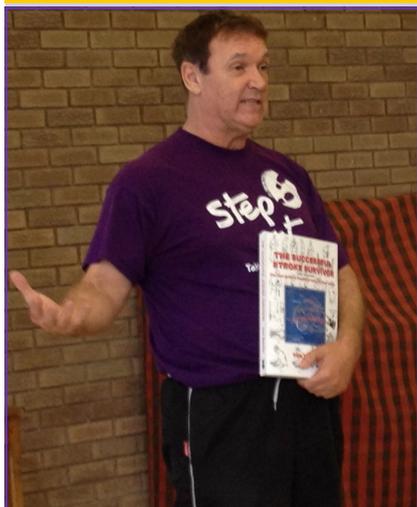
If you would like more information or an assessment form please, contact Annamaria Berger (BA Hons, QCS, MA).



Phone: 07903373451

Email: conductiveenablement@outlook.com

The Successful Stroke Survivor



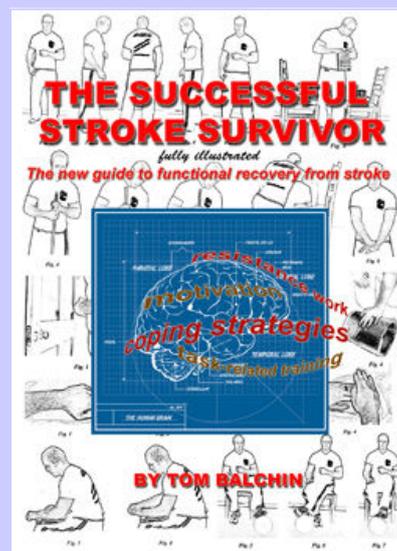
I met Andy Rumbold at a recent local stroke club meeting as he set out to relate his story and with that how the “Arni Technique” has helped him gain strength and independence again. If you haven’t heard about this technique I will explain. It concerns a book written by Dr Tom Balchin, called The Successful Stroke Survivor.

Dr Tom Balchin had a major brain haemorrhage back in 1997, which left him paralysed down the left side of his body and in a wheelchair, but being a young man decided to try and gain some strength and movement back to enjoy life as he should. Luckily he met an innovative and expert physio-therapist whose aim was to help him gain self reliance as soon as possible. Being positive helped him establish emotional stability, and with that came the focus for physical strength. Ten years on virtually all movement functions have returned via a combination of martial arts, resistance training and other approaches which form the now established “Arni technique”.

Whilst this book is certainly a very weighty tome it contains many different exercises which stroke survivors can utilise according to the severity of their conditions. It sells for around £35, which some may consider expensive, but the amount of in depth knowledge and explanations/ exercises to assist you is definitely money well spent.

Andy Rumbelow described how the system works. If your need is to learn how to pick up a cup of tea, then that’s what one needs to develop, specific movements to enable the strength and hand/ arm functions to promote the actions to drink independently again. This will teach you a new pathway through the brain, which is different to the one lost through having a stroke. Repetition, over and over again using both hands initially, and then slowly building up to being able to drink using just one hand again. As Andy said this can take many months or years, but has been clinically proven that recovery is still on-going many years after the stroke actually took place.

Andy showed us how one specific leg exercise he practiced was to get strength and direction to walk again. Whilst he has little if any feeling in his foot, the constant repetitive adjustment of keeping his left leg in the correct position allowed him to walk again. As Andy explained, he likens the focus as learning to play the piano. You may have the instrument, and can get a tune from it, but to master the art of fluent play one must practice day after day, hour after hour to get to the point that others will enjoy what they hear. However in this instance, he gained the joy after regular practice of being able to walk again.



At what age can one have a stroke?

This gentleman on the right is Stuart Cooper, who is Community Development and Partnerships Manager at the “Life After Stroke Centre” in Bromsgrove. It is part of the Stroke Association network which does much to champion better awareness for prevention of strokes, as well as offering solutions for survivors. Stuart is one of those people who discovered that age is no barrier when strokes strike, having succumbed at the age of seven.



Stuart’s left side was affected and although he appears to have reasonable dexterity, as seen in this photo, this has only been achieved by extreme hard work. I know from a comment he made recently that he is still achieving renewed movements. He is very proud that finally he can apply a cuff link into both sleeves of his shirt. This has been twenty two years in the making! Stuart did say that at seven he had never used cuff links, so it wasn’t a case of retraining old brain pathways, but establishing a new one.

Now one has to see that to achieve repair or renew pathways you are actually re-building your body so diet is extremely important. Maybe to start with eating will be problematic as swallowing can be difficult, but there is always the option of “smoothies” so that fruit and vegetables can be taken this way. It is essential to have variety in the diet, to ensure the vast array of nutrients are absorbed by the body.

After a stroke, fatigue is one factor which has to be overcome. Survivors tire very easily and will often give up on eating because they are “too tired to bother”, but of course this in turn leads to further tiredness. Eating a bigger meal earlier in the day is therefore a better regime to follow, and will provide energy to achieve more.

Luminosity, is a word meaning brain training, something which groups of health professionals are using to determine possible outcome after various conditions or age related illnesses. Currently one university research programme is looking at “ Can Luminosity improve cognitive problems immediately following stroke?”

Motivation and positivity are areas where family and carers are essential. Praise for just the smallest achievement encourages more. Rehabilitation after a stroke is a life long activity, so don’t give up in “middle age”. Think how long it takes a baby to walk, be inspired to “get up and go”, and take a leaf from their book by keep trying.

Aphasia and UK Connect

Connect is a charity for people living with Aphasia, a communication disability which occurs after a stroke. Connect aim to improve the lives of people living with Aphasia and communication disability, equipping them to reconnect with life.



connect
the communication disability network

Registered charity
1081740

- ◆ They provide information and support to help everyone understand aphasia and its impact
- ◆ They support people with aphasia to develop and deliver services which they need and want
- ◆ Provide training and consultancy to a wide range of service providers
- ◆ Champion the rights of people with aphasia and communication disability

Ten top tips for talking with people with aphasia



Connect have produced this leaflet to help others learn to communicate better with those who have aphasia.

Each statement makes sense but in every day life we are used to rushing and don't stop to consider others.

Perhaps if one thinks about the delay in speaking on a phone to someone abroad, knowing that a few seconds will elapse before the reply will come down the phone.

That's the same principal as speaking to someone with aphasia. Just because they are sitting next to you, you cannot expect an immediate response.

Look at this text, and notices the spaces between statements.

It allows more time to get the message across.

Connect produce a quarterly newsletter which anyone can receive either in hard copy of via their website: www.ukconnect.org. They would love to hear from people affected by aphasia, to add to the bank of stories used in the publications to inspire others and get the message across that help is available.

PLORAShelping predict recovery

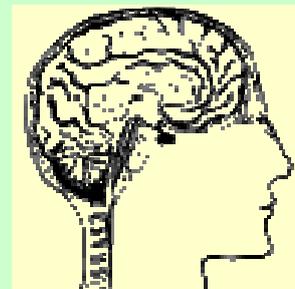
What is PLORAS?

Predicting Language Outcome and Recovery After a Stroke.

Back in 2010 researchers based at the Institute of Neurology in London published a report into Cognitive Neurology, Brain Imaging and Stroke, details of which can be found on-line.

This complex study considers two things:

- ◆ To be able to comprehend language after a stroke
- ◆ Be able to produce speech after a stroke



As the brain uses a complex system and interaction between different areas to understand language, this is a difficult task to undertake. The lesion which appears on the brain after a stroke also needs to be recognised and compared to others. Gathering the MRI scan details of many patients and comparing results, enables researchers to grasp the complexities, which after comparison can suggest possible outcomes for new patients. This requires a huge data base of speech and language recovery details accumulated from the widest possible source. Studies are on-going.

The use of functional imaging will enable patients to be tested many times after a stroke to map change in pathways. It is possible for people to develop new ways to carry out tasks using slightly different methods, and sometimes our brains are able to create such new pathways. With these results researchers are hoping to build a store of findings to enable better prediction for stroke survivors in the future.

Researchers look for patterns by grouping people with the same area of damage. This will enable predictions to be made based on what is already known from the patients previously tested, which includes scans and results of language tests (speaking, understanding, reading and writing).

It is hoped that Herefordshire will soon be involved with this aspect of PLORAS research. So if you are asked to be part of their work, you will have a basic understanding of what it is all about.

I anticipate that at our event on 21st May a research nurse at Hereford Hospital will be present, who will soon be engaged in PLORAS. Part of the work is to examine people at all stages post stroke with any element of Aphasia/ Dysphasia. Further details will appear on the HDU website after the event.

To look at PLORAS videos and see other aspects of the research go to:

<http://www.ucl.ac.uk/ploras/stroke-survivors>

Personal Health Budgets

There are two different versions of the documents on these budgets available on our website of the official guidance to Personal Health Budgets, and I have adapted the easy read version to be able to print details of their Q & As in this newsletter. If you wish to check out the full versions they can be found on the **Information** page of the HDU website: www.herefordshiredisabilityunited.org.uk

At our event on 21st May we are expecting our speaker Paul Ryan, the Local Lead for Personal health Budgets, to attend and I am sure there will be the opportunity for attendees to query and clarify needs. However here are some aspects to assist you.



From April 2014 people with disabilities, and health conditions which last a long time can ask for a Personal Health Budget.

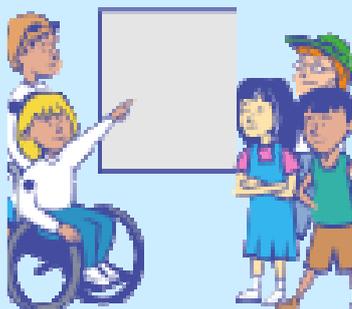
A Personal health Budget is money to pay for your healthcare. At the centre is your care plan, which helps you decide your health goals together with your local NHS team.



Who decides who can have a budget? How big it is and what you can spend it on?

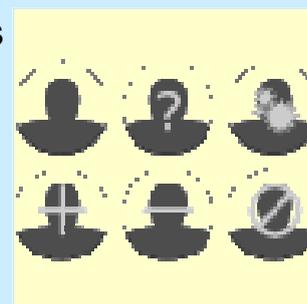
You should always be told what you can have before you start planning what you can spend it on.

You agree the best way to spend the money with your local health team which could be your doctor or care manager.



Can you have a Personal health Budget as well as one from Social Services?

Yes and you can join them together to make a better plan.



How will I manage my own care?

You will not have to do everything. You and your family and carers will agree a health plan with the NHS.

www.dh.gov.uk/personalhealthbudgets

www.tinyurl.com/dhbudgets

For more information

Taking control of personal care and health!

Some people already get a personal budget to pay for support from social services, such as a Direct Payment. Now Personal Health Budgets work the same way.



You must spend the money on things in your care plan that keep you healthy and safe, which the local NHS has agreed to.

If things are working well at the moment you do not have to change them. But a Personal health Budget means you can change things if you want to.

Personal Health Budgets can work in three different ways.

1. A Notional Budget.

Your assessor will tell you how much there is for your care. You say how you want the money spent. If the local NHS team agree this meets your needs they can arrange the care and support for you.

2. Real Budget held by a third party.

An organisation or charity, looks after the money for you and helps you decide how you want to spend it. They are called the Third Party.

3. Direct Payment for healthcare.

You are given the money to buy and manage your own healthcare and support. Your local NHS team must agree that this meets your need, and advise what you spend the money on.



You use a Personal Health Budget for

- ◆ Personal care
- ◆ Training to help you look after your health
- ◆ Equipment to help meet your health needs.

Personal health Budgets should help all people get the best services from the NHS. They should not make things worse for anyone.

You do not have to use a Personal health Budget if you do not want to. If you are not eligible for these budgets you can still ask the local NHS team for different ways to support your needs.



Helpful products/ information found at Naidex

The Duo Clip on handle

If you have a favourite mug but can no longer successfully hold it why not utilise a “Duo” clip-on ergonomic handle? Place this over your mug, then you can hold it with two hands.

The plastic clip on allows you to use the same set of mugs as your family, and also protects your hands from the intense heat of a hot drink. It works best with straight sided mugs.

Cost £12.99 from: www.suchandsuchdesign.co.uk



A specialised straw to help those with swallowing issues.



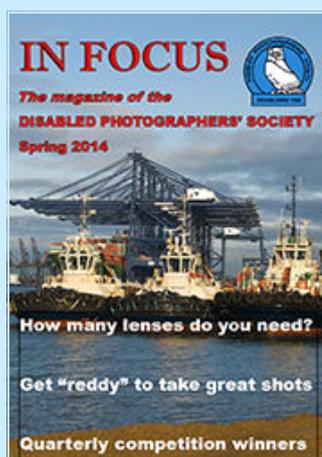
If someone is affected by Dysphagia then this product idea may assist with drinking, as it can help those with weak swallow action. A Uniflow Straw is a distinct variety as it contains a one way valve.

The liquid once drawn up remains in the straw if you take your lips away. Sounds strange, but those who lack the strength to keep sipping will find this helpful. The straw also reduces the flow rate of liquids and therefore prevents the user from drinking too fast and choking, by reducing air ingestion. The straws are reusable, but are unsuitable for thick or fizzy fluids.

A pack of 15 straws costs £14.99. Available from: www.suchandsuchdesign.co.uk.

Are you looking for inspiration ?

The Disabled Photographers Society, may well be able to help. It's a charity dedicated to promoting the use of photography to disabled people, their carers or groups of people interested in helping disabled people.



The charity run by volunteers is able to offer advice on adaptations to photographic equipment so that users are able to continue or even start to pursue this hobby.

There is an annual membership, competitions, long term loan of equipment, quarterly magazines or simply just advice to adapt your own equipment.

Details: Disabled Photographers Society, 37, Orchard Close, New Barn, Longfield, Kent, DA3 7JP.

Website: [http:// www.disabledphotographers.co.uk](http://www.disabledphotographers.co.uk)

Life in the technological age!

There are many who feel that Personalisation has done much to ensure choice for those living with disabilities, and that is true. Those applying cuts to budgets however do not appreciate the cost to individuals who really are stretched. Many take it for granted that they can make and keep appointments relatively easily, but put yourself in someone else's position just for a few days and see the difference.

Decision makers consider this scenario below!

Monday April 6th 2014 was an awkward day for me. I'd been quite ill with a chest infection, and was taking my second antibiotic's prescription. Also my usual Personal Assistant rota was going haywire, with one P.A. off for personal reasons, another on holiday, and one off sick.

On the Friday before, the holidaying PA and I had rearranged the rota to include 10 hours agency care and help from a retired PA. I need 24/7 live-in care, have full mental capacity but without full-time help I would not last in the community. If anything interrupts my planned schedule, life becomes more awkward.

The Monday in question started with a problem the day before; my wheelchair arm piece had gradually been skewed to an angle by my strong arm movements. Screws attaching it to the chair arm snapped in half, and my PA would have to take the wheelchair to Hereford for repair. The firm could do it later that morning, so I had to change into a light-weight, manual jalopy, in which I would be static until my PA returned.



At first I wanted to fill the time with my electronic reader, but that would not open. Fortunately I have other easily accessible books, downloaded from the Internet (mostly classics) and I had plenty to read that day.

My PA loaded up my wheelchair, but could not start my vehicle. We contacted the AA, who sent someone quickly – the longest I've waited for an AA man was 4 hours! I was pleased that this one came within 45 minutes, but he found the battery was flat from the last PA to use the vehicle leaving a door open.

So the duty PA recharged the vehicle while taking the wheelchair to Hereford and back to Ross. However, the reader still is not working; it needs a new battery which was ordered well before Easter! So 2 done and 1 to go.

I've had worse days of course. I've known 6 equipment items go wrong over 24 hours, admittedly not with my rota and illness to boot! But when you have impairments to cope with, any hitch with equipment, rotas or whatever, just makes life that more difficult.

Written by Anthea Penfold, a committee member for HDU

Diabetes...how to prevent it developing

Diabetes is a condition many are aware of but do not really understand or prefer to ignore. It's when there is too much glucose in your blood because the body isn't processing it properly. Glucose comes from the digestion of starchy and sugary goods, such as bread, rice, pasta, biscuits as well as being produced by the liver.

Diabetes increases the risk of stroke. Strokes occur when the blood supply to the brain is interrupted. This could be due to diet when the arteries become furred by deposits of fat, or too much glucose which damages them making them hard and narrow.



People with diabetes are two to three times more likely to have a stroke than those without the condition. Another factor for developing diabetes is being overweight. Experts say that losing just 5-10% of your body weight can help you lower your blood sugar considerably, as well as lower your blood pressure and cholesterol levels.

Your risk is higher if you have a "spare tyre" and is closely linked to insulin resistance and diabetes. You are at increased risk if as a woman the waist measurement is over 35 inches, and for a man over 40 inches.

Whilst there are many different factors which may increase your likelihood of developing diabetes, a sensible diet can definitely help. Some people develop diabetes after a stroke, which then has a greater impact on their emotional wellbeing.

So what can you do to help yourself? Be truthful, and keep a diary of everything you eat. This will bring it to your attention just how many treats and what quantity of processed foods you are consuming. Increasing fibre in the diet slows down the rate which the body absorbs the nutrients and stabilises the blood sugar, preventing "highs and lows" which again will affect your blood pressure and heart.

Try the easier method of understanding food with the traffic light codes: red being only as a rare treat, yellow in moderation and green as regular items on your plate.



RED: French/ white bread, rice, pasta, baking / mashed potatoes, sweets, chips, corn flakes, rice krispies, water melon, dates, parsnips, doughnuts and processed foods are just a few to avoid.

YELLOW: Puffed wheat, quick cook oats, new potatoes, couscous, whole wheat bread, pineapple, dried fruits, bananas, pop corn, ice-cream, burger buns, instant porridge, are some to be limited.

GREEN: Most pulses like baked beans, tomato soup, whole wheat spaghetti, peanuts, oat bran bread, pearly barley, most fruit and vegetables, buckwheat flour, all bran, long grained rice, lentil soup, lean meats and many more besides

Person centred programme needs

Communication

1. Speech & language therapy
2. Peer support groups
3. Accessible and Aphasia friendly information
4. Facilitating conversation groups

Care and Support

1. Personal care
2. Primary care services
3. Regular reviews
4. Individual budgets

Practical Help

1. Occupational therapy
2. Help with daily tasks
3. Advice on returning to work and benefits
4. Accessible transport and leisure

Mental Health & Emotional Wellbeing

1. Psychological support
2. Access to leisure, education, activities and work
3. Support groups and help lines
4. Counselling and support

Short Break Provision

1. Carers and family
2. Carer training
3. Family and carers support groups
4. Care and family

Re-enablement

1. Physiotherapy
2. Expert patient programme training
3. Information and advice
4. Lifestyle advice

These six boxes represent the different areas which stroke survivors and their family will need to access.

Item ONE in each box should be a ONE to ONE therapy offered by public services.

This information comes from part of the National Strategy in 2007 to secure improvements for stroke survivors, and is aimed at commissioners, social care and strategic health authorities. It was issued by the Department of Health.

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

Equality and Human Rights Commission

Freepost RRLL-GHUX-CTRX, Arndale House,

Arndale Centre, Manchester, M4 3AQ

Tel: 0808 800 0082 Website:

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

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

Email:



Stroke Association information

Email: info@stroke.org.uk

Phone 0303 303 3100

Textphone: 18001 0303 3033 100

Autism Seminar 25th June

Hinton Community Centre, Hereford

Details to follow

Check the website for latest information

Network News is produced by Herefordshire Disability United,

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

Tel: 07817 473813

Email: info@hdu.org.uk

Website: www.herefordshiredisabilityunited.org.uk