July 2013

JOUR VOICE

Registered Charity No 1148256 Free: donations welcome!

£300,000 to boost work of parents and carers

The Parent & Carer Council Shropshire and Parents Opening Doors(PODS) in Telford & Wrekin, have together secured a grant of £300,000 to support their work for the next three years.

In an email to supporters, the PACC committee says that for the past 12 months the two organisations have been working on a lottery bid for the Reaching Communities Programme.

We are really pleased to be able to announce that we have been successful in this bid and have secured a grant of £300,000 to support our work for the next three years,' they say.

This funding will enable PACC and PODS to continue to develop their work, the main focus of which will continue to be on providing parent carer participation opportunities, accessible and relevant information and the chance to access a peer-to-peer support network.

'The funding comes at a key time for parent carer forums with the increased role they will have to play in the delivery of the SEN reforms in particular,' the email says. 'The funding will enable participation coordinators to be recruited for both Shropshire and Telford & Wrekin, along with increased administrative support. There will also be a Face 2 Face coordinator recruited to deliver the Face 2 Face Scheme across the two areas, offering support from trained befrienders to more families.

'We are really excited about this news. There is so much work to be done and we hope that the funding of these posts and the associated activity, will enable us to take full advantage of the current opportunities for parent carers to be involved in decision making on an individual and strategic level. We also want to provide more opportunities for families to meet and share experience and knowledge, because we know for our previous work how much this is valued.

'We would like to thank everyone who contributed to the successful bid, but in particular our thanks go to Jill Cleveley who worked so hard gathering the not inconsiderable amount of information that was needed during the application process.'



What is this man saying that matters to you?

See page 4

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AND MUCH, MUCH MORE!

The 'Safe Places' hate crime initiative launches on 4 July. See our next issue for a full report.



Headway is Sainsbury's charity choice for second year running

by Lizzie Evans, Fundraising and Publicity Officer at Headway Shropshire

At Headway Shropshire, we normally have to shout loud to let people know who we are. Many don't know that we are a local charity providing help, rehabilitation and support to people with acquired brain

injuries, their families and carers. We find ourselves suffering from being a largely unknown voice but we keep shouting and we keep hoping we are going to be heard.

So last year we were amazed to discover that we had been chosen by the staff and customers of Sainbury's Meole Brace to be their Local Charity Partnership of the year. You can't



imagine the excitement we felt, we genuinely hadn't thought such an honour possible.

The year flew by and we were touched by the response from both the staff and customers. People took the time to talk to us and find out more about us. It was wonderful.

We were also amazed by the generosity of all those that so kindly donated money to us and completely overwhelmed by the response of the staff, they were so enthusiastic and threw themselves into fundraising events in their own time.

So to discover that we have been chosen to be the Charity Partnership again this year...well I can't tell you how emotional this

is for us. Thank you to every single one of you that has supported us and for agreeing to help us for a further year but most of all, thank you for listening!

Headway Shropshire is based at Holsworth Park, Oxon Business Park, Shrewsbury, SY3 5HJ. Tel 01743 365271, fax 01743 365563.

The national Headway website is https://www.headway.org.uk

Carers Week brings big publicity reward

Sainsbury's actively support Carers' Week nationally, and locally that meant carer-related charities being offered table space for the whole of the week, which ran from 10-14 June.

SDN was among those offered space at the Shrewsbury Sainsbury's, along with the Stroke Association, Macmillan Cancer Support, Headway Shropshire, Age UK, Shropshire Parent and Carers Council, Crossroads, Parkinson's Association, Carers Support, SRDS and British Red Cross Young Carers.

'We made the most of it with a good display and a table groaning under the weight of literature,' said Ruby Hartshorn.

'We must have done something to attract public interest, because by the end of the week this is what had been picked up - 98 membership forms, 24 car stickers, 25 pens, 21 hate crime place mats, 30 copies of *YourVoice*, six copies of *Severn* magazine featuring an article about SDN and 39 leaflets telling people about SDN, 33 Just-textgiving leaflets and 42 Givingabit leaflets, 12 Givingabit posters and 25 Givingabit flyers.' [Givingabit



and Justtextgiving are two new ways of supporting your favourite causes – well worth reading up on!]

'I have also received five telephone enquiries since Carers Week. For us, it was a very valuable chance to display information without having to staff the table all the time. We were also able to collect donations if we wanted to, and we did so for a few hours. As well as reaching the public this opportunity was a great way to network with others who were taking part.'

Pictured above are Ruby and SDN chairwoman Sonia Roberts with Sainsbury's manager Peter Briggs and two of his colleagues.













Somee of the members of the steering group are (from above left) Peter Hopkins from Shropshire and Telford Aspergers Carers Support; Margaret Butler, from Radbrook Carers Group; Margarete Davies, from Crossroads Care, and Sue Brown, care support worker with the CCG; Sandra Griffiths, carer and former social worker, who chaired the launch event; and Jackie Taylor, Shropshire Council's facilitator for partnership boards. At right, part of the meeting at work.

United voice for family carers

A forum that brings together the views of family carers and the many groups and organisations that support them has been launched for Shropshire and Telford & Wrekin. More than 30 people from different carer groups and other supporting organisations, including SDN, came together at Mears Shropshire Home Services in Shrewsbury to map out a structure for this umbrella group that will speak for them all with one collective voice.

The forum, the first in Shropshire, is

so new it is still developing a name and a logo as a result of the many suggestions made at the launch. Eager to move forward, the steering group has already met to plan the most appropriate way ahead as a result of the input gained from attendees at the launch. This includes contacting all those who showed an interest in the launch, building the membership and starting work on some items that were brought up.

The most important thing was the energy and enthusiasm of the dele-

gates to get started. Some items will take longer than others to progress, but the steering group has taken on board all the issues raised as it recognises how much work there is to be done and that, as with all new groups, it will take time to work through everything.

The group meets again on 16 July and will look further at the logos that have been designed and potential names for the forum. We hope to give a more complete report in the August YourVoice.

Spreading the word at Morrisons

Morrisons in Shrewsbury has very kindly offered SDN the opportunity to have a two-day information stand and collection at the supermarket on Friday 16 and Saturday 17 August

Ruby Hartshorn, who is organising the event, said: 'We really appreciate the support given to us by the management and staff in allowing us to do this and are very pleased to be able to have our information stand at Morrisons.'

While this is partly about raising money to fund the work of Shropshire Disability Network, it is also about making people aware of SDN. 'We will have a selection of leaflets available and volunteers on hand to talk to shoppers,' said Ruby. 'We must engage with the public if we are to succeed in our

work, spreading the word to those who may benefit from knowing about us.

'Help is needed from members and supporters to staff the stand throughout the day. In fact, it will be impossible without your help. If you can spare one or two hours to help us raise awareness of SDN by handing leaflets to shoppers and talking with them about us we would like to hear from you. If you feel you can help, please call me on 01743 340832 or email enquiry@shropshire-disability.net.

'We hope you will feel you can help us on the day but as a rota needs to be produced in advance please contact me as soon as you can. I promise that no-one will be left to be at the stand alone, there will always be at least two people working together.'

Shake, rattle - and give!

Shrewsbury and District MS Society is holding a collection in Shrewsbury on Saturday 17 August and all assistance will be gratefully received. Considering the recent Church Stretton tin rattle raised an incredible £540, let's see what the county town can do!

ESA majority

Figures from the DWP show 52% of ESA claimants are now being found eligible for the benefit - the first time a majority of those making initial claims have been awarded ESA.





Above, deaf members listen through a BSL translator

SDN's first Members' Meeting in Oswestry

Don't shoot the messenger!

Colin Smith from the Department of Work and Pensions was quick to ask members not to 'shoot the messenger'. In other words, these were not his policies; he was merely the bearer of bad news.

He spoke and answers questions about Personal Independence Payments (PIP) and Universal Credit, another major change to the benefits system being rolled out later this year.



Colin lingered on the shortcomings of the old system (DLA), which had been in existence for 21 years and was proving far more costly than the country could afford. But he said did not seek to suggest that PIP was in any way an answer to all the complex questions about disability benefits.

He acknowledged there would be both winners and losers under PIP. Extensive questioning from members meant the meeting ran 20 minutes over time.

First glimpse of a new look?

Rosemary Wallen and Roz Ryder, from People2People, take a look at possible new styles for the SDN website, which members were urged to give their opinions on.





Anne Johnston from Shropshire Housing Alliance, assisted by a colleague, spoke about changes to Housing Benefit and other wide-ranging benefit reforms and how they could impact on people with disabilities. She urged members not to ignore the changes and if they were in any doubt at all to seek advice from the SHA or similar organisations. In particular, a reform that could adversely impact on tenants was the bedroom tax, with tenants possibly facing costly week increases for 'spare' bedrooms. There were a lot of questions, with many members very concerned.

The speakers are seen above with SDN members Alan and Sherry Townsend.

Why NHS and private must mix

A talk was given by Niki Clarke, who specialises in upper and lower limb rehabilitation, and Claire Godfrey, a speech and language therapist, about their work in the NHS and private practice. Nicola also wrote this: "I am a



member of SDN and I'm a neurological occupational therapist who works in both the NHS and private sector. Primarily I treat people who have lost the function of their upper limb/limbs following a neurological illness or surgery.

My private business is called Neuropossibility. In my 20 years' experience in the NHS I believe that, on the whole, it provides a fantastic service to people who have had any type of neurological impairment. However, the cost of services mean that the amount of 'on-going treatment' session patients receive is continually reducing. Therefore private treatment also offers people an option of receiving extra sessions. I will visit people at home and set up a home programme which individuals are then able to continue themselves. This also means I don't have to visit as often, which reduces the cost.

I enjoyed the SDN meeting and found the talks very interesting. Although I came to the meeting to talk about my services by taking up the opportunity to have a stand to promote my business, I fully intend to attend meetings in the future as I really enjoyed it."



Hidden carers worth billions to the state

Shropshire Rural Community
Council (RCC) is in the process of
evaluating its Carers Support
Service and is asking people to
spare a few minutes to complete a
survey which will help it keep
services relevant.

The RCC says that recent research by Carers UK shows that the care provided by friends and family to ill, frail or disabled relatives saves the state £19 billion every year.

Yet the main carers' benefit, Carers Allowance, is £58.45 for a minimum of 35 hours - equivalent to £1.67 an hour - and is currently received by 600,000 people.

In Shropshire more than 34,260 people are now caring, according to the 2011 census.

'If you provide unpaid help or look after a family member or friend who is ill, disabled, frail or elderly who can't manage without your support then you are a carer,' says the RCC. 'You can benefit from information and support for yourself to help you in your caring role.'

To find out more call the RCC on 01743 341995.

Passport to peace of mind for carers

A new 'passport' is being launched to help Shropshire's growing army of unpaid carers.

Tthe document will help carers ensure the person they care for gets the help they need when in hospi-

tal, respite care or other settings.

Carers will be able to write information, comments and suggestions in the 'Who I am' passport, which is being launched to coincide with World Alzheimer's Day on 21 September.

The passport enables you to tell health care staff about the person you care for and provide any information you think is important about help they may need in hospital or



respite care. You can write information, comments and suggestions. There is a red section for 'must know', an amber for 'important' and a green for 'helpful' information.

'This will be particu-

larly useful to those who care for someone with dementia,' said Diane Cuff of Shropshire RCC Carers Support Services, which has launched the venture in partnership with Commissioners in the PCT, Shropshire Council, Telford & Wrekin Council and Telford Carers Contact Centre.

Helen Swindlehurst of the PCT said: 'The passport is essential reading and will be extremely helpful to staff within health and social care to gain accurate information about their patient or client. It enables carers to record important details of the person they look after, ensuring the right help is given.'

Jean Breakall, a carer in Shrewsbury, said: 'This passport will greatly reduce my anxiety if my mother goes into hospital. It is so easily identifiable and will ensure health staff have the right information.'

Doreen Jones, a carer in Telford said: 'This will be really useful when my husband goes into respite care. It will give me peace of mind that staff know what is important for his care.'

To request a copy of the Who I Am Passport contact either Shropshire RCC Carers Support Service on 01743 341995 or Carers Contact Telford on 01952 240209.

Bedroom tax - minister taxes credibility

Government minister Steve Webb very recently reassured MPs that 'There are no indications that evictions will result from the removal of the spare room subsidy' ('Subsidy' is Government-speak for 'tax') and also that: 'At present there are no plans to adjust the rules relating to the removal of the spare room subsidy. Concerns relating to disabled tenants, including those whose accommodation has been adapted for their needs has been taken into account.' If a government minister says so, then it must be true. Visit http://tinyurl.com/nozo3w4 to see for yourself.

Young carers 'damaged'

The BBC reports that about 250,000 carers are young people and that their education and job prospects are at serious risk. It reports the Children's Society as saying that one in 12 young carers spends more than 15 hours a week caring for a parent or sibling and half of these youngsters are likely to have special needs or an illness. [From Shropshire ME Group Newsletter, June]



The greater the need, the less likely is help

Many people with MS are struggling to access social care and facing pressure to meet the cost of care that allows them to live an independent life.

Even more worrying, the people with MS under the greatest financial pressure are those most in need of care and support - but they are the least likely to receive it.

Proper support should be an entitlement, not a luxury.

'We are calling for personal and social care needs to be met through the same entitlement to free services as applies to health-care, irrespective of age,' says the local MS society branch.

'In MS Week over 6000 people joined the campaign to stop the MS lottery, including celebrities Chris Hoy, Scott Mills, Sally Gunnell, the Maccabees, Russell Tovey and Beccy Huxtable.'

Find out more:

http://mslottery.mssociety.org.uk/c are-and-support.

Log onto the campaigns blog to share your comments: http://www.mssociety.org.uk/campaigns-blog/stop-ms-lottery. [From MS branch newsletter,

May/June 2013]



Thumbs up from Vic as he goes through the town centre

Trouble hits our marathon man

Vic Davies, an SDN member and volunteer, ran the inaugural Shrewsbury Marathon for us. He did very well but had to drop out at 21 miles (you can read the full story in next month's YourVoice).

We can assure you Vic is fine and has done SDN proud by not only raising between £250 and £300 but raising the profile of SDN as well.

Many charities had more than one person running on their behalf, but Vic was the solitary person running for us. So if anyone would consider running for us at future marathons or half marathons, please contact us. Cheers, encouragement and support are so important and Vic is thankful to all who sent him messages and to his sponsors.

Now we must all get behind Vic as he prepares to run for us again on 15 September in the Lake Vyrnwy Half Marathon. Well Done Vic, we are all proud of you. Many thanks. - RH

Will you have the top table at the tabletop?

SDN is holding a tabletop sale on Saturday 3 August at Radbrook Community Centre in Shrewsbury, with tables on offer at just £5.

Each table sold comes with a raffle ticket, so some lucky group will get their money back in the draw at the end of the day!

Call Eirlys, one of SDN's volunteers, on 01743 588790 to book your table. Payment is due at the time of booking and cheques should be payable to Shropshire Disability Network. All cash payments will be receipted.

SDN will have its own table at the sale plus running a tombola and raffle, and will be selling refreshments.

Events like this help other

causes to fund-raise, and for SDN they are an essential part of the continual trickle of money needed to keep us in the black. Renewables such as stationery and toner cost us about £200 a month, plus insurance, postage and meeting rooms hire. We also have to buy new display equipment periodically.

But very importantly they keep SDN in touch with many of the organisations whose causes we champion. Never before has the disability community needed communication more!

(By the way, if anyone wants to buy a table and give the proceeds to SDN, the treasurer would be very pleased! Call Eirlys on 01743 588790 or email her at eirlys36evans@gmail.com to discuss)



Portal for care' that has many partners across whole coun

Shropshire Partners in Care, which describes itself as 'the Shropshire, Telford & Wrekin information portal for care,' is a not-for-profit company representing more than 200 independent nursing, residential and domiciliary care companies.

It works in partnership with local authorities, health and the voluntary sector to support development of adult social care, providing information, support training and signposting to relevant services.

Workforce development is promoted through the Care Workforce Development Partnership which has been successful in bringing funds into Shropshire and Telford & Wrekin to support further training. Recognising the need to improve recruitment in the care sector, SPIC has introduced 'The Care Ladder' website specifically to



'Zero tolerance' of adult abuse was the theme of a conference organised by Shropshire Partners in Care at the Lord Hill Hotel in Shrewsbury. Pictured are David Coull, Vice-chair of Shropshire Partners in Care and Chief **Executive Officer of Coverage Care Services; Karen** Littleford, Safeguarding Trainer and Development Worker, Shropshire Partners in Care; Stephen Chandler, Director of Adult Services Shropshire Council; Jane Randall Smith, Chief Officer Healthwatch Shropshire; Dave Robson, Service Delivery Specialist (Safeguarding) Telford & Wrekin Council; Debbie Price, Chief Officer, Shropshire Partners in Care; Claire Smout, Project/Care Liaison Officer, The Care **Workforce Development Partnership/Shropshire Partners** in Care; and Steve McGill, Chief Executive Officer Condover College.

> meet local need. SPIC is widely represented on local and national bodies and encourages close links

with those responsible for administering care services. In 2010 the Shropshire, Telford & Wrekin Dignity Network was established with the main aim of advancing the dignity in care agenda and the implementation of the Department of Health's 10 point Dignity Challenge.

The Shropshire, Telford & Wrekin Dignity Network aims to promote the ten points of the Dignity Challenge. Part of the network's activity involves sharing learning in relation to dignity. In 2012 a Dignity Survey was sent out across the Health and social care sector. The results demonstrated that there is still scope to do more and the network would like your support in raising the profile of dignity and the Dignity Challenge in Shropshire and Telford & Wrekin. Why not visit the Dignity in Care Network website

to learn more - http://www.dignityincare.org.uk/ - or call 01743 860011.

Art is good for pain rel

I am a member of the Telford & Wrekin Fibromyalgia Support Group, which is run by Helen Plant. As a number of us in the group had artistic talents in one form or another, Helen decided to arrange a fortnightly art get together where members showed other members their particular talent and how to do their particular specialty.

I took along a travelling iron and encaustic waxes and demonstrated how to apply the wax to the iron and spread it across the non-absorbent paper, although my main artistic talent is oil painting. We had sketching going on, acrylic painting, macramé, bead jewellery, card making, recycling last year's fashions,

SDN member Carole Lawrence knows from experience how art can help overcome suffering

scrapbooking, and more. Future meetings hope to include icing flowers and painting pebbles. Other talents in the group include photography, cake making and knitting.

You don't need to be particularly arty or talented; the purpose is to allow people to just have a go at various things.

One of the main enjoyments is chatting and laughing together and focusing on our art endeavours, which helps to take your mind off

your pain - like a sort of meditation. Not to mention the lovely cakes that members sometimes bake and bring along for us to enjoy with a cuppa.

The group is not only for those with fibro, but welcomes their carers and family along as well. We meet on the first Tuesday of each month from 11.00-1.00, normally at the International Hotel in Telford (but this can change if we have a speaker, so check beforehand).

For more information about the group contact Helen on 0844 887 2392 or email tandwfibrogroup@yahoo.co.uk

The website is www.telfordfibro.co.uk or find us on Facebook at Telford & Wrekin Fibro Support Group.



Atos doctor condemns methods used for tests

A doctor who worked for Atos has publicly criticised its methods as unfair. Greg Wood, a former Navy doctor, resigned from Atos after working as an assessor for two-and-a-half years. He told the BBC the system was 'skewed against the claimant.'

Claimants have to score a required number of points in order to qualify for the full sickness benefit under the Employment and Support Allowance.

Atos denied Dr Wood's allegations and said: 'We do not deviate from government guidelines in our training. We do not have targets for getting people on or off benefits. We have a large team ... who provide a professional and compassionate service.'

Dr Wood says Atos assessors are not free to make truly independent recommendations. He says he felt compelled to speak out because it was 'embarrassing to be associated with this shambles.'

The assessments - or fit to work tests - sparked protests from disability campaigners after their introduction in 2010.

Dr Wood criticised some of the tests which he says contain 'dubious concepts and shaky reasoning.' He claims assessors are told that if a claimant can walk from the kitchen to the sitting room, it proves they can walk 200m; and if a person can dress themselves once during the

Atos is 'surprised someone thinks we are unethical'

day that is proof they have enough concentration and motivation to hold down a job.

He says these rules are not published in handbooks and guides, instead they are simply spoken about in training sessions.

Atos senior vice-president Wayne Gibson said the rules detailed by Dr Wood were incorrect and several questions were asked to build up a complete picture, alongside the medical evidence. Atos was 'surprised that someone thinks we are unethical.'

Dr Wood, who was given special responsibility to champion mental health at Atos, says: 'I was instructed to change my reports, to reduce the number of points that might be awarded to the claimants. I felt that was wrong professionally and ethically. My view is the Government has

tried to catch more people in the net than the current test allows by pulling strings behind the scenes to get the result they most desire.'

Mr Gibson said a report was only changed if there was insufficient medical evidence to back it up.

Dr Wood says the people being most adversely affected by the system have significant, mid-ranging disabilities, such as Parkinson's disease, mental illness and head and spinal injuries.

He also claims some of the most severely disabled people are being asked to attend face-to-face assessments, instead of the normal practice of examining their application on paper. He says he saw a lot of people who had suffered severe strokes and brain damage.

The DWP said that between March and May 2012, 58% of decisions to award the full sickness benefit were made on paper only, without face-to-face assessment.

Employment minister Mark Hoban said: 'When we came to office one in 10 people were getting the highest level of support. That has now gone up to three in 10.'

He said the assessments had undergone several independent reviews and were devised in conjunction with health professionals and charities.

[From Shropshire ME Group Newsletter, June 2013]

Carers Trust website help

The 'Getting help' section of the Carers Trust website offers information on respite care, taking care of yourself, employment, holidays and days out, and carers' stories. There is also a site for carers aged 18 or less which is a community for chat, serious discussion and advice- http://www.youngcarers.net

Annual meeting date for County ME group

Shropshire ME Group will hold its AGM at Bayston Hill Memorial Hall on 23 July, starting at 7.00pm. More help is needed to run the group, organisers say, and all volunteers are welcome. In particular they would like to find a new Youth Representative for 12-25 year olds. The duties include support and fellowship through contact, running the Facebook page and implementing the volunteer's own ideas. [From Shropshire ME Group Newsletter, June 2013]



Shropshire Skills Match pairs ability with needs

Shropshire Skills Match is a new online 'micro-volunteering' system that matches people's time and skills with the organisations that need these skills but which for various reasons (cost, scale, lack of availability) can't acquire them.

It works in two ways. Firstly, it allows volunteers to post their skills and the time they have available. Organisations can then browse these skills, match them to their needs and make direct contact with the volunteer.

Secondly, organisations can post their skills shortages or opportunities. These can be small projects – eg, 'Can you suggest a new tagline for our website?' or 'Can you help us write a job description for a new position?' – or bigger ideas such as 'We need people to help

clear a site' or 'Can you spare an hour to help leaflet an area?'

People with skills and time to share can find out how they can make a difference. The Shropshire Skills Match website can be found at www.ShropshireSkillsMatch.org.uk

'Shropgeek' - a collective of professionals from Shropshire's technology, media and design world - very generously built and donated the site totally free. Building the site in this way is the first prime example of what Shropshire Skills Match is about!

The High Sheriff of Shropshire, Diana Flint DL, officially launched the website during Volunteers Week. [From Shropshire Infrastructure Partnership Newsletter, June 2013]

Chemists' advice fails shopper test

A Which? mystery-shop of 122 high street pharmacies has found worrying differences between companies. Mystery shoppers visited large chains, including Boots, Lloyds and Superdrug, plus supermarkets, smaller chains and independents, and were given unsatisfactory advice on 43% of visits. Independent pharmacies were worse than the leading chains and supermarkets. Over half were unsatisfactory. Details at http://www.which.co.uk/news/2013/05 /can-you-trust-your-local-pharmacysadvice-319886/?intcmp=HPcarousel1Anewspharmacyadvicemay 20 [From: Health Information

Delayed in traffic

News June 2013]

Readers with good memories will remember we were to run part two of Hyden's driving article this month, but it has been held over to August.

Charity's loans and grants aid families of disabled children

Disabled children's charity Newlife Foundation is making a dramatic difference to the lives of families through equipment loans.

The charity has provided more than 6000 items of disability equipment, at a cost of more than £8.5 million, since 2005. Last year (2012/13) alone, 1000 Newlife Equipment Grants were made at a total cost of £1.5 million.

The grants funded items such as powered and manual wheelchairs, buggies, specialist beds, car seats, sleep systems, and much else, but they are just one of the practical support services Newlife offers to families of disabled and terminally ill children.

The charity's services are all accessed through the national

Newlife Nurse Helpline, which is staffed by disability-experienced health professionals who are able to provide information and guidance to thousands of families.

For those families whose children are receiving end of life care, Newlife's 'Just Can't Wait' emergency equipment loan service aims to get equipment to homes within just 72 hours, wherever they are in the UK.

Just Can't Wait can make a huge difference to children in helping parents to manage their pain and care. Despite this being a very sensitive service to promote, around a hundred families have been supported in the past 18 months.

Another Newlife loans service, Kit Boxes, provides specialist sensory

and developmental equipment for children with a range of disabilities. The Kit Box loan service was launched in 2011, as a direct response to families' concerns about lack of access to suitable toys and aids for use at home.

Each box contains around £300 to £400 worth of assorted equipment tailored to specific developmental and sensory needs, and is available on a 12 to 18-week loan.

To find out more about Newlife
Foundation for Disabled Children,
visit www.newlifecharity.co.uk.
The Newlife Nurse Helpline can be
contacted on 0800 902 0095;
alternatively email
nurse@newlifecharity.co.uk.
The charity can also be found on
Facebook and Twitter.
[From Access magazine]

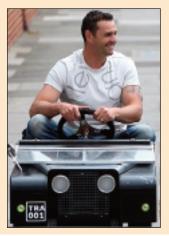


A son and father team in North Tyneside have come up with the ultimate motoring fashion accessory ... mobility scooters disguised as everything from a London taxi to a Harley Davidson motorbike. Or you can choose a Land Rover or Jeep!

Among those who think the idea has a lot going for it is singer Robbie Williams who rides a mobility scooter Harley in his latest video. The scooters are designed and made by Andrew Wylie in Whitley Bay. He says: 'I used to drive a taxi for disabled children and that's what gave me the idea. Tthere wasn't enough being done for kids so this is what we came up with, but now we customise scooters for everyone. No-one wants to feel disabled and this way they don't have to.'

Prices can be a bit steeper than a conventional scooter, however – the Harley costs £6000!

Mobility can come in many disguises





Robbie Williams in a scene from his new video, and Andrew Wylie in his 'Land Rover'

But there's nothing like a Shropshire field!

Since giving up driving, for my safety and that of other road users, I now get around on a mobility scooter, which gives me great independence – but they never go as fast as I would like. So it was great to have a blast on a quad bike and get up to 30kph.

I needed help to get my leg over the

seat, but once on the controls were easy, just like a scooter - accelerate with your thumb. The instructor was first class and kept a close eye on us so I felt very safe, and crash helmets were provided. Dave and I spent 90 minutes tanking round the fields at Bulthy Hill Farm, Halfway House.

As we went midweek there were only

two of us, so we were able to stop for good photo shots and the scenery was fantastic. The farm has a large gravel car park, and the toilet block has a couple of steps to get inside. For more information look at www.borderquadtrekking.com or call 01743 884694, Mobile 07970 884694 - Hilary Fisher [From MS newsletter, June 2013]

And while on about scooters, don't miss the bus

Some smaller models of mobility scooter can now be taken on low-floor buses. Go to the website http://tinyurl.com/m2zukme for an explanation of how to get permission and which scooters are suitable.

You can take your scooter on the bus if <u>all</u> of the following apply:
- your local bus company is running a scooter permit scheme

- your scooter is a Class 2 type and meets certain size limits
- the bus company has assessed you in safely using your scooter on the bus.

Permit schemes have been developed across the UK by the Confederation for Passenger Transport (CPT).
Arriva appears on the list.

If your bus company has signed up to the CPT scheme, it will issue a credit-card size permit, which can be shown to the driver to confirm that you are allowed to travel with your scooter.

Visit the website for more info on this and other tips for the disabled. [From Shropshire ME Group Newsletter, June 2013]

Read yourself well ... through your local library

Public libraries have launched a service called Reading Well Books on Prescription to help people through self-help in book form. This means you can go to your library for books which experts and many GPs have endorsed as helping with conditions such as anxiety, depression, low self-esteem and phobias. One in four people will experience mental health problems during their lives.

There are some six million people with anxiety and depression, yet 75% get no treatment. Reading Well Books on Prescription uses bookbased cognitive behavioural therapy to help people understand and manage common conditions. Visit

http://readingagency.org.uk/news/media/reading-well-books-on-prescription-launches.html [From: Health Information News June 2013]

Hamar Group dates

The MS Society's Hamar Group meets on the first Thursday of every month at the Hamar Centre, which is part of Royal Shrewsbury Hospital. The local branch says it is a good way to meet up with others and urges MS sufferers to come along and try it out. From 10.30 to 11.30 there is an exercise session followed by lunch, with a speaker at 1.00.

The next two meeting dates are Thursday 4 July and Thursday 1 August.





How does a wheelchair get down the stairs?

Dilemma: You're in a wheelchair. You need to get to the other side of a road but there are no crossings and no dropped kerbs. It looks like you're in for a heavy bump down and a challenge to get back up again once you've crossed over. How do you do it?

It's times like this when a wheelchair skills course can help. Since 1990 the charity Go Kids Go has been providing just that, teaching people to approach using a wheelchair in a positive way. Among the success stories are Paralympian and TV presenter Ade Adepitan.

Pete Donnelly became disabled in a

motorbike accident in 2006 and is paralysed from the chest down.

He has been teaching wheelchair skills for five years and is quite advanced, even being able to bring a beer back from the bar in a pub - a useful and sociable skill. He also negotiates stairs in his chair, but advises others not to attempt this without training.

Pete is a volunteer with spinal injury charity Back Up, where he teaches other paralysed people how to get the most from their chairs. 'It's not about doing a lot of tricks, it's about doing what you need to do to get back to the life you want to live,' he

says. The Whizz-Kidz charity also runs skills classes. It provides chairs for children but wants recipients to 'know how to use them, to have fun and to be safe.'

[From BBC News - Ouch]

Here are contact details for the three charities named, which can also be found on Twitter or Facebook

Go Kids Go, http://www.go-kids-go.org.uk/, tel 01482 887163

Back Up, Jessica House, Red Lion Sq, 191 Wandsworth High St, London, SW18 4LS; Tel 020 8875 1805; email admin@backuptrust.org.uk

Whizz-Kidz, 4th floor, Portland House, Bressenden Place, London, SW1E 5BH; Tel 020 7233 6600; www.whizz-kidz.org.uk/

The autistic community has a word for it!

There is a slang word that people in the autism community use to describe the noises and movements they sometimes make to feel calmer - stimming, short for the medical term self-stimulatory behaviours.

Stimming might be rocking, head banging, repeatedly feeling textures or squealing. You'll probably have seen this in people with Autism Spectrum Disorder (ASD). It is a term used widely in the ASD community.

Why do people with autism stim? There are many reasons. The animal behaviourist Temple Grandin, who is on the spectrum, says most people stim simply because it feels good. In Autism Digest in 2011, she

said dribbling sand through her fingers was a feeling that used to calm her. Referring to her own childhood experiences, she said that stimming 'may counteract an overwhelming sensory environment, or alleviate the high levels of internal anxiety these kids typically feel every day.'

A real life example is that it could stop sounds hurting your ears. As an adult, Grandin seems to control the sensory overload a little better but says some people need to stim to 'refocus and realign their systems'.

UK campaigner Robyn Steward says she relaxes her wrists and lets her hands flap up and down when she's happy or anxious. A public speaker with autism, Stewart thinks that for her, it's the rhythmic nature of stimming that does the trick. So, in short, stimming is often done to block out unwanted sounds or visuals. Is it just people on the autism spectrum who stim? No. Neuro-typicals, or people without autism also self-stimulate, eg nail biting, hair twirling and foot tapping.

NTs, as they're known for short, can usually control their stims and tend to do those that are considered more acceptable in public than those done by people with autism. There are blogs and web forums where people on the spectrum discuss stimming, compare stims and discuss public reactions.

[From BBC News – Ouch]



And then there were none . and then even fewer!

The exceedingly small Universal Credit pilot scheme may prove to be even smaller than expected, if the results from the first day at Tameside Town Hall are anything to go by: not a single person turned up to claim, (reported in The Guardian)

Concerns have been raised that people trying to claim Universal Credit online rather than in person will have difficulties due to the absence of a 'save' button on the form

For example, if you get logged off because it takes you too long to find information you need to complete the form, then everything you have done will be lost and you will have to start all over again.

However, the Universal Credit form's problems are as nothing compared to those faced by people trying to use the Department for Work and Pension's online claim forms for DLA and AA.

The official antics over Universal Credit, PIP and DLA continue. If the results were less than a tragedy for the disabled, they would be laughable

According to the Department itself, the forms don't work with any version of Internet Explorer more recent than version 6 or with such new-fangled browsers as Firefox, Safari or Chrome. They also don't work with the screen-reading software used by many visually impaired claimants.

Also, with the multi-million pound spend on Universal Credit software still not producing any results, it is unlikely that cash will be found for improving AA and DLA claims software in the near future.

Moving swiftly on to Personal Independence Payments ...

The Government has admitted that there can be no PIP online applications (see http://tinyurl.com/lzj3ohg).

The outdated IT system in use requires applicants to fill in the 56-page application form by hand or by lengthy phone-call, which will clearly be far too much for many applicants. [Thanks to Shropshire ME Group Newsletter, June 2013, for this information]

NHS 'infographic' poster

The changes to the NHS that came into force on 1 April are complex. To help explain them, NHS Employers has published a new 'infographic' poster, which is intended for both patients and staff Visit:

http://www.nhsemployers.org/Aboutus/latest-news/Pages/Thenew-NHS-in-2013-infographic.aspx

An organisation called Nesta has produced a business case for the programme and a report which makes the case for changing the ways in which healthcare is organised, by showing how it can better combine the very best scientific and clinical knowledge with the expertise and commitment of patients themselves. Visit: http://www.nesta.org.uk/people powered health

Footnote: Nesta describes itself as an independent charity with a mission to help people and organisations bring great ideas to life through providing investments and grants and mobilising research, networks and skills. It forms partnerships with innovators, community organisations, educators and investors.

[From: Health Information News June 2013]

Cerebra awards for youngsters

Children's charity Cerebra has launched its annual awards and is inviting nominations for under-16s with a neurological condition or brain injury. Eight winners will receive an iPad and a Cerebra trophy. The charity wants parents, carers, professionals, friends and family simply to explain why the child they are nominating deserves to win - be it for a particular accomplishment, courage, academic achievement, or any other reason. The closing date is 6 September. Visit the Cerebra website or contact Melanie Dean at Cerebra on 01267 242 556 or email melanied@cerebra.org.uk [from Access magazine]

Deaf interpreting survey

The Association of Sign Language Interpreters and Deaf Interpreters Network are keen to gather data regarding Deaf Interpreting and Translation work. If you are Deaf and work as a Deaf Interpreter/Translator or in similar field, they would be very grateful if you could take few minutes to fill in a questionnaire. Just click on the link

http://www.surveymonkey.com/s/H8F8VJX. Responses are needed by 31 July.



Why society needs to talk about suicide

Stephen Fry, talking about his suicide attempt, said: 'Now, you may say, how can anyone who has got it all be so stupid as to want to end it all? That's the point, there is no "why?" it's not the right question. There's no reason.'

At the same time, the media is full of speculation about why the teenage girl of a famous singer allegedly tried to take her life, including theories from the girl's mother.

If someone is experiencing such pain and distress that they are thinking about ending their life, then they are in a terrifying and lonely place. It can also be very frightening for those close to them, as they struggle to understand and know how to help.

It is not surprising that we seek to find out why - so that we can fix the problem, reason away the fears. As Stephen Fry tells us, though, that will not work. So, how can you start the conversation if you are worried about someone? If that someone is you, then start by, well by just starting to talk to someone about it.

It is that simple step, that can feel so overwhelming, so impossible, that could be the start of the move back from the negative and despairing place you are in to one where you can see and look forward to a future.



One of the big stories in recent weeks has been Stephen Fry's admission that he attempted suicide last year while filming a TV documentary. Paul Farmer, chief executive of Mind, the charity of which Fry is president, explains why we need to talk about suicide

If you don't have a family member or friend that you can talk to, then there are organisations that will listen. Samaritans has been listening to people for 60 years, which in itself is proof that you are not alone.

Other organisations, like Mind, have helplines or other services where people will listen and support you to get the help you need and deserve.

In 2011 there were 6,045 suicides in the UK, an increase of 437 on 2010.

Of course, that means there were many more attempted suicides and even more who thought about suicide but fortunately did not take any action. I wish there were statistics on how many people thought about suicide but then were able to access help and so were glad that they never carried it through.

What if you are worried about someone else? Mind has listened to what people who have experienced suicidal thoughts have told us - and they ask us to listen. We should listen to what is said, even if it is upsetting. We should not dismiss expressions of helplessness or not recognise the depth of despair. We should be accepting and listen to what ideas people have to help themselves rather than jump in with our own solutions. However, we should also be prepared to encourage and support people to seek help.

It might feel like a difficult conversation to have, but here's a start. Instead of asking why, perhaps we could start off with asking how. How are you? How can I help? And then being prepared to listen to the answers. [From Access magazine]

Techniques shown to beat MS fatigue

Researchers funded by the MS Society, at Bournemouth University and Poole Hospital, have developed an effective method of helping people with MS to manage their fatigue. The programme (FACETS) incorporates 'energy effectiveness techniques' such as lifestyle decisions and ways of working that maximise energy, with cognitive behavioural strategies, which help participants learn helpful ways of thinking about fatigue. A

team at Bournemouth University has completed a trial of the FACETS intervention and found 40% of participants who received FACETS as well as their normal care, had a meaningful improvement in fatigue levels, compared with 19% of those receiving current local practice only. Read more on the MS website:

http://www.mssociety.org.uk/msnews/2013/05/ [From MS branch newsletter, May/June 2013]



You are not alone

Going to our site is all it takes to meet others who understand what you are going through:

www.shropshire.gov.uk/community.nsf

Shropshire Self Help Groups Telephone 01691 656882

Sponsored by Shropshire Council, Telford & Wrekin Council, and the NHS





If your organisation or cause is not listed here please let us know. Email the editor at newsletter@shropshire-disability.net or write to him: Peter Staples, 8 Gorse Lane, Bayston Hill, Shrewsbury, SY3 0JJ

Shropshire Council Disability Services - www.shropshire.gov.uk/disability.nsf

Telford & Wrekin Adult Social Care Directory - services available and how to access them

http://www.telford.gov.uk/site/scripts/download_info.aspx?fileID=116&categoryID=100010

A4U Disability Advice Centre - Guildhall, Frankwell Quay, Shrewsbury SY3 8HQ; 01743 256218; advice@a4u.org.uk

Autonomy - self-help and social for Aspergers in Shropshire, Telford and Borders - autonomyshropshire@yahoo.co.uk

Care Farming West Midlands - www.carefarmingwm.org.uk; stewart.scull@carefarmingwm.org.uk or Mobile:07957 839634

Carers Direct - 0808 802 0202 www.nhs.uk/carersdirect/Pages/CarersDirectHome.aspx

Community Council of Shropshire - www.shropshire-rcc.org.uk/ 4 The Creative Quarter, Shrewsbury Business Park, Shrewsbury, SY2 6LG; 01743 360641; fax: 01743 342179

Community Directory for Shropshire, Telford & Wrekin http://www.shropshire.gov.uk/community.nsf

Disability Arts in Shropshire -01743 272939/271676; www.dasharts.org

Disability Directory – Information, aids and mobility services www.ableize.com/Disabled-Groups-and-Clubs-by-County/Shropshire/

Disability Football Directory 01952 407198 http://www.disabilityfootball.co.uk/Madeleysports.html

Disability-friendly holiday accommodation

www.friendly-places.com/categories/disability-friendly/disability-friendly.asp?Location=Shropshire

Disability Resource Centre, Lancaster Road, Shrewsbury, SY1 3NJ 01743 450 912; robin.durham@shropshire-cc-gov.uk www.the-svab.org.uk. RNIB: www.info.rnib.org.uk/exe/Agencies/Details.pl?480

Disabled and Wheelchair Athletics Directory

www.apparelyzed.com/disability-directory/adaptive-sports/disabled-athletics/

Enable - supported employment services for people with disabilities in Shropshire and Telford, Unit 4, Owen House, Radbrook Road, Shrewsbury, SY3 9SR enable@shropshire.gov.uk. 01743 276900

Headway Shropshire (brain injured and families) Holsworth Park, Oxon Business Park, Shrewsbury, SY3 5HJ 01743 365271; www.headwayshropshire.org.uk

Healthwatch

Shropshire - 4 The Creative Quarter, Shrewsbury Business Park, Shrewsbury, SY2 6LG; 01743 237884; enquiries@healthwatchshropshire.co.uk; www.healthwatchshropshire.co.uk

Telford & Wrekin - Suites A & E, The Place, Oakengates, TF2 6EP; 01952 384990; info@healthwatchtelfordandwrekin.org.uk; http://www.healthwatchtelfordandwrekin.org.uk

Parent & Carer Council Shropshire

www.paccshropshire.org.uk/parent-and-carer-groups PACC provides an index of support groups for children with disabilities in Shropshire. The following groups are listed on the PACC site. Where possible we list direct contacts, but refer to the PACC site for full details) Allsorts (South Shropshire, for behavioural conditions) 07813043841 www.paccshropshire.org.uk/parent-and-carer-groups/71-allsorts Bridgnorth Buddies (Parent-led, Special Needs) 07968 544182 or 07790 780631; email Buddies20@yahoo.co.uk

www.paccshropshire.org.uk/parent-and-carer-groups/72-bridgnorth-buddies

Haughton School, Telford, drop-in for parents of pupils with more complex special needs) 01952 387551 or 01952 387552; www.paccshrop-shire.org.uk/parent-and-carer-groups/83-haughton-school-drop-in Onevision (visual impairment) 01952 385269

/www.paccshropshire.org.uk/parent-and-carer-groups/77-onevision STACS (Aspergers,16+) 01952 254594 or 01939 260273; email louise.griffiths@carerscontact.org.uk

www.paccshropshire.org.uk/parent-and-carer-groups/76-stacs Autistic Supporters (if you suspect your child is autistic, or has recently been diagnosed) 01743 356298

www.shropshireautisticsupporters.co.uk/?q=node/2

Deaf Children's Society 01952 770019; email: nat4sdcs@aol.com www.ndcs.org.uk

Down's Syndrome 01743 233802, 01948 880110 or 01588 640319 www.dsa-shropshire.org.uk

Dyslexia Association 01743 231205; www.thesda.org.uk Wheelchair Users 01743 350460 or 01952 252243

SKiD (Shropshire Kids Insulin Dependent, associated with Diabetes UK) 01743 873724 or 01743 364366; email: home@morkot.go-plus.net SPECTRUM (Autistic Support group) email: netgriffiths@fsmail.net www.spectrum.t83.net/

Telford STAA (supports parents/carers of children with ASD, ADHD, and challenging behaviour) 01952 457439 or 01952 617758; email: julie@parentpartnership-shropshireandtelford.org.uk or lesley@parentpartnership-shropshireandtelford.org.uk

Steps (help for parents/carers, lower limb abnormalities) 01743 355363 PODS (Parents Opening Doors - Telford, forum for views on services) 01952457439; email: julie@parentpartnership-shropshireandtelford.org.uk

Landau - supported employment services for people with disabilities, 5 Landau Court, Tan Bank, Wellington. TF1 1HE, 01952 245 015, admin@landau.co.uk

Listen Not Label - User Led Organisation for disabled and carers in Telford and Wrekin (Tina Jones, manager), 01952 211421 Meeting Point House, Southwater Square, Telford, TF3 4HS

Marches Community Enterprise

01584 878402 or 07891094901

ME Connect - Helpline 0844 576 5326 between 10.00-noon, 2.00-4.00 and 7.00-9.00; meconnect@meassociation.org.uk

Motor Neurone Disease Association - MND Connect 08457 62 62 62 mndconnect@mndassociation.org

Multiple Sclerosis Society - 01952 250038; www.mssociety.org.uk/telford

NHS Choices - www.nhs.uk/Pages/HomePage.aspx

Omega (National Association for End of Life Care) - www.omega.uk.net/

OSCA Citizen Advocacy - Roy Fletcher Centre, 12-17 Cross Hill, Shrewsbury, SY1 1JE; 01743 368370; info@oscacitizenadvocacy.org.uk; www.oscacitizenadvocacy.org.uk

Parent and Carer Council (PACC) Shropshire - making parents and carers aware of developments that affect their children and giving them a voice - www.paccshropshire.org.uk; PO Box 4774, Shrewsbury, SY1 9EX; 0845 661 2205; enquiries@paccshropshire.org.uk

Parent Partnership Service - www.parentpartnership-shropshire-andtelford.org.uk/#/useful-links/4551168089



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PODS - independent forum in Telford for families of children with disability or additional need; Jayne Stevens 0777 534 2092 or 07824 631 297; info@podstelford.org; www.podstelford.org

Primary Care Trust www.shropshire.nhs.uk/Get-Involved/

Scope (Cerebral Palsy) - www.scope.org.uk/services/shropshire

Shrewsbury Dial-a-Ride - Sundorne Trade Park , Featherbed Lane, SY1 4NS. Enquiries 01743 440350; Direct Line 01743 440744; Mobile 07891094901, linda@shrewsburydialaride.org.u

Shrewsbury Hard of Hearing Club - URC Church Hall, Coleham Head, Shrewsbury, SY3 7BJ; Contact Erica Horner 01743 873540, ericahorner2@googlemail.com

Shropshire ME Group- www.shropshiremegroup.org.uk; 07516 401097

Shropshire MIND - www.shropshiremind.org Observer House, Holywell St, Shrewsbury, SY2 6BL 01743 368647

Shropshire Peer Counselling and Advocacy Service www.shropshirepcas.co.uk/default.htm

Shropshire Volunteering Team - Promote your volunteering opportunities. http://shropshirevcs.org.uk/site/volunteering/

Shropshire and Staffordshire Heart and Stroke Network Lambda House, Hadley Park East, Telford, TF1 6QJ Email: yuen-ting.cheung@shropshirepct.nhs.uk 01952 228490

Sight Loss Shropshire (formerly Voluntary Association for the Blind) The Lantern, Meadow Farm Drive, Harlescott, Shrewsbury, SY1 4NG; 01743 210808; SVABadmin@shropshire.gov.uk

VCSA - Voluntary & Community Sector Assembly www.shrop.net/shropvcsassembly

Voluntary Association for the Blind (see Sight Loss Shropshire)

YV services directory

This is a 'bulletin board' of services to the disability community. Any service that is genuinely for the benefit of people with disabilities is welcome to up to 40 words free. If you have a logo or artwork we will try to include it, but can't promise. Email your text to the editor at newsletter@shropshire-disability.net or write to him: Peter Staples, 8 Gorse Lane, Bayston Hill, Shrewsbury, SY3 0JJ

Sign as you speak: 1Starfish - to become a better communicator learn how to sign as you speak. Total Communication Training Courses for private, public and voluntary sectors. Also Makaton courses. Contact Mandy at www.1starfish.co.uk or 01743 891885 or 07939 600126

Used medical and mobility equipment: The British Red Cross sometimes has donated medical and mobility equipment for sale for a reasonable donation. Call Christine Hunt on 01743 280073 for further information. The donations received help maintain the medical loan department, which is an invaluable service offered by the Red Cross.

Shropshire Handyperson Service: Small jobs at £15+ VAT per hour, no call-out fee, 01743 458 347 mhishropshire.enquiries@mearsgroup.co.uk

Into the depths of charity law

A blog has been published explaining a recent report on the Charities Act 2006 and charities law. It is by Elizabeth Chamberlain, senior policy officer at the National Council for Voluntary Organisations, and it concerns the report by the Commons Public Administration Select Committee after months scrutinising the Act. Visit: http://blogs.ncvo.org.uk/2013/06/06/what-mps-said-about-charity-law-your-2-minute-guide [From VCSA]

Telford Carers Contact Centre news

If you are registered with the Carers Contact Centre or Telford & Wrekin Council as a carer of an adult in Telford & Wrekin, you can borrow a pass giving unlimited free access to Ironbridge Gorge Museums for up to five days. It is valid for up to five people and also includes 10% discount on purchases from the Museum shops. For details of how to apply please contact us on 01952 240209

Carer events coming up in Telford & Wrekin include:

- Wellington Carers Group, 10 July, 10.30-noon at Wellington Medical Practice; Contact 01952 262062 for details
- Leegomery Carers Group, 11 July, 10.30-12.30 in the Training Room, Leegomery Community Centre. Phone Lara or Louise on 01952 240209 for details.
- Pamper Day, 16 July, 9.30-12.30 at Haybridge Hall, Hadley, TF1 6JG. Booking is essential phone 01952 240209
- Carers Walk Newport, 17th July, 10:30, Meet at car park opposite Cosy Hall, Water Lane, Newport

To learn more about the Carers Contact Centre and how it can help you, either phone, write, email or call in to the office: Carers Contact Centre, The Liz Yates Centre, Lightmoor, Telford, TF4 3QN; Telephone: 01952 240209; Fax: 01952 591026; Email: admin@carerscontact.org.uk

We are not alone in brutality

Other countries are no better than ours when it comes to the senseless brutality of the state against the needs of the defenceless individual. Here's an example from Denmark. Karina Hansen is a severely ill ME/CFS sufferer forcibly removed from her home by Danish psychiatrists who are denying her parents and lawyers access to her. A petition has been started on her behalf, aimed at the Danish Health and Medicines Authority, and asking for understanding and correct treatment for Karina (http://tinyurl.com/m8r3u9t) [Based on an item in Shropshire ME Group Newsletter, June 2013]

By making space available for paid advertising SDN hopes to offset the costs of the printed version of YourVoice, which is proving a great asset to readers who do not use computers.

This is a basic advertisement space 98mm by 66mm. It costs £10 per issue, and
advertisers get a free design and copywriting
service. Their product or service will be seen
both by our print and online readerships.
It's a bargain! Interested?



On the face of it ...

Changing Faces is a charity for people and families who are living with conditions, marks or scars that affect their appearance.

Its work is divided into two areas: It aims to help individuals lead full, confident and satisfying lives, giving practical and emotional support to adults, children and their families. It can also provide training, support and advice to professionals in health and education.

The other area of its work is to do with changing minds. 'We aim to transform public attitudes towards people with an unusual appearance. Our goal is "face equality" and we promote fair treatment and equal opportunities for all, irrespective of how they look,' says Changing Faces, which lobbies for integrated health services; influencing schools and workplaces to create more

inclusive environments; and pushing for anti-discrimination protection and enforcement.'

Changing Faces uses the word 'disfigurement' as a noun but avoids its use as an adjective (ie, it won't say 'a disfigured child' but rather 'a child with a disfigurement') It recognises that the word is not positive and that some people, particularly parents and young people, may not want to use it to describe their own or their child's condition or appearance, preferring terms like 'visible difference', 'unusual appearance' or the name of the condition.

There are more than a million people in the UK who have a disfigurement. In 2007, Changing Faces commissioned a thorough search of all existing studies, data and websites to create a better estimate of the incidence and prevalence of disfiguring

conditions. The research reached the following conclusions:

- 542,000 people have a significant disfigurement to the face.
- 92,000 have congenital or birth conditions
- 66,000 have disfigurements from accidents
- 40,000 have cancer-related disfigurements, from surgery for skin cancer.
- 100,000 have disfigurements from facial paralysis, including stroke.
- 220,000 have disfigurements related to skin conditions like psoriasis, vitiligo and acne.
- 1,345,000 have significant disfigurement to their face and body.

Some 415,500 people are expected to acquire a significant facial disfigurement in the period of a year, with some conditions being transient while others are life-threatening as well as disfiguring.

Free social network to support vulnerable

Family members, friends and care professionals will soon be able to make use of a free social networking service - Yecco - to help coordinate support for vulnerable individuals.

The main aim of Yecco is to relieve the demands placed on carers and to foster more effective communication between the carer and client/family member and other third parties.

The new site will have a number of features, including a shared calendar, a built-in 'Yecco Messenger', the ability to schedule alerts and reminders and a news-feed.

The site also offers a series of forums, links to external care resources, a directory of service providers and an online retail operation. Yecco apps for Android-based smartphones and tablets are already available at the Google Play store, ready for when the site goes live.

To find out more about Yecco prior to its official launch sign up for email notifications at www.yecco.com. [From Access Magazine]

Newsletter for voluntary groups set to launch next month

A new bi-monthly newsletter for voluntary organisations in Shropshire and Telford & Wrekin is due to launch next month (August). Its primary purpose will be to carry news about voluntary organisations in both areas. It is now accepting articles and ads, with a copy date of 9 August. Submissions should be sent to leslie@oyeznews.org.uk [From SIP newsletter]

Fact sheets on reforms

In the year that is seeing the biggest changes to the benefits system since it was created well over half a century ago, Disability Rights UK has produced a wideranging series of welfare reform fact sheets which are available free.

DRUK says the fact sheets are regularly updated to keep pace with changes. They can be found at http://www.disabilityrightsuk.org

All SDN members and supporters - and anyone who wants to criticise us - are very welcome to express opinions or promote events in YV. Email us at newsletter@shropshire-disability.net or write to the editor at 8 Gorse Lane, Bayston Hill, Shrewsbury, SY3 0JJ