

Carers' Gazette

News for carers in Pembrokeshire
Issue 33 - November 2010

A day in the life of Shan Roberts, Carer

Shan was brought up in Newport and went to school in Fishguard. She moved to Newmarket at 17 years old and was a professional jockey. Shan had her three children there and moved back to Pembrokeshire 14 years ago. She felt she was brought up in a lovely place and wanted the same for her children.

Who do you care for?

I care for my son Andrew who is 18 years old. He was diagnosed at 2½ with Duchene Muscular Dystrophy when still living in England. In Wales babies have a heel prick at birth which brings up this disorder, but in England they don't do it. Andrew has two sisters, I had an older daughter and when Andrew was born I realised that something wasn't right. He was then diagnosed from a blood test. From the age of eight Andrew has been in a wheelchair.

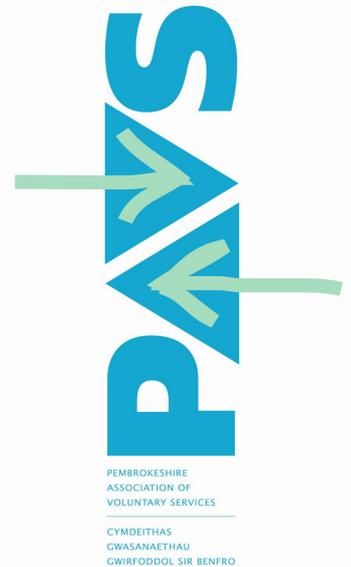


for his A levels, but as his condition deteriorated it was uncomfortable and exhausting for him. Andrew studied at home doing an Astrology course with the Open University. He enjoys rock music, we go to the Download rock festival every year and also go to see rock bands in Cardiff.

What is your usual daily routine?

Andrew needs total support with everything. He needs washing, being moved into his chair and onto the toilet. Andrew has trouble swallowing and is fed by tube 3 to 4 times a day. He only has movement in his right hand fingers with which he can drive his own chair.

Andrew went to mainstream education in Ysgol y Preseli where he did his GCSEs. He went back



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If you would like to receive regular news via e-mail please let me know by sending a message to

Nicole.vanschie@pavs.org.uk

Newsletters are also available electronically at www.pavs.org.uk/

We would like to hear from you if you wish any carer's news to be included in the Carers Gazette or if you have any ideas for improvement.

The next deadline is 27th January 2011.

Please send articles with your pictures to: Carers Gazette PAVS

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I keep him comfortable in the chair throughout day, and make sure pain relief is adequate. Andrew is on nocturnal ventilation, he needs turning throughout the night to keep him comfortable. I get respite at night at least twice a week when Andrews's careworker comes.

What support do you have?

I am at home all day, every day to care for Andrew apart from when there is a careworker. Replacement care comes in one morning, one early evening and two nights per week and Dad is on stand by. Most of the support is through continuing care (Health) and some from social care in the form of Direct Payment with the help from the Rowan Organisation. We didn't want changes in careworkers for personal care so the Direct Payment works for us, we can have the people we know to come in and care. Andrew was the first child in Pembrokeshire to receive Direct Payments.

When a careworker comes in I go out and train. I coach a running club in Fishguard, organise races and do longboat rowing with the Newport ladies team. I am training for the Snowdon marathon, I won last year and hope to run well again this year. Andrew will go to Ty Hafan for respite that race weekend; he can go there until he is 19 years old.



What has been your worst experience?

The worst experience has been being in hospital, Andrew's condition is rare, so facilities for his needs aren't there, we can't move in the hospital room with the wheel chair. They don't have the equipment and they don't have the expertise, I have to be there to care for him and have to sleep on a mattress on the floor.

What has been most helpful?

Direct Payment has been most helpful to be able to be at home. Here is where we feel comfortable. We have the support Andrew needs and with Direct Payment we are able to make the right choices for his care. We are trying to keep home life as normal as possible, I want to care for my son and he wants me to care for him.

Action for Children is also always there to help; we have had a key worker.

What would you like to see changed to make it easier for carers?

Improvement in hospitals would take the pressure off me. The surgery is very supportive; my GP appreciates my expertise and listens.

What advice would you offer other carers?

The best thing is to find something for yourself, keep the mind active and your body fit. I went to college and got some qualifications, but it would be impossible to go out to work now. I have found my way with caring and running, I am quite happy with it.

Carers' Forum was held at St Patrick's Hall in Pembroke Dock on the 20th October 2010. After a presentation by Jina Hawkes, Primary Care Projects Manager the forum discussed the **'Hywel Dda Health Board 5 year plan'**.

Some feedback from the forum: *"Good to have the chance to air a few points and felt as if there was some hope of getting somewhere in the future."*

"Great to take part in the active conversation with carers, a lot of useful information discussed."

A day in the life of Judith McNamara, Disability Inclusion Worker



What is your role?

My role is to support disabled children and young people from the age of 14 to 25. I work full time for Pembrokeshire County Council and am seconded to Action for Children for about one day a week to be a keyworker for 5 families/carers with disabled children with profound and complex needs.

Describe a typical working day?

I could be visiting a school or the college, usually at lunch time to have informal chats with the disabled young people; they tend to be of the sixth form age. I could be meeting with 20 young people in schools in a week. I could be liaising with Special Educational Needs Co-ordinators (SENCOs) of schools, or attending an annual review of a family/

carer with a disabled child.

In my role as a keyworker I support carers by listening to their needs, co-ordinating services, liaising with agencies and helping the disabled young people through the transition period. This is predominantly transition from school into life, which could be going to college, into a social setting, work experience and sometimes to a residential situation.

I also co-facilitate the Youth Forum 'Young Voices for Choices'. We meet every three weeks at the Garage in Haverfordwest, approximately 20 young disabled people take part in it with some young people as volunteers.

What is the best part of your job?

I think seeing the young people gaining confidence, although it is a slow process. To see them have the confidence after a few years, becoming able to stand up in front of people, and speak on behalf of other young people. It is about disabled young people to achieve what they can achieve.

We have a good rapport with the families/carers, which I believe is a support for them although informal. I would like to make it easier for carers and take the burden away from them.

How much of your time is spent working with carers issues?

Yesterday I was working with carers issues nearly the whole day with an annual review and writing up the report afterwards. There are days I don't spend time on carer's issues. Originally it was one day per week but in practice it is on an as and when basis. I will stop what I am doing and try to sort out a difficulty a carer has. It is also nice to be there for carers when something good happens and parents/carers are happy and pleased.

What is the biggest problem you encounter?

The biggest problem is lack of time. I like to give more time, more support. My job wouldn't be so fulfilling without this keyworker role, but I can't always do as much for carers as they need.

Background:

Judith is from Liverpool where she went to the 1st purpose built Comprehensive School and after that to the Mabel Fletcher College. She has always wanted to work with children and trained as a nursery nurse. After a gap year she moved into Special Needs Education. In 1974 Judith came down to live in Pembrokeshire with her then fiancé whose job was based here. She worked at Portfield School for three years before she had her two sons. They bought a farm when their oldest son was 6 weeks old and have been farming for 33 years.

If there were no carers, what impact would this have on your work?

I would throw my hands up in the air, not knowing where to turn. If there were no carers we wouldn't have the facilities and services to help and care for all the disabled young people.

What sort of support do you offer carers?

I mainly support carers with their disabled young person by helping them get an extension to their home where needed, liaising with social services and other organisations, organising short breaks (respite care) and with benefits, pointing them in the right direction. I also support the families/carers by making visits to different places for the transition and by finding out for them why things don't happen.

What changes would you like to see to benefit carers?

I would love to see services being available to the young people to give them the best quality of life and for the families/carers to have to battle less. I would just like the support they need to be there for them, they are often under so much pressure because of the caring role. Information should be more readily available; lack of knowledge makes it so much harder. In a way I am an advocate for the young people and their carers. There is a great need for a generic advocacy service for carers.

CARERS RIGHTS DAY

Friday 3rd December 2010 from 10:00 am to 1:00 pm
Letterston Memorial Hall,
 Station Road, Letterston SA62 5RZ



'Know Your Rights'

Carers give so much to society yet, as a consequence of caring, they often experience ill health, poverty and discrimination. Nationally Carers Wales is a campaigning, policy and information organisation of and for carers. They make a difference to carers' lives by:

- campaigning for a better deal for carers
- informing carers of their rights and what help is available
- training and advising professionals who work with carers
- working across Wales through its membership and networks of branches and affiliates

Carer's Rights days are organised to help carers find out what their rights are.

Organisations in Pembrokeshire who provide information, advice and services to carers will be present on the day with a stand. During the event you can learn what your entitlements are and talk to organisations present. Come along, bring a friend or another carer you know.



Carer's response to last year's Carers' Rights Day: "Excellent day, lots of useful advice"

We can help with travel and replacement care costs. The event closes with a free lunch. For more details or to book a place on the day, please get in touch with Nicole van Schie, Carers Development Worker on 01437 771196 or Nicole.vanschie@pavs.org.uk

A LIFE OF MY OWN

Presentation by Noel Evans, carer,
on Carers Day 2010

Thank you for inviting me to speak to you today, although, having looked around and seen all the important people here and knowing what's in my speech, I think I'm in real trouble.

I retired in 2004 and they say that retirement is when you stop lying about your age and start lying about the house. Many of you will know that if you are a carer that's not the case. I became the named carer for Marj, my mother-in-law, who is now over 90, confused, immobile and highly dependent in 2004. Marj needed care because she started to fail physically, becoming unsteady on her legs and also showing signs of confusion. A lot of things have changed in my life since then.

I retired under an early release scheme when I was 57. Of course this meant a drop in my income and although I claim a carer's allowance and have accessed my pension, it makes a significant difference. In order to assist with caring, my wife has also recently gone part time – a further reduction in the family income. This is at a time when costs of heating, laundry and special food and other items are increasing due to the specialised needs of the person being cared for.

Caring is a major time commitment. Due to her high dependency, we do not leave Marj alone for any length of time. This means that my wife and I seldom go out together. We miss going out on the spur of the moment – we can only do it occasionally when we have arranged for respite time in advance and then we can't go very far due to restricted respite time. It has also meant that I've had to give up some of my hobbies. I no longer sing in a choir and I've given up being a chapel deacon as both of these activities require commitment and regular attendance which cannot be guaranteed if you are a carer.



Although we are grateful for the opportunity for residential respite care, we worry that the attention which residential homes are able to give is not the same as the one-to-one care we can give in our own home. As a result we have not taken a proper holiday of a week or more outside Pembrokeshire since 2004. The best we've managed has been two night break away and we only took that break because I won it in a competition prize.

When you become a carer the attitude of family and friends can change. I have friends who do not understand the responsibilities and commitment which caring involves. They think I can drop everything at a moment's notice to go somewhere - which I can't. They think we can do what we've always done and that's not the case when you are a carer. Also visits by family and friends drop off. You have to ask yourself why – are they embarrassed by the disabilities, are they afraid of being asked to help? As a result both the person being cared for and the carer become more isolated and lonely. You are "out of the loop".

The fact that you cannot do what you want when you want can lead to feelings of frustration and even resentment. The role of the carer is not sufficiently recognised by the government. Carers provide an invaluable service for a small amount of carers' allowance. We have some help from Pembrokeshire Care for which we pay and it is less than an hour a day over two sessions. A few hours respite support which we receive weekly is provided by voluntary agencies that have no government funding.

However, there are upsides to caring. It is very rewarding to know that you are doing the best you possibly can for the person being cared for and knowing the trust and love given in return. I also appreciate the help and support which is given by Crossroads in Pembrokeshire and Pembrokeshire Care. In fact, I value their help so greatly that I have

joined the Friends of Crossroads in Pembrokeshire and am privileged to have been appointed Chairman. Most of you will know that Crossroads provides free respite time for carers. Recently the organisation has become Crossroads Mid and West Wales and the Friends were formed to make sure that money raised in Pembrokeshire was used for the benefit of carers in Pembrokeshire.



The other great benefit which I have experienced since becoming a carer is looking after Marj's little Westie called Oscar who is a great character, very friendly and ensures that I get some exercise. He is great company both to Marj and me. However, even taking him for a daily walk can be difficult. I try to do it before the carerworkers come to get Marj up in the morning, but there is no guarantee what time that will happen – sometimes it's 8.15, sometimes it's nearly 11 o'clock. This makes it difficult to plan the day.

You never know, when and under what circumstances any of you may be called upon to become a carer or even to need care yourself. It can happen to anyone at any time and it makes a huge difference to your life. I feel particularly for young carers and am pleased that there is special support for them. I would urge those of you with influence to lobby for more support for carers of all sorts, who are so very valuable to our community, so that they can indeed have a life of their own.

Pembrokeshire Friends of Crossroads next fundraising events:

A Fashion Show was held in Solva Memorial Hall on Friday 8th October. This was organised and presented by Bella Prickett of Window on Wales in Solva. Bella and the team of models, dressers and helpers provided a wonderful snapshot of the autumn fashion for us to see which is available to purchase in the shop.

It was a very enjoyable evening that included a glass of wine and lots of lovely Raffle prizes, and so far about £450 was raised. Many thanks to all who helped and supported the evening.

The next event for the Friends is a Christmas Bingo in the Cricket Club Haverfordwest on Wednesday 24th November. Please join us for "eyes down" and good luck.

For more information please ring the Crossroads Haverfordwest office 01437 764639 or the Secretary Graham on 01437 720163.



Crossroads Saturday Clubs

Crossroads has been delivering dementia group support here in Pembrokeshire for 2 years. The Saturday clubs open at 10am and close at 4pm. In this time we offer activities appropriate to each individual's needs. Staff have recently completed training in Cognitive Stimulation Therapy (CST), group activities that enables people to explore new experiences and focuses on what people can do as oppose to what they can not. People attending will also receive a hot meal and refreshments throughout the day.

We have availability in the following areas Milford Haven, Pembroke Dock and now Fishguard, these are offered on either a weekly or fortnightly basis. All venues have disabled access. You must be able to make your own way there. If you would like further information then please contact Crossroads on 01437 764639



Have you ever wondered about returning to college or maybe work?? Have you thought about it and decided that it wouldn't be any good for you because you have no time, no money or even someone to look after the individual you care for....? Or, are you facing life after caring for someone and wish to get back into learning or work? We can help.

Would it be helpful to have access to free courses to update your skills or even a social event to help rebuild your confidence? Would the offer of experienced care support from qualified and caring people whom you can trust, help you?

The Care to Work Project can offer Life Skills, IT training, accredited and non accredited courses, offer work experience and volunteering opportunities, to prepare you for returning to the workplace. Once part of the project you will benefit from ongoing support from an experienced Project Officer, receive help with travel and subsistence costs and have support in finding a suitable job or placement. The Care to Work Project is run in partnership with Crossroads Care and the Mid and West Wales Chamber and funded by the Big Lottery and the European Social Fund to give you all the support you need to return to work or learning. If you wish to become a part of the project or just want some further information, please call Marie Wright on 07792 566 799, Project Officer for Pembrokeshire. I will be pleased to hear from you.



Y Loteri Genedlaethol
Awarding Funds from
The National Lottery*



Mental Health Carers Support Group *formerly known as Carers in Mind*

Support for the partners, relatives and friends of people suffering mental health problems in Pembrokeshire. You don't have to face your difficulties on your own. We offer:

- Someone to talk to
- Practical advice
- Information

We meet on the 2nd Wednesday of each month from 2pm till 4pm at PAVS, 36-40, High Street, Haverfordwest, 01437 769422

For Mental Health Carers Support Group call: Sabine 01348 881320
Joy 01646 687113 or Fred 01646 697268

Ataxia South Wales

Ataxia is the name given to a group of neurological disorders that affect balance, coordination, and speech. There are many different types of ataxia that can affect people in different ways. We are a very friendly and supportive branch of the National Charity Ataxia UK covering South Wales based in Carmarthenshire and meet on Sundays in Llanelli.

If you would like more information contact:

Alan Thomas on 01994 448397 or email onamission.thomas@btinternet.com

To visit our website go to: www.ataxiasouthwales.org.uk

Communities 2.0

Communities 2.0 (pronounced Two Point Zero) aims to help individuals, communities and social enterprises in modern Wales to use technology to enhance their lives.



How can we help you?

PAVS Circuit Riders (ICT Support Workers) can offer advice and support on almost all aspects of ICT for you, your group or organisation.

You may want to

- o Shop safely online
- o Talk to your family with video calls for free
- o Get an email address.....and more!

Where will we be working?

We work with voluntary groups and organisations based in, or who work in, the priority areas of:

**Haverfordwest, Castle & Garth, Milford, Hubberston & West
Pembroke Dock, Central & Llanion, Pembroke, Monkton & St Mary North**

Contact us on 01437 771197 to see how we could help you.

Pembrokeshire Carers' Emergency Card Support Service

Do you worry about what would happen to the person you look after if they were suddenly taken ill or had an accident?

If the answer is 'YES' then the Carers' Emergency Card Support Service is the service for you.

What is the Carers' Emergency Card?

It is a credit card sized card that you carry with you at all times. It is used as an instant source of identification in the case of accident or sudden illness. The British Red Cross and Crossroads – Mid and West Wales will hold your number and details where help can be co-ordinated to assist you both, while you are receiving attention. By making a brief phone call, help can be summoned for the person you look after.

How does the service operate?

You register with the service by completing an enrolment form. This form holds information about you, the person you look after and the action needed to be taken in the event of an emergency. The British Red Cross and Crossroads hold this information. You are issued with a small laminated card.

What are the Benefits?

- Carers are offered 24 hour a day emergency cover.
- Carers feel less anxious and more free to go out.
- Carers have the peace of mind if something happens to stop them getting home.

You can join the service by completing an enrolment form which can be obtained from the British Red Cross, telephone 01792 772146, fax 01792 784910.





Pembrokeshire Investors in Carers

Following a successful pilot project in 2008/9, the Investors in Carers Scheme at Bronze Level to all GP Practices is now being extended across Pembrokeshire. This standard is awarded to GP Practices who can successfully demonstrate that they have processes in place to effectively identify carers and provide appropriate information and signposting to further support.

The project is overseen by the PAVS Carers Development Worker and delivered in partnership with the British Red Cross Ceredigion Carers Support Service.

Carers own health can suffer when taking on a caring role, both physically and mentally. You maybe doing more physical work such as moving and handling the person you care for. The worry and lack of sleep all takes a toll on your own health. The Investors in Carers Scheme works with GP practices to raise awareness of the issues and concerns that carers have. This helps to raise awareness of carers for both the GP practice and patients. We encourage carers to register themselves as a Carer with their GP practice. If you haven't already done this and would like to, please ask at your GP's reception desk. Your GP, nurses and other staff can provide you with help and support that you may need, either now or in the future. For example, some flexibility with appointments, sign posting to other agencies etc.

Newport surgery is the Welsh Winner for the RCGP and Princes Royal Trust for Carers inaugural **Caring about Carer's Awards (Wales)**. They were nominated by a Carer.

Newport Practice Manager: *"I would like to say that it was taking part in Pembrokeshire Investors in Carers Scheme for GP Practices in conjunction with PAVS, British Red Cross and Pembrokeshire/Ceredigion LHB a few years ago that raised my awareness and gave me the incentive to continue to thrive to protect the well being of Carers within our Practice."*



Health Social Care & Wellbeing Strategy Pembrokeshire

The 2011-2014 HSC&WB Strategy for Pembrokeshire is being developed. In developing the strategy it will be important to reflect how the work of voluntary sector organisations contribute to the proposed strategy priorities **and** to hear ideas for new projects which could make a contribution. If you have any comments on how your organisation does or could contribute to the proposed priorities (below) or if you would like to discuss developing a project in line with the proposed priorities, please contact Michelle Copeman at PAVS.

Proposed priorities:

- Improving health and well-being of all people
- Develop and implement a physical activity plan for Pembrokeshire that addresses equality in the provision of, and access to, a broad range of physical activities to promote well-being.
- Provide appropriate primary, community and social care services that will enable access to the right service at the right time in the right place and reduce the demand on acute hospital services.
- Provide support and advice for carers to improve their wellbeing and the wellbeing of the people they care for.
- Provide affordable and appropriate housing and make better use of public buildings to support the development of sustainable communities

- Work in partnership to provide appropriate and timely information to individuals on access to services and advice so that decision making is easier and more effective.
- Provide community transport services that meet a wide range of needs to enable appropriate access to health care and social activities (shopping, library etc)
- Work towards the implementation of the 'Our Healthy Futures', Strategic Framework for Public Health Wales document, to improve quality and length of life and provide fairer outcomes for all.
- Work in partnership with the voluntary sector where their skills and expertise can complement services provide by other health and social care professionals.
- Develop and train our workforce to enable appropriate engagement with individuals at a community level.
- Work towards integration of appropriate professional resources within the community, encompassing a partnership approach between agencies and multi-disciplinary teams.

For further information please contact:

Michelle Copeman on 01437 771192 or
Email: michelle.copeman@pavs.org.uk

Building strong bridges



Withybush General Hospital Stroke Service

The acute stroke unit (ASU) at Withybush General Hospital is comprised of 6 acute stroke unit (ASU) beds and 8 stroke rehabilitation beds as part of a 24 bed ward. The service is supported by a multidisciplinary team comprised of:

- Consultant Physicians
- Stroke Specialist Nurse
- Physiotherapists
- Occupational Therapists
- Senior Dietician
- Specialist Speech and Language Therapist

In response to the Stroke Services Improvement Plan and as part of the All Wales Stroke Services Collaborative, in Pembrokeshire, we are actively measuring clinical outcomes through the use of care bundles as follows. Care bundles are pathways which enable us to measure the quality of care we provide and we have been actively monitoring ourselves on the quality of care for acute stroke patients within the first 72 hours of a stroke.

As a result, swallowing and nutritional screening are areas where we have provided further training and support to enable staff to meet the objectives of ensuring the best standard of care. We are still trying to improve the pathway for stroke patients to be diagnosed early and have direct access to an acute stroke bed which will help us further improve our patients' experience.

Our Plans for the Future

Sustaining the improvements made to date in addition to continuing to review performance in other areas where compliance against the RCP guidelines could be improved is integral to providing a robust stroke service.

An area of priority is to improve access to the ASU and plans are being developed to enable safe and effective patient flow for acute stroke and stroke rehabilitation patients. We actively participate in the Royal College of Physicians (RCP) National Sentinel Stroke Audit and the aim is to meet the RCP criteria for acute stroke units, ensuring patients reach an ASU within 4 hours of admission.

Young Carers in Mind

The last few months we have been developing an under 8s programme. We have 4 young carers under the age of 8 in the Haverfordwest area who we maintain contact weekly. Activities range from teddy bears picnics to swimming, visits to the pet shop and park and recently to see a film at the Torch theatre.

A lot of these activities are first experiences for this group of children who are reliant on unwell parents to provide their respite. This is the most rewarding of programmes as the young carers have such a great time.

We have also separated the over 12s so that we can meet their needs with regards to activities. The next over 12s trip will be paintballing in Tenby which was a unanimous decision by the children in that age group. At the moment and definitely coming up to Christmas we are running a Haverfordwest swim on a Tuesday and a Pembroke swim on a Friday. We have street dance on a Thursday and Karate in the Tenby area on Friday and all four activities are very popular.

One to one sessions are a very important part of our work as its at these times that we are able to help young carers to develop skills to look after themselves physically and mentally so as to create resilience and feeling of wellbeing for now in and in the future - prevention is better than cure.



Young Carers Forum



Young Carers Forum News

We had a busy summer holidays. Eleven young people, which included 6 young carers, took part in the John Muir Discovery award which involved days out at Broad Haven, Stackpole and Little Milford woods. We explored rock pools, did bush craft, explored the area including finding out which plants can be used to make tea and did conservation work at Stackpole. The last part was to share our experience and the presentations were shown at the Activity Day in October half term when they were presented with their certificates.

We also had a trip to Oakwood as a reward for all those who have attended forum over the past year and taken part in all the workshops, consultation and participation events.

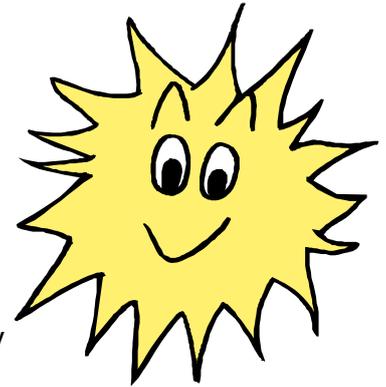
In October half term we held another activity day which was attended by 20 young carers. During the day there were workshops on the Annual Director's Report and consultation on the draft Children and Young People's Plan along with art and cookery workshops with a Halloween theme. In the afternoon there was swimming, sports and dance using the new dance mats at the Leisure Centre.

One of our young carers is assisting with the interviews for the staff for the new advocacy project. In half term they met young people from Ceredigion who are taking part, did workshops on interviews and put together the interview questions ready for the interview panel in November. Contacts for the Forum are Mel Richards 01437 776534 and Nadine Farmer 01646 680863 emails: Melanie.richards@pembrokeshire.gov.uk and Nadine.farmer@pembrokeshire.gov.uk.

Holiday Breaks for Carers

Carers are invited to apply for a holiday break grant to enable them to take a flexible, much needed holiday or break of their choice, to help to continue in their caring role. The holiday breaks for carers scheme has the following main conditions:

- All carers must be living in Pembrokeshire and be providing care to someone aged 18+.
- Grants of up to £250 are allocated to carers towards their holiday break.
- Applications within 12 months of the end of the caring role will be considered if the carer has been unable to take a holiday because the person they cared for was too ill.
- The decision will be made by a panel made up of the Carers Development Worker, Voluntary Sector Representative and Carer Representative.
- There is a limited amount of funding available, therefore one grant per family is usually allowed only every other year.



Mrs Sheila Hodson's account of her holiday break: *"Thank you so much. I have just returned from a much needed rest in Rojas-Spain where I was able to relax and strengthen, knowing my sister was being looked after and safe with friends. I love my sister very much, but I do begin to struggle at times when I get very tired as I am not too well myself, to be able to switch off for a while helps tremendously. I just read and rested for the whole two weeks (and visited a market!) So many thanks again for your most generous help toward my respite break, as I would really have found it a struggle to meet the cost. I feel so refreshed and energised after my break and feel I can carry on again now in looking after my Sister. "*

Benefit changes 2010

Changes to benefits relevant to carers:

- Carers Allowance earning limit increased from £ 95 to £ 100 from 12 April 2010
- DLA High Mobility on the basis of severe impairment - Claims started to be assessed from 15 October 2010. Entitlement and payment will not start until 11 April 2011.
- Bereavement Benefits—Telephone claims allowed for bereavement payment, widowed parent's allowance, bereavement allowance and Social Fund Funeral Payments since 29 July 2010..
- Home Responsibilities Protection— Replaced by National Insurance Credits for those getting child benefit for a child under 12 and some carers from 6 April 2010
- Carer's Credit—If you are caring for 20 hours or more a week and not already claiming Carer's Allowance, you could qualify for Carer's Credit.

For more information about Carers Credit you can visit www.direct.gov.uk/carers which takes you to the 'Caring for someone' page on the Directgov website. Underneath 'Carer's Allowance' there is a heading 'Guide to financial support for carers'. If you click on that it will take you to their page about financial support for carers. The information about Carer's Credits is on that page. You can then click on the link called 'Caring and your pension'.

Here is a direct link to that page:

www.direct.gov.uk/en/CaringForSomeone/MoneyMatters/DG_10038111

Getting your voice heard

With the axe falling on public sector spending, it is vitally important that your voice doesn't get lost. When vital services for you and the person you look after are at severe risk of being restructured or cut, your voice needs to be heard loud and clear. Now more than ever, your involvement to save a service or to help shape the future of services in your own local area is crucial.



Carers Wales has been given funding to support carers and groups of carers to play their part in helping to influence local and national services. The project aims to build your confidence and give you the knowledge to help you campaign locally. It will also help you to learn from each other, share your knowledge and your caring experiences and to inform policy at local and national levels.

Carers Wales will gather local information from you to feed into national policy and offer you opportunities to represent carers at a national level. Pat McCarthy, who heads up the project, is out and about Wales visiting carers groups and meeting individual carers arranging local focus group meetings.

Pat also offers training sessions on how to get your voice heard. Topics such as, how to develop an effective campaign are covered, as are the skills needed for success, how to present your case; how to highlight a particular issue of concern, and how to make progress.

If you, or your carers group feel that you could benefit from this and would like more information, please contact Pat McCarthy on 02920 811370 or pat.mccarthy@carerswales.org

From Carers Wales newsletter, published with Carers Wales' permission

Pat McCarthy has been invited to the next Carers Forum. The sessions will be held on Wednesday 2nd March 2011 for a morning or an afternoon with a light lunch or tea afterwards.

Wales Carers Summit

The Wales Carers Summit was an extremely successful day. A carer said: "Very good, excellent speakers, very informative, an excellent event."

87 delegates, including carers and representatives of health organisations from across Wales attended the summit. The aim of the day was to enable carers to discuss the way the NHS needs to change things in order to support carers better. The summit was also broadcast live on Carers World Radio and 67 people used this to join the event. Comments and questions were posted on the chat room throughout the day. The recurring theme was the importance of carers having their voices heard; how they could become key partners and be involved in shaping how services are developed and delivered in the NHS.

The Summit opened at 10.45 and everybody was warmly welcomed by Mary Trinder, Chair of Carers Wales Committee. Hywel Francis MP and a Vice-President of Carers UK also welcomed people to his constituency, Aberafon. He spoke about how he sponsored the Carers Equal Opportunities Act 2004 and how Carers Wales, Carers UK and carers themselves were vital in ensuring its successful passage through Parliament.



Roz Williamson, Director of Carers Wales gave an overview of the work of Carers Wales and Carers UK. Delegates were updated on recent developments affecting carers and she highlighted the need for carers to get involved and to speak out in order to shape policy and change the way services are designed and delivered. Given the current economic climate and potential cuts to services, she emphasised that it is more important than ever need for carers to get involved to make sure that carers are not expected to fill all the gaps.

One of our keynote speakers, Michael Williams Chair of Betsi Cadwalader University Health Board was ill and Win Griffiths, Chair of Abertawe Bro Morgannwg University Health Board kindly stepped in at the last minute and talked about ways that the NHS can engage and consult with carers.

Stephen Yorke, a long-standing member of Carers Wales and a carer representative on Betsi Cadwalader University Health Board stakeholder reference group, explained how involvement as a carer with Carers Wales has had a positive impact on his own life. In particular, he explained how getting involved in changing things for carers has given him the confidence to speak up and get his voice heard.

Maggie Titterton, the Development Officer for Carers Wales, emphasised the important role that carers themselves play in changing things, and how Carers Wales hope that in each new NHS trust in Wales there will be a formal structure to engage with and involve carers in all plans to develop services.

The final speaker in the morning was Gwenda Thomas AM, the Deputy Minister for Social Services and the Assembly's Carers Champion. She has led on the development of the new Carers Measure and emphasised how important she feels it is for a duty to be placed upon statutory health and social services to consult with carers both at a personal and at strategic levels. A full copy of the Minister's speech will follow.

The presentations were followed by questions and comments from carers.

During the afternoon there were small discussion groups to look at carers' experiences of the NHS and to think of solutions on how things can be improved for carers. A recurring theme from the feedback of each group was the lack of communication from health professionals to carers and patients. A number of solutions were put forward on how to remedy the failings that were identified that carers and the people they look after had experienced.

CARERS Wales the voice of carers

Below are comments received from delegates (carers) on whether the day met with their expectations:-

- Was excellent and very humbling for me to listen to people with so much experience and stress that are very clear about what they need but do not get listened to!
- It was informative, I especially enjoyed hearing the different stories from carers and was pleasantly surprised that LHB representatives were willing to listen and pick up on individual cases and didn't excuse gaps in services.
- Our table were struck by what could be described as "buck passing" in the morning Q & A session (while recognising panel members acknowledged each LHB will determine its own policy).
- This was the first Carers UK Summit I have attended. I found the summit interesting and informative.

Independent Living NOW!

Disability Wales are campaigning for a National Strategy on Independent Living for Disabled People in Wales.

They have launched an online petition on the National Assembly website calling for Welsh Assembly Government action.



The **Independent Living NOW!** Campaign will run from April 2010 to March 2011 and provides an opportunity for all disabled people in Wales to make their voices heard ahead of the 2011 Welsh Assembly elections. The campaign was launched on 28 April 2010 at Future Inns, Cardiff Bay and some of the aims are:

- to raise awareness and understanding of what Independent Living means for disabled people in Wales
- to call for a National Strategy for Independent Living
- to develop a Manifesto for Independent Living throughout the campaign to influence policy makers
- to collect disabled people's stories to establish an evidence base for Independent Living in Wales

Manifesto for Independent Living

Disability Wales/Anabledd Cymru calls for a National Strategy on Independent Living for disabled people in all impairment/age groups to build on existing policy and legislation, and including specifically:

1. A barrier free transport system, including all modes of transport
2. Improved access to information, advice, independent advocacy and peer support services for all
3. Improved access to Person Centred Assistive Technology
4. Availability of accessible and supported housing to meet individual requirements
5. A comprehensive range of options and genuine choice and control in how personalised care and support is delivered
6. Enabling access, involvement and social, economic & cultural inclusion for all disabled people



You can show your support for the campaign by signing the petition and by spreading the word.

The shortened direct link to the petition is <http://tiny.cc/ILNow>

All signatures are very welcome, the more the merrier (and more influential).

For more information please go to <http://www.disabilitywales.org/>

If you ask mePauline Jones

If you were Prime Minister for the day, what one thing would you change to make life easier for carers?

That all carers would receive the attendance allowance regardless of their age.

What was the last book you read?

The Island by Victoria Hyslop. I did enjoy it because I have visited the island in Crete.



If you could ban one thing, what would it be?

Bad language

If you won the lottery how would it change your life?

I would be able to help my grandchildren.

What is society's worst fault?

No respect for people or property

What makes you angry?

Not being able to work as hard as I used to.

What makes you happy?

Being with my family.

Which one word would your friends use to describe you to a stranger?

Reliable.

Did you know?

Improving the lives of carers in Wales

The [Carers Strategies \(Wales\) Measure 2010](#) has been approved by the National Assembly. The NHS, local authorities and other statutory bodies in Wales now have a duty to publish a strategy for the provision of information and advice to carers before making decisions about the provision of services to the people they care for.

Accessible Holidays

Holidays for all in the UK and abroad

<http://holidaysforall.org/> is a website designed for people with sensory and physical impairments, their friends and families.

This website provides a list of reputable holiday companies. You can read about what they have to offer and match them to your care requirements. If you would like more information on Holidays for All, or to receive there brochure in other formats, please call 08451 249973.



An online radio station 'Carers World Radio' produces programmes and talks specifically for carers:

www.carersworldradio.com

This newsletter is available on our website too at: www.pavs.org.uk/carers. If you would like a copy sent to you please forward your details to **Carers Gazette, PAVS, FREEPOST SWC4881, 36-38 High Street, Haverfordwest, SA61 2ZZ** or email: Nicole.vanschie@pavs.org.uk

Name Carer: Yes/No

Email.....

Address

.....

Postcode Telephone.....

Age Group: 0-20 20-30 30-40 40-50 50-60 60-70 70-80 80+

Ethnic Origin:.....