

Brachial Plexus Injury Newsletter

In this edition...

Welcome to the Summer 2013 edition of Brachial Plexus News. There's lots of interest in this edition.

We have...

- DLA changes to PIP
- Patient Story
- Patient Held Record
- Roadshows



DLA (Disability Living Allowance) changing to PIP (Personal Independence Payment)

From April 2013 DLA is being replaced by PIP.

PIP is aimed at helping towards some of the extra costs arising from a long term health condition or disability & is based on how a person's condition affects them, not the condition that they have. PIP is not means-tested or subject to tax & it is payable to people who are both in employment & not in employment.

What the changes mean for patients;

PIP involves a more objective assessment, with a face-to-face consultation with an independent health professional for the majority of people.

- PIP includes regular reviews so that people continue to get the right support
- PIP is based on an assessment of the persons needs. It will not consider what impairment / disability a person has. It will consider how the person's impairment / disability affect their life, considering their ability to carry out a range of everyday activities.
- Information will be gathered from the person, as well as health, social care & other professionals who work with & support them.
- PIP may involve a face-to-face consultation with an independent health professional as part of the assessment process. During the consultation questions regarding the person's circumstances, their impairment / disability & how this affects their daily life will be asked.
- At present there are no plans to replace DLA for children under 16 or for DLA recipients who were aged 65 & over on 8 April 2013.

More information on this change can be found at:

<https://www.gov.uk/pip>

Living With Brachial Plexus Injuries:

Caroline's story

I sustained a right sided brachial plexus injury in April 2006. The injury happened when I was having surgery to my left shoulder. How it had happened exactly, couldn't be explained, but following the necessary investigations, the diagnosis was confirmed and I was referred to Mr Hems and the Brachial Plexus Injury Service at the Victoria Infirmary, Glasgow.

At this time it was difficult to predict the rate and extent of recovery but I was lucky.

I didn't require any surgery and was started on a programme of physiotherapy and occupational therapy: the aims being to try to regain as much function as possible to my arm and hand and to get back the independence I had lost.

I was introduced to Beverley Wellington, Clinical Nurse Specialist, early on and I had a number of sessions with her during which time my emotional reactions to my injury were explored and it soon became evident that I would need her help and expertise in order to aid and support my recovery.

I had been working as a neonatal midwife and had had several problems with my shoulders, needing surgery. The last operation was done with the intention to allow me to return to work. As my particular area of nursing was in a clinical area which necessitated full range of movement and dexterity, as a result of the injury I was forced to give up what had been a very rewarding career. It also meant I was unable to re-register as a nurse and midwife as I would be unable to complete the required hours of practise by the time re registration was due. I was declared eligible for ill health retirement and so left the profession.

The injury was devastating in many ways; the physical recovery was very slow as I had been told to expect, and it was very difficult to accept the inability to perform daily tasks that I had previously taken for granted. The help and care

from Jane Green, physiotherapist, and Leslie Wallace, occupational therapist were outstanding.

Mr Hems too was always positive. The team recognised that one of the ways to help me regain independence was to encourage driving again and I was referred to the Astley Ainsley centre in Edinburgh where as a result I drove (with much trepidation) for the first time since the injury. I have to admit here that it took me some time and much persuasion to actually change to an automatic car and acknowledge the need for a steering wheel handle.

A major issue for me was the acute loss of confidence and identity as a person who enjoyed an active lifestyle. My roles as a wife, mum, housewife and nurse were all affected badly and it took many sessions with Beverley to allow me to accept not only what had happened but how to recognise the new normal for me and move forward from the changes to my life after the injury.

Slowly my recovery continued to the point where my independence is greatly improved, which allows me to live my life in a way which suits me. I still need minimal help with certain things, but I'm constantly aware that the outcome could have been so much worse; for this I am very fortunate.

Beverley always was aware of my distress at my loss of career and when the opportunity of voluntary work presented, she urged me to apply to see what possibilities were out there. Putting a toe in the water was a daunting thought but the role of a volunteer doesn't carry the same pressures as regular employment and for me, it was a great place to start. As a result, I'm delighted to say that for the last 3 years I have been volunteering for the Patient Information Centre at the New Victoria Hospital.

I work with a breast feeding support group which allows me to use my midwifery experience. The group is designed to help mums who breast feed meet other mums with the opportunity to ask for

continued over...

Caroline's story (cont.)

help /support if needed. For the last year I have also volunteered with 'Hairmony', a service provided to help patients experiencing hair loss mostly as a result of chemotherapy. Two very different services but both equally rewarding for me.

I have also played a part in Patient Information Centre awareness sessions, and part of the Better Together programme carrying out patient experience questionnaires.

Working as a volunteer in a hospital environment has been invaluable for me; it has given me back

a sense of identity, purpose, confidence and self esteem that I didn't think possible. The feeling of being part of health care again is so positive and I know through feedback that my input is appreciated and helps both services maximise their efficiency.

I will always be grateful to all the team in the Brachial Plexus Injury Service, and for the push; thanks so much Beverley!

Caroline

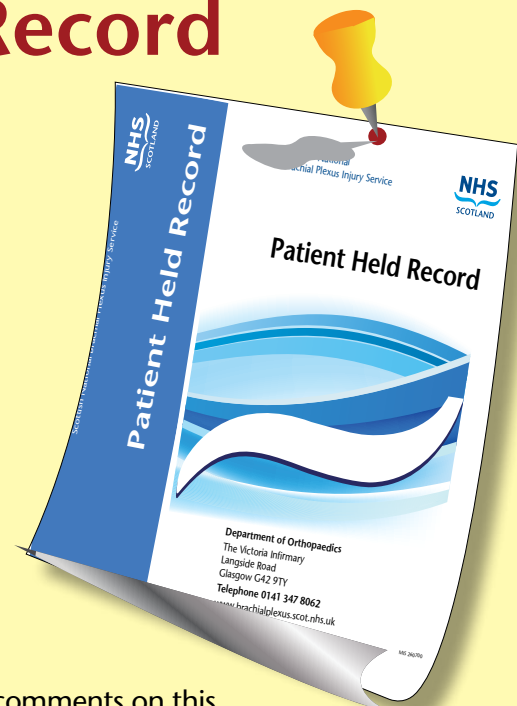
June 2013

New Patient Held Record

Do you ever walk out of a clinic consultation and can't remember what was discussed or struggle to understand the meaning of the information told to you??

This is a common occurrence and more so when we're talking about such a complex injury as those to the brachial plexus. So we decided to help you and also help us to understand what happens to you every step of the way.

Beverley has been working on a Patient Held Record for a few months along with Claire. This record in A5 size mini folder with inserted pages is designed to allow you some ownership of your healthcare journey and allows for communications of vital information to be noted at clinic appointments. You will be encouraged to bring this to every hospital / GP attendance to ensure improved and continuous communications to happen.



Any comments on this are welcome although initial feedback from patients has been positive and welcoming of this 'diary' of events!

BW

Roadshows

As part of an ongoing project to provide service developments we have started some educational road shows where team members will visit other healthcare providers (hospitals) to highlight the service, how to access it and what we can do together to help patients in all areas of Scotland.

The first road show was delivered by Beverley and Claire in April and covered Dumfries & Galloway Royal Infirmary and then Borders General Hospital in Melrose. There was a fair bit of local interest from staff on site, some of whom had no knowledge of our service and some who had used it but welcomed further details of how to use us to the maximum for our patient's benefits. It is hoped to repeat the road show in another geographical location in the next quarter.

Any suggestions for locale are welcome. Please contact Beverley for further information or to discuss us coming to your area.

BW

Baby news



We are delighted to announce that the team physio, Lyndsay Pawlikowski, had a baby boy called Blake Norman, born on 25th January 2013 (15 days early!) at 1.55am weighing 7lb 8oz.

Congratulations to both proud parents. Lyndsay is hoping to return to work in August.



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