

*Learning from best practice*

Consistently our research shows that many patients and carers receive excellent local services, while others sometimes are let down, receiving minimal understanding or help. Hence it is not difficult for us, in our reports and elsewhere, to make practical recommendations based on best practice. We are most grateful when clinicians, commissioners or managers respond. We welcome ideas from readers for future research priorities, as we continue our work representing the needs of neurology patients.

*Living with incontinence*

Recommendations from our survey 'Living with Incontinence', included:

- a standardised care pathway,
  - more training for GPs and nurses,
  - more referrals to specialised services for full assessments,
  - review the policy on free continence care products,
  - better quality information,
  - more help from voluntary groups,
- all to reduce the misery of living with incontinence. Our thanks to the LINK for funding this and to all who took part.

*Living with two or more conditions*

Our focus group on co-morbidity involved ten people, who had over two-dozen conditions between them! We would not suggest this portrays the full picture of life with multiple conditions but it is a taster.

The findings will be published in full shortly. They will highlight the need for:

- prompt and accurate diagnosis,
- consistent use of care pathways,
- better desktop tools for GPs,
- better co-ordination across teams,
- holistic care at all times,
- better information,
- better hospital ward practices,
- better support for carers,
- more nurse specialist posts,
- neuro training for psychology staff
- better care planning/coordination,
- more case conferences,
- more use of 'named clinicians'.

There is some excellent good practice in place, from which improvements can build. We will bring the report on this complex subject to the attention of those who can most influence change as soon as possible.

*Wheelchair users second focus group*

We were delighted to be asked by the West Berkshire NHS Wheelchair service to run a second focus group for local wheelchair users, to give further general feedback and to generate ideas for information for the service's new website, which was a very productive exchange. Delegates also were asked about experiences when using therapy services at Royal Berkshire hospital and some excellent ideas were raised

Ideas flowed to improve access to the service and to ensure a more reliable spare parts service. Some staff awareness training is also now planned.

## *Coping when systems falter*

Our next focus group will be on 14<sup>th</sup> October on '*Coping when health and social care systems falter*'. Details later.

## *WBNA Conference 2014*

We are delighted that Professor Mike Wilson is organising our 2014 all-day conference, which will be on 6<sup>th</sup> March.

This will be on '*Neuro-rehab: facts, fears, future*' and will include practical workshops and a top line-up of speakers at Wokefield Park. Dr Faraz Jeedi is again our clinical advisor.

Put this date in your diary now!

## *Hydrotherapy and specialist rehab gym*

Negotiations continue to secure a suitable plot for a hydrotherapy pool and specialist rehab gym for Newbury and Thatcham. It remains a high priority for us to sponsor this excellent project.

## *Neurology and the CCG Federation*

The four, new NHS CCGs (Clinical Commissioning Groups) in Berkshire West have united into a federation.

Months ahead of taking over its commissioning role on 1<sup>st</sup> April it set up a Long Term Conditions Board. Plans include to recruit an epilepsy nurse specialist and to knit the local neuro staff into one, close team. A service for those with ME/Chronic Fatigue Syndrome is planned. A great start!

We continue to press for the Neuro Needs Assessment to be completed, knowing there is much more that could be done to improve local services, particularly on the prevention front.

## *NHS England*

From 1<sup>st</sup> April NHS England will operate through 212 CCGs and 27 local area teams. NHS Berkshire West is part of Thames Valley Area, covering Berks, Bucks and Oxon. Welcome Aarti Chapman who will lead the Thames Valley Neuro Network. The role will be key to driving improvements in the specialised services needed by neuro patients. We are delighted that she will be at our open meeting on Thursday 9<sup>th</sup> May. Join us if you can! Details below.

Of the many ways in which the NHS will measure its performance, sadly very little attaches to outcomes for neuro patients, so keeping neuro on the NHS priorities list will require much hard work on all our parts. Happily, the NHS is creating a Clinical Reference Group for neurology.

This will provide clinical advice on specialised services, and promote equity of access to high quality services.

## *Dates for your diary*

### **Open meeting dates for 2013:**

All 1.45 for 2 pm, St Joseph's, Newbury

May 9<sup>th</sup> Aarti Chapman, NHS Thames Valley

Jul 11<sup>th</sup> Dr Marko Bogdanovic RBH Neuro

Nov 14<sup>th</sup> Tim Goadby Brain Injury Rehab T'st

### **Other dates:**

Sept 26<sup>th</sup> AGM 7 for 7.30 pm Padworth

Oct 14<sup>th</sup> Focus Group 2 pm Padworth

Mar 6<sup>th</sup> 2014 Conference Wokefield Pk

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