Welcome to the 3rd edition of the North East Lincolnshire (NEL) Neurology Newsletter. Work continues on developing Multiple Sclerosis, Motor Neurone Disease, Epilepsy and Parkinson’s services and we are pleased to report some good progress.

Dr Lazarus, Consultant Neurologist for Diana, Princess of Wales Hospital (DPOW) said: “Many professionals from a range of organisations are working together to improve and develop the services we offer locally. Whilst there is still much work to do I am pleased to see that patients are already benefiting from some of the work implemented so far, for example, the local Parkinson’s service has come a long way from inception and now provides very up to date comprehensive, diagnostic, therapeutic and rehabilitative services for patients. The service goes way beyond just making a diagnosis and offering treatment but offers services which try to help patients to not only deal with the disease but live with it as comfortably as possible.”

“The Epilepsy service at DPOW has received a boost with the arrival of a full time Epilepsy Specialist Nurse, Mrs Carol Ogden. Carol runs the epilepsy service with me and we have established dedicated clinics. We are in the process of designing and implementing a first seizure pathway and clinic. Full investigative facilities are available locally. Vagal nerve stimulator programming are planned at DPOW. On the anvil are community epilepsy clinics and a living with epilepsy education programme for patients and family members. Patients needing surgery or opinion at a tertiary centre are referred on to Hull or Sheffield but can continue to receive nurse specialist and other services in their local area. With proper treatment many people with epilepsy can then lead normal lives.”

“We are working with out of area specialist centres and the Strategic Clinical Network for Neurology to develop appropriate pathways and seamless care for patients so they can access services in the right place at the right time.”

“Part of my role, and the role of the Nurse Specialists, is to provide talks and education sessions on neurological conditions to professionals in the local area. If you are interested in receiving a talk about one or more conditions then please get in touch. We are in the process of designing a NEL event on Epilepsy and this will be advertised in the coming months.”

Dr Lazarus, Consultant Neurologist, Northern Lincolnshire & Goole NHS Foundation Trust

**Multiple Sclerosis (MS)**

We are planning a patient, family and carer engagement event to learn about the experience of patients and family/carers living with Multiple Sclerosis (MS) in North East Lincolnshire (NEL)

The aim is to learn about what matters to you in the care you receive. The information will influence the way MS services are developed in NEL.

If you are living with MS or if you are a family member or carer of somebody living with MS and would like to take part in the event please contact; elaine.johnson13@nhs.net

Elaine Johnson on Telephone: 0300 3000 537

Sharalyn Anderson
NEL Neurology Nurse Specialist - Multiple Sclerosis
Tel; 01472 721342
Living with Parkinson’s Education Programme

Tracey Osborne, Parkinson’s Nurse and colleagues are delighted to hear the success of the free programme that aims to help patients and family understand and manage symptoms related to Parkinson’s.

One patient that attended the January 2014 programme was Peter Mawer, a Housing Support Worker for L&H Homes in Grimsby. He attended the event with his wife and his boss, who was keen to understand more about the condition.

Peter said: “The service I have received is excellent. It was a relief to be diagnosed and knowing the range of support available for me prevented it from being a traumatic experience”.

Brian Noble, Peter’s Supervisor, said: “At L&H Homes we believe that people are one of our greatest assets. After Peter was diagnosed with Parkinson’s last year we looked carefully at the re-adjustments that we would have to make to help him to continue working.”

The programme takes place four times a year

Parkinson’s Stand at Community Fun Day

There was a great atmosphere at the Community Fun Day at People’s Park, Grimsby on 3 May 2014.

The event promoted local services which included a Parkinson’s stand hosted by Vicky Henderson, Senior Community Physiotherapist, Jenny Blythe, Information Support Worker, Parkinson’s UK and Ann Harrington, Parkinson’s volunteer buddy (pictured above), along with colleagues and friends from Louth. They chatted to patients, family and carers, providing them with useful leaflets and information about the condition and local services.

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Charity — MND Association

The MND Association is the only national charity in England, Wales and Northern Ireland that funds and promotes global research into MND and provides support for those affected by the disease. They do all they can to enable all those living with MND to receive the best care and achieve the highest quality of life possible. Locally they have a Regional Care Development Adviser, and a Grimsby & Cleethorpes branch of the MND Association. In addition, there is the MND Connect helpline & the website, with an online forum. Please use any of the following contacts for more information: -

Regional Care Development Adviser
Jane Evans - Telephone; 01142 585235

Local Branch – Nancy Fawcett – 07824 859517
MND Connect Helpline – 08457 626262
www.mndassociation.org
Keeping you informed

The Community Dental Service provides a specialised dental service for patients who are unable to access treatment in general practice because of their physical needs. These patient groups include those with chronic neurological conditions who are unable to attend a regular dentist. We offer both clinical treatment and home visits for those who are truly housebound, and have the facility within our Cromwell Road clinic to treat patients unable to transfer from a wheelchair.

We welcome written referrals from all healthcare providers working with these patients (although we request that patients who have a general dental practitioner continue to receive treatment with them until they are unable to do so). We can be contacted by telephone initially on 01472 255680.

Tell us what you think...

We are keen to engage with patients, carers and professionals, if you would like to;

Tell us about your experience, provide your views, tell us about what type of education, awareness raising or training you would like to receive and in what format i.e. leaflets, seminars……

Please contact;  Donna Redhead, Service Manager, NELCCG  email;  Donna.Redhead@nhs.net

Epilepsy

There has been a lot of change since the last Newsletter. We told you about the recruitment of Jonathan MacCormack as the new NEL Adult Epilepsy Nurse Specialist. Unfortunately, we have had to say farewell to Jonathan as he has now left the NHS after 21 years service. We wish him well in his new venture.

We are pleased to welcome Carol Ogden who has been successfully recruited as the new full time NEL Adult Epilepsy Nurse.

Carol Ogden
Adult Epilepsy Nurse Specialist
Tel:  01472 302 308

Carol started in the NHS 31 years ago, and worked as an Epilepsy Nurse for Hull & East Yorkshire Hospitals for approx. 13 years.

Carol currently provides clinics alongside the Consultant Neurologist at Grimsby hospital and is intrinsically involved in the work to develop the new Epilepsy 1st Seizure Care Pathway, community clinics and an epilepsy education programme.

Support is also available from:
Epilepsy Action; www.epilepsy.org.uk
Epilepsy Society; www.epilepsysociety.org.uk
Epilepsy and your wellbeing online course available at;  http://learn.epilepsy.org.uk

Epilepsy Awareness Week  18 - 24th May 2014

Helping raise awareness of Epilepsy with a stand in the main entrance at Diana, Princess of Wales Hospital
Pictured:
Left;  Michelle Oates
Epilepsy Action Volunteer
Middle;  Carol Ogden
NEL Epilepsy Nurse Specialist
Right;  Ellie Hardy
Epilepsy Action Volunteer

NEW

Social Group for Epilepsy Patients & Friends

Are you, or someone close to you living with epilepsy?

A local group from Epilepsy Action meet on;
1st Thursday of every month - 11am to 12.30pm
for tea, coffee and a chat at
Grimsby Minster Café
St James Square, Grimsby, DN31 1EP

Facebook;  EpilepsyActionGrimsby
For more information contact:  Cliff Challenger 01274 640064

Epilepsy and your wellbeing online course available at;  http://learn.epilepsy.org.uk

NEL Community Dental Services

The Community Dental Service provides a specialised dental service for patients who are unable to access treatment in general practice because of their physical needs. These patient groups include those with chronic neurological conditions who are unable to attend a regular dentist. We offer both clinical treatment and home visits for those who are truly housebound, and have the facility within our Cromwell Road clinic to treat patients unable to transfer from a wheelchair.

We welcome written referrals from all healthcare providers working with these patients (although we request that patients who have a general dental practitioner continue to receive treatment with them until they are unable to do so). We can be contacted by telephone initially on 01472 255680.
I was diagnosed with Parkinson’s in September 2009 and the first help I received was several months later when the Parkinson’s Support Worker, Irene Morris, came to help me fill in a Blue Badge application form.

Around the same time, Vicky Henderson, the Parkinson’s Physiotherapist, came to see me for the first time and after several visits, she asked me if I would like to take part in an eight week physiotherapy-led rehabilitation programme. I agreed and in January 2010, I began attending Hope Street clinic once a week.

At the end of the eight-week programme, Vicky assessed me to see how much progress I had made and then asked me if I would like to become an expert patient. I said yes and on 2nd April 2010, I completed the process to become an official volunteer and started my new role as a Parkinson’s Rehabilitation Buddy, helping other patients with the same condition as me.

When new patients first attend the clinic, my role is to put them at ease and let them know that I understand how they feel because I have Parkinson’s myself. I explain to them what will happen during the programme and then I support them and help them in any way I can during their time with us in the Parkinson’s Rehabilitation group.

As well as providing group rehabilitation, the Parkinson’s team also holds a drop-in session at Hope Street on the first Wednesday of every month and together with Vicky, Jenny, the Parkinson’s UK Support Worker and Tracey, the Specialist Parkinson’s Nurse, we all help people with Parkinson’s, answering any questions they may have and helping them to fill in forms.

Vicky Henderson, Senior Community Physiotherapist (pictured below) says; “having a buddy to support and develop the Physiotherapy Parkinson’s exercise group gives patients attending confidence and adds an invaluable extra dimension to the service which cannot be achieved by healthcare professionals alone. Ann, has been a patient in the Physiotherapy lead Parkinson’s exercise group at Hope Street Specialist Service and understands how patients arriving for the first time feel. She is able to share her story of the difference attending has made to her life. I am sure patient attendance and willingness to exercise would not be the success it currently is without the buddy involvement. We are always looking for more Parkinson’s buddies to join the team.”

Are you interested in becoming a Buddy? If so contact Emily Mumby on 01472 313400 for an initial chat about the different types of volunteer roles and the process involved.

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The Neurological Alliance - launches national survey

The Neurological Alliance is a campaigning organisation – it promotes itself as a collective voice of over 80 brain and spine charities and other key stakeholders in England. They work with member organisations and campaign locally and nationally for better services for the 10 million people in England living with a neurological condition.

The Neurological Alliance has launched a neurological patient experience survey which can also be found by visiting: - www.neural.org.uk It is open to anyone with a neurological condition living in England and will close on Monday 15 September 2014.

The survey has been developed with the ambition of collating vital information about the experiences of care received by people affected by neurological conditions. The findings will help provide an understanding of what progress is being made in improving neurological services, and what still needs to happen.

The Neurological Alliance
Tel: 020 7584 6457
www.neural.org.uk
Patients, family, carers and professionals told us they wanted a local education event for professionals to attend who are involved in the care of people living with one of the four conditions. On 6th March 2014 an event was held in response to this repeated request. Some of the aims were to provide an understanding of the needs of people living with these conditions, provide tips to support timely diagnosis and also to share information about services within the local area. It also provided an opportunity to meet the local specialists and representatives involved in neurological care.

A total of 150 local professionals attended the event ranging from GP practice nurses, GPs, hospital consultants, doctors, nurses, care home managers and carers, dentists…… and many more professionals.

There was a range of information stands such as; Carers Support, End of Life Care, Parkinson’s UK, MS Society and MND Association.

In the day there were 4 break out presentations for each condition with question and answer opportunities. Each delegate attended all 4 sessions and the presentations were given by the local Nurses Specialists alongside Parkinson’s UK, Epilepsy Action, MS Society and MND Association charity Managers.

In the evening 3 local Consultants gave presentations; Dr Lazarus, Dr Kamath and Dr Riaz.

We have received some excellent feedback from the event which will help us design even better events for the future. An event for Epilepsy is already being planned.