

# Hampshire Neurological Study Day – April 2013

An overview of the Hexagon  
Neurological Pilot

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# Aims of session

- To give a brief overview why the Hexagon Neurological Pilot was needed
- To summarise how the Pilot was set up and who was involved
- To use a case study to demonstrate the impact the pilot has had
- To summarise the results of the Pilot

# What is The Hexagon Neurological Pilot?

- The Hexagon Neurological Pilot started October 2012 and ran for 6 months
- A joint venture between Hampshire County Council, Southern Health & Voluntary Sector
- It was available to anyone who:
  - GP surgery was within Eastleigh & Chandler's Ford
  - Over the age of 18 years old
  - Had a confirmed Neurological Diagnosis

# What is the Hexagon Neurological Pilot?

- Its aim was to be pioneering service for people with Neurological condition
- It was designed to be a one stop shop where any medical or social issues could be addressed
- In essence this didn't happen but a new way of providing education on Self Management did.

# Why was a pilot needed?

- In October 2011 a workshop was held with 26 people who were affected by a Neurological condition
- They were asked what would you spend resources on, what professionals did well and what needed improving
- As a direct result of this workshop an integrated multi disciplinary pilot was developed which would be overseen by the community matrons

# Where did we start?

- When it came to develop this service we didn't know where to start
- We held an open day at the Hexagon (going to be the venue) and then decided to offer some taster sessions to service users we already knew
- We held 4 one off taster sessions which were: WRAP, Fatigue Management and two circuit based exercise groups

# We were in the Daily Echo

Rachel Harrison tells MELANIE ADAMS about her pivotal role in getting a pioneering project off the ground to help sufferers of neurological conditions

## ONE-STOP-SHOP IS A FIRST FOR HAMPSHIRE

D. Echo 11/9/12



LEFT AND RIGHT: Rachel Harrison (right) and other sufferers of neurological conditions attend a session to help overcome fatigue



**G**ROWING up she was the clumsy one, who would always be falling over things. But as she watched her friends grow more graceful in their teenage years, Rachel Harrison couldn't seem to shake her clumsiness which saw her falling more and feeling exhausted.

So, when aged just 17 she was given the devastating diagnosis that she was suffering from a rare neurological condition, she felt a strange sense of relief that there was finally a reason behind everything that was happening to her.

However, unlike other medical conditions that can be tackled with treatments and drugs, Rachel quickly became aware that people living with neurological conditions were often left to their own devices to cope because there is no cure or tablet that can help.

Determined to get that changed, Rachel has played a pivotal role in helping Hampshire health bosses to set up a groundbreaking project like no other seen in the UK before which has the potential to make a huge difference to the lives of those struck down by neurological conditions, such as Parkinson's, MS and Motor Neurone Disease.

The pioneering pilot offers patients with any form of neurological condition a one-stop-shop where they can seek help, advice and friendship to cope with the daily challenges they face.

From workshops on how to deal with chronic fatigue, to clinics and exercise sessions, the unique scheme launched by Southern Health NHS Foundation Trust at the Hexagon Centre, in Chandler's Ford, was designed around what those living with the conditions had been calling for.

People like Rachel, vice-chair of the

Hampshire Neurological Alliance, who was diagnosed with Friedreich's Ataxia which is a rare genetic progressive neurological condition that affects just one in 40,000 people.

Despite facing such a life-changing diagnosis at such a young age, Rachel has taken an inspirational approach to dealing with the condition that slowly attacks the nervous system, leaving most sufferers wheelchair bound by their mid-40s.

"I have always been of the attitude that you have to embrace what you can do", said Rachel, who studied maths at the University of Southampton.

"I had always been a clumsy child but a lot of children are. However, when everyone else was growing out of that and becoming more graceful, I was getting even clumsier and would fall over everything. Then I would start to get very tired and shake a lot, which was quite frightening.

"I was diagnosed during my A-Levels which was in some ways helpful because they gave me a reason to keep going.

"In some ways getting a diagnosis was a relief because I had always felt that I didn't fit in, having all this trouble to do things, so when someone was able to confirm there was something wrong with me, it made me feel more normal, knowing there was a reason for it.

"Looking at what you can't do only makes you unhappy and in reality, everyone has their own limitations. And this is why this project is vital because it focuses on what you can do, and helps you maintain that independence for as long as possible.

"Even for those people who are quite good at managing the condition there is always more you can learn and pick up new ideas."

The pilot starts next month, offering two morning sessions on Tuesdays and Wednesdays to anyone who feels they can benefit from them.

The aim is to allow the project to evolve depending on the needs of the services users - starting initially with one-on-one sessions to find out what people would like and then move to group sessions, clinics and physiotherapy if there is the demand.

A vital aspect of the pilot is that while there will be specialists nurses, occupational therapists and physiotherapists on board, it will also act as a fountain of information regarding other services available that could help make life easier.

Rachel, who does volunteer work and is chair of governors at Cherbourg Primary School, added: "This is really important. There's very little standard treatment for a lot of neurological conditions because there are no cures, it is just about maintaining what you do and making slight improvements.

"So it is less attractive for NHS funding, which often sees it neglected and leaves many people feeling isolated, thinking there is nothing they can do, but there is.

"That is why this project is really exciting because there is nothing else like this out there and Hampshire really is leading the way when it comes to making a difference to the lives of

people with neurological conditions.

"This is a groundbreaking yet simple approach. Bring together all of the expertise of staff and the experience of patients to help individuals learn more about their condition and find ways of coping with it.

"A central point of contact is what patients have been asking for. By working together we can hopefully improve individuals' quality of life and let them know how to access the help that is out there."

What helps to make this pilot so unique is the collaboration between Southern Health, local councils, charities and those living with neurological conditions - something that has never happened on this scale before.

Heather Fortnum, the lead for specialist nursing for Southern Health, said: "This is just the start. We hope that this pilot project will bring benefits to people in the Chandler's Ford and Eastleigh area.

"But if it proves successful we want to expand the work into the rest of Hampshire. We know there is a lack of support and there's a lot of evidence to suggest that practical advice and support can really help people with neurological conditions.

"Having a condition can be incredibly hard for people and their families to accept, but there is help and support out there and there's a lot we can do."



Hampshire  
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# What did we do in the Pilot?

- Positive feedback from the taster sessions so time to launch the pilot
- The pilot was going to be led by the individuals' needs & goals so no real idea what we were going to do until we started
- MDT (nurse, Neuro Physio and OT) agreed to meet weekly to discuss new referrals



# Care Pathway

Service user refer into service



Holistic screening completed by nurse – goal lead.



MDT meet to discuss screening & formulate care plan



Service user receive care plan



Interventions completed

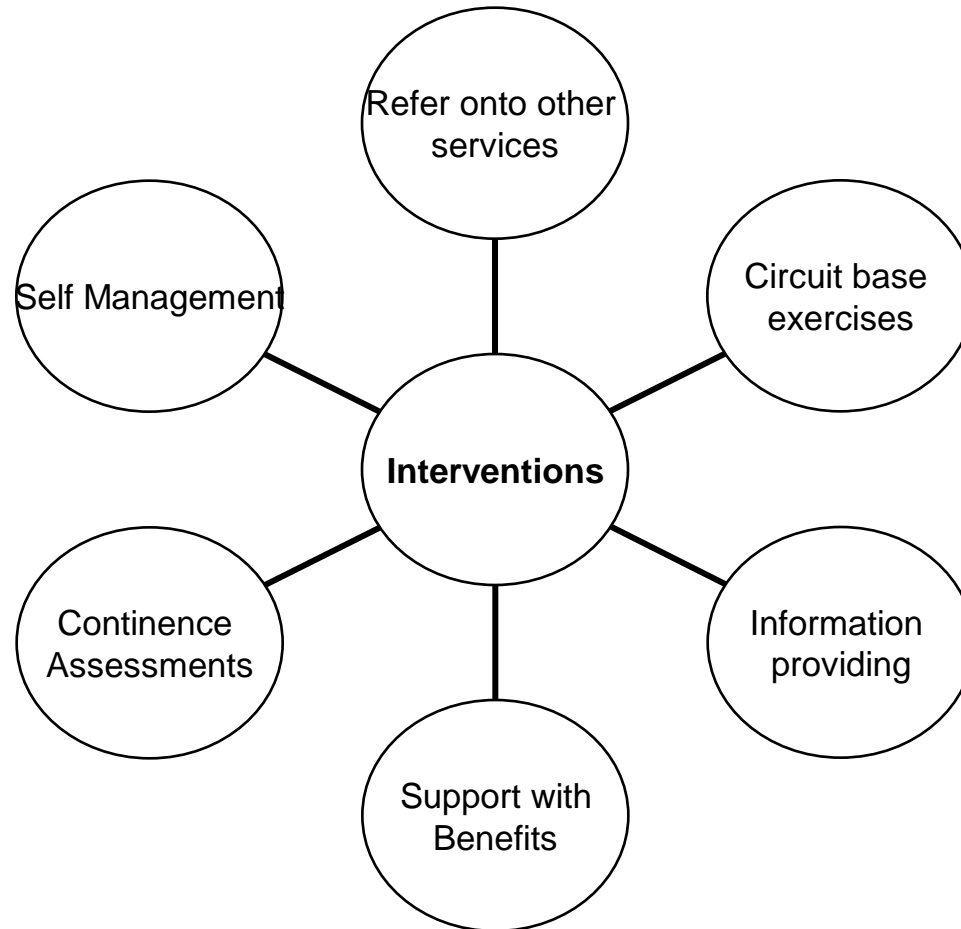


Review by Nurse



Discharge from Service

# What were our interventions



# Self Management Education

- These sessions were completed in groups of 8-10 people.
- Some were one off sessions but others ran over 6 weeks
- New way of working for MDT
- Positive experience for people attending
  - Learn from each other
  - Share views and ideas
  - Heard other people experiences

# Case Study

- Tim was referred by GP
- Acquired brain injury
- Socially isolated, stop working, no motivation, low in mood, poor balance, no purpose in life
- Came for screening – no goals – given up
- Suggested volunteering at Hexagon
- Been volunteering – more positive/motivated – attended group sessions – uses techniques to help with stress/anxiety

# Some facts from the pilot

- Only had 30 referrals
- Everyone seen already known to a member of MDT – not getting to newly diagnosed or people who have slipped through the gaps
- Were not able to include the voluntary sector as much as we hoped

# Results

- We don't know as we are in the process of evaluating service
- Initial feedback from service users positive
- Waiting for ethical approval from Hampshire County Council to send out questionnaires

# Next Steps

- Review and discharge all service users.
- Feedback to the stakeholders group and write a report with the finding
- My thoughts: Fantastic service but needs additional resources. Hard to do on top of day job. Will use principles of pilot in future joint working scheme



# Conclusion

- Hexagon Neurological Pilot has run for the past 6 months
- Haven't seen the amount of referrals as first thought
- Majority of service users seen already known to a member of MDT - ? already doing a good job
- Positive experience for service users and staff

# Any Questions??

