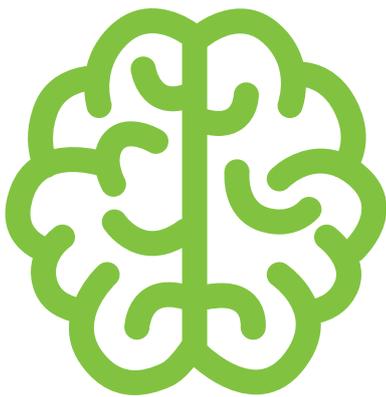


Focus on Neurological services

An overview of issues raised by patients who are using neurological services in East Kent



Neurological services cover a wide range of conditions from neurological rehabilitation to physiology rehabilitation. Patients have been contacting Healthwatch Kent to share their experiences of the service particularly in East Kent. As a result we offered to bring together patients, voluntary organisations and health professionals to discuss the issues and explore how the experience of patients could be improved both now and in the future.

26 people came to the event including patients, carers, voluntary organisations who offer support to neurological patients as well as health professionals from East Kent Hospitals who treat the patients.

What were the issues?

Cerebral Palsy

- Many services available to paediatric patients are not available from the adult service such as Occupational & Physiotherapy
- We heard about symptoms being confused for mental health or learning difficulties. We heard from a patient who had been placed on the learning disability register but he has cerebral palsy

Appointments

- Patients find it difficult to travel to appointments especially epilepsy patients
- People told us they had been diagnosed whilst on their own and not given any support on how to find support from the voluntary sector
- Annual reviews were not always being done. One person told us they have been waiting for three years for an annual review.
- Patients shared how text messages can support patients to attend and alter their appointments easily on other parts of the UK

Discharge

- Neurological patients often need a longer recovery time or tailored rehabilitation but they felt it wasn't always considered
- People felt hospital transport services wasn't meeting their needs
- People shared stories of being delayed in hospital for lengthy periods while they await care packages

Workforce

- Problems recruiting specialist neurologists. When one leaves there is often a 'vacuum'. Better organising and supporting the wider MDT with secretarial support so that when a consultant leaves, care can consistently continue. Hospital Trusts are not proactive in providing care during the gaps. There is also a lack of specialist nurses for such illness as epilepsy. There are no motor neuro nurses in West Kent, MS nurses are reduced in number and are covering wider areas.
- Specialist nurses were valued by all

Postcode lottery

- Neurological services vary across Kent. For example in West Kent there is currently no neurological rehab service and only one MND nurse.
- Attendees felt continuing healthcare was discharged differently across Kent with different care packages being offered

Products

- Patients would like input when products are changed. For example catheter and continence products have been changed recently but the new catheters are very thin and the patient needs to use more of them so ultimately it costs more.

Wheelchairs

- This was a hot topic for many of our attendees with a range of experiences being shared.
- Many patients and professionals talked about long delays to get a wheelchair with patients being discharged from hospital in a 'normal' chair. A clinician told us they have waited over a year for a wheelchair for a child and it has yet to be provided
- Long delays for adults and children to get repairs for their wheelchair. Powered wheelchairs are often taken away for weeks to be fixed leaving the patient with no mobility

Information

- Patients and professionals felt that more information about support groups and forums being available for everyone would be helpful

Next Steps

Healthwatch is supporting the Kent Physical Disability Forum to escalate the concerns we heard about wheelchair services to both the Health Overview & Scrutiny Committee as well as directly to the commissioner and provider of the service.

Together we agreed to ask Hospital Trusts if they could consider a text message system for appointments.

Healthwatch offered to approach East Kent Hospitals to explore how a hub of information could be developed for patients

Healthwatch will talk with Kent Community Health Trust and East Kent Hospitals to encourage them to involve patients in decisions about products such as catheters

Everyone agreed that they would like to continue this very constructive discussion. Healthwatch will discuss with the organisations involved the best way to achieve that

What difference have we made?

We are proactively raising the issues around wheelchair services in partnership with the Kent Physical Disability Forum which is funded by Healthwatch's parent company, Engaging Kent

"I've had Multiple Sclerosis for over 30 years and I've never been to an event like this."

Thank you to everyone who attended. #itstartswithyou

Together we can make a difference