HEALTH SCRUTINY PANEL

A meeting of the Health Scrutiny Panel was held on 10 September 2019.

PRESENT: Councillors D P Coupe, A Hellaoui, D Rooney, M Storey and P Storey

ALSO IN ATTENDANCE:
Rowena Dene, Collaborative Care Group Manager - NT NHS FT
Dr Janet Walker - GP Medical Director, ST CCG
Michael Houghton - Director of Commissioning, Strategy and Delivery, ST CCG
Craig Blair - Director, ST CCG
Hannah Fryett - Commissioning Support Project Officer, ST CCG
Dominic Gardener - Director of Operations, TEWV
Elizabeth Moody, Deputy Chief Executive, TEWV
Representatives from Ehlers-Danlos Teesside
James Cain, Local Democracy Reporter

OFFICERS:
Caroline Breheny - Democratic Services Officer
Ann Marie Johnson - Legal Advisor
Esther Mireku - Consultant Public Health, Middlesbrough and Redcar and Cleveland Council

APOLOGIES FOR ABSENCE Councillor J McTigue, Councillor J Rathmell, Councillor S Hill, Councillor R M Sands.

DECLARATIONS OF INTERESTS

None declared.

19/13 **MINUTES - HEALTH SCRUTINY PANEL - 9 JULY 2019**

The minutes of the Health Scrutiny Panel meeting held on 9 July 2019 were approved as a correct record.

19/14 **WEST LANE HOSPITAL - FURTHER UPDATE**

The Deputy Chief Executive / Director of Nursing and Governance and Director of Operations for Teesside at Tees, Esk and Wear Valleys (TEWV) NHS Foundation Trust were in attendance at the meeting to provide an update to the panel.

The Deputy Chief Executive apologised on behalf of TEWV to the relatives of the young people in receipt of care at West Lane and especially those of the two young people that had died. It was emphasised that TEWV was devastated by what had happened not only as an organisation but also on a personal level as well.

It was advised that a Notice of Decision from the CQC had been received by the Trust on 23 August 2019, which required the closure of the wards at West Lane Hospital. As part of the closure there were specific conditions imposed which required TEWV to provide a detailed plan for patient moves and to ensure that the safety of existing patients was assured. The reasons behind the notice included:-

• Concerns relating to the death of service users
• Concerns about documentation of key aspects of care including care plans, risk management and observation and engagement
• There were issues in how staff managed patient plans which meant that there could be inconsistent approaches and care was not managed in line with risks
• Staff were struggling with maintaining the right balance of maintaining safety and implementing the principles of least restrictive practice
• Some service users felt unsafe on the wards.

It was explained that the Trust's immediate priorities on the 23 August 2019 had been to communicate to patients, families and staff the decision by CQC and to progress the

arrangements for the services closure. The Trust had since focussed on the following actions:-

- Safe transition of patients to alternative providers
- Co-ordination of support for families and carers
- Enhanced support for community and crisis teams to avoid the need for admission
- Support for staff to maintain services whilst the hospital closes

It was confirmed that at the time the notice was issued there were 11 patients on the wards. Since the 23 August, patients had moved to specialist care settings across the North East and North West in line with their care needs. A number of patients had been discharged home. The remaining patients had active plans to progress their transfer or discharge which included developing specialist packages of care around each patient to facilitate their discharge home. This work continued with NHS England helping to support the transfers and care packages. It was anticipated that the West Lane Hospital wards would be closed before the end of September.

In terms of planned future actions there would be full engagement and participation in the various review processes which would include child death reviews and a NHS England independently commissioned review.
The future delivery of services would be informed by the investigation outcomes and wider consultation and engagement with stakeholders. It was confirmed that there would be ongoing communications with scrutiny regarding plans.

The Chair thanked the Trust for its update but added that there seemed to have been a number of warning signs about problems at West Lane with staff that were suspended and complaints made by children about how they were treated. Yet these was not picked up. It was emphasised that there were a lot of people who would be looking for answers to ensure that this never, ever happened again. The Deputy Chief Executive of TEWV advised that this was a fair criticism and reflected the conversations that had been held by the Board and at senior management level.

Reference was made to the possibility of the service reopening in the future and it was advised that careful consideration would need to be given to the model of care TEWV provided. The Chair emphasised that if the unit was to re-open TEWV would need to ensure that the safety of the children and young people in there was absolutely paramount.

AGREED that a further update be provided to the panel by TEWV at the appropriate time.

19/15 **EHLERS-DANLOS SYNDROME / HYPERMOBILITY SPECTRUM DISORDER: CO-ORDINATING CARE IN SOUTH TEES**

A number of representatives from Ehlers-Danlos Teesside (a patient-led support network co-ordinating their own care on Teesside) were in attendance at the meeting to provide the panel with some insight about the condition and highlight a number of issues they felt needed to be addressed.

The panel was informed that Ehlers-Danlos Syndrome (EDS) effects 1 in 3000 people, with that being revised upwards every year. Three years ago, the statistics showed 1 in 200,000. It was a genetically dominant condition and there was a 50 per cent chance of the condition being passed onto your children. As it stood, there was no clear diagnostic or clinical treatment pathway for Ehlers-Danlos Syndrome patients in Middlesbrough or in Teesside. One lady in attendance had been fighting for three years to access genetic counselling in Middlesbrough. She potentially had the life limiting subtype of the condition (there are 13 subtypes) and wanted a definitive diagnosis.

It was explained to the panel that under the current system patients with EDS in Teesside had been diagnosed by rheumatology, genetic or dermatology specialists, although a number had had to travel as far as Wales and London for a diagnosis and many were still fighting. Above all, as a community, they wanted to avoid the next generation of EDS patients being lost in the system like so many of them had been. Repeated hospital admissions, frequent A&E visits and endless GP appointments at an enormous cost to the NHS.

In preparation for the meeting Ehlers-Danlos Teesside advised Members that it had developed a protocol to get the ball rolling in Middlesbrough with the potential to save an inordinate amount of clinical time and money across the board. The actions the support group was keen to see implemented were highlighted as follows:-

• The Royal College of General Practitioners Ehlers-Danlos toolkit rolled out in all GP surgeries across the borough. This would empower GP's to support patients to self-manage reducing the number of doctors' appointments needed.
• Implementation of the new EDS classification criteria for non-experts by the International Ehlers-Danlos consortium 2017 in hospital clinics and GP surgeries. EDS classification for non-experts, and of the diagnostic checklist for hypermobile Ehlers-Danlos Syndrome (hEDS) which is the most prevalent subtype - hEDS diagnostic criteria.
• Incorporation of the National Genomic Test Directory for rare and inherited diseases within the Northern Genetics Service.
• An A&E protocol would reduce unnecessary hospital admissions and diagnostic testing for EDS patients. This would include training for emergency frontline staff and enable them to deal with EDS patients quickly and efficiently. EDS patients were complex and confusing patients and did not present 'typically', taking up clinical time whilst Doctors googled how to treat them.
• Ehlers-Danlos awareness within clinics at South Tees hospital, with ideally at least one clinician within each discipline at JCUH signed up for Project ECHO so they have the support and confidence to manage EDS patients and their co-morbid conditions in a clinical setting and in the community, once again supporting savings as well as boosting morale.
• A point of contact within South Tees NHS FT and the local CCG for Ehlers-Danlos Teesside to liaise with to implement these changes.

Finally, if the support group were able to liaise with South Tees NHS FT, a member of the network had had the innovative idea of bringing a centre of excellence to the area. There were currently no connective tissue disorder services in the North-East. The nearest clinic was Sheffield but only one of EDS Teesside members had ever been there after being wrongly diagnosed for 36 years. Efforts had previously been made by the lead Physiotherapist at JCUH to liaise with the lead EDS Rheumatologist in the UK for such a service to established. This had fallen by the wayside but needed to picked up again in order for these changes to be made.

The panel was informed that many EDS patients were currently independently fundraising to travel abroad for treatment. The cost of treatment could be upwards of £100,000. The support group was keen to instil confidence in doctors that these treatments could be carried out in Middlesbrough, making the cost of treatment cheaper for patients, with the potential to also generate income from private patients and patients travelling from abroad. There was a distinct need for this care. Currently there were only two hubs worldwide in Barcelona, Spain and Arizona, USA delivering such treatment. A Yorkshire resident had recently spoken about the difference this operation had made to her life with EDS on ITV news. The leading neurosurgeons for EDS patients in Europe, who were based at the clinic in Barcelona were currently bringing in patients from all over the world. EDS Teesside was confident a similar hub could be established in Middlesbrough.

Ehlers-Danlos Teesside advised that the above proposals were what were needed to make the lives of EDS patients easier, the lives of medical staff easier and to reduce the cost of unnecessary diagnostic pathways. There was also the potential to make Middlesbrough a hub of power and sustainability for connective tissue disorders in the North-East and across Europe.

A number of statements had been submitted by Members for Elhers-Danlos Teesside to be shared with the panel. Prior to introducing those statements it was advised that this close knit community had already lost a member in the short time it had been established. She was 32 years old and was survived by her 9 year old son.

Statements from fellow members:-

- Although we knew EDS was a genetic condition and I have a diagnosis, my children were seen by paediatric services including physiotherapy, doctors, occupational therapy, musculoskeletal and genetics for years to deal with their physical health needs. I finally took them to see Professor Grahame in London at great expense where they were given a diagnosis. This led to the discovery that my youngest son has vascular type EDS associated with a low life expectancy. I would like to see children of people with EDS automatically screened by knowledgeable professionals for the condition.
- I'm terrified. My neck collapsed in March and I still I can't get any answers. Every time I leave the house, I'm terrified I'm going to be internally decapitated by travelling in a wheelchair and using taxis. Every medical appointment is a judge and jury of my life. I'm tired and I don't know how to fight the system anymore. My house is inaccessible to me. My wheelchair is inaccessible to me. I have no independence anymore. I have to rely on others and I hate it.
- For me living with a chronic illness was a constant fight. You were always fighting with your body, your mind and the world around you. You shouldn't have to fight for medical care. There should be a standardised pathway for all EDS/HSD patients. That way both medical professionals and patients know where they stand.
- I have been fighting for a diagnosis since 2015. Having to fight for your medical needs to be met is beyond exhausting; physically and mentally. I mention EDS and almost all doctors don't have a clue what I'm talking about. I did have a paramedic once that took it upon himself to research the condition after having a previous patient, which was amazing. My middle son was also showing many signs and when I brought this up with his paediatrician, he has since been discharged because he didn't have a clue what it was. I can't afford for me or my kids to get a private diagnosis, which is devastating, otherwise I would have been diagnosed a very long time ago. I have a life limiting condition that isn't understood. I wish to live in a world where everyone understood. We have a very long way to go but the first step to that would be making our health professionals understand, be trained to treat us effectively, and be diagnosed quickly to enable us to receive the correct care.
- Based on the experiences of others who also have the condition I do not feel it would be beneficial to seek or pursue an official diagnosis given the lack of pathways and patient care available. Instead I just manage the symptoms unsupported by the NHS which has included repeated dislocations as a child and currently includes muscle wastage and severe chronic pain.
- Pain, always in pain and doctors not understanding why. Feeding tubes every three months because my body rejects them. They coil up and need replacing. I'm having injections in my coccyx every four months. I get around in an electric wheel chair, as my hips shift and the shoulder dislocates on walking with a stick any distance, and the amount of medications! Iron injections with anaphylactic episodes but not because I'm allergic, just because my body is attacking itself as well as the breast cancer drug Tamoxifen to name a few. I have had bone infusions as the bones were low in calcium. My bowel was not working and I have a floppy bladder. All part of your a normal day with Ehlers-Danlos and your kids could have it too.
- Pain, constantly in pain, and it was only getting worse. Shooting pains, night pains, pains from the cold, pains from doing normal things and all I heard from doctors was 'take paracetamol'. I'm constantly wishing I could do something to numb the pain. It disturbs my sleep; I'm mixing hot water bottles and ibuprofen and nothing was helping. Also being told in occupation therapy here's all the handy tools that you can use to help you get through the day and then 5 minutes before the end of the session I'm told if I want these items I will have to buy them; hundreds of pounds worth of equipment. Dislocations, falls, faints, severe pain and no energy and I'm still not entitled to a scrap of help.
- Ehlers-Danlos syndromes were a group of connective tissue disorders. The Hypermobile type that I have was characterised by but not limited to: Joint hypermobility; loose/unstable joints which are/can be prone to frequent dislocations and/or subluxations; joint pain which is often debilitating; hyper-extensible joints (they move beyond the joint's normal range); early onset of osteoarthritis. There were other problems that can occur such as a mitral valve prolapse on the heart, digestive issues and the list goes on. The biggest issue for most of us is chronic, debilitating musculoskeletal pain coupled with fatigue and a catalogue of other problems. I have

the above as well as spinal arthritis, knee issues including arthritis, carpal tunnel, arthritis in other locations, and a catalogue of spinal issues on top of arthritis. I do suffer from digestive issues and have had dislocations and have a lot of pain in various joints and areas of the body. Getting out of bed some days feels impossible, not just because of the pain but the affect it can have on your mental health can be quite huge. I am a full-time university student and a very active involved Dad and husband and I remain fairly active in general for a person with my condition. My problems started about 5 years ago with my spine and knee and certain other issues which I've had since birth that have gradually worsened. I was finally diagnosed last year and I have declined considerably since, particularly with my spine, all of which I have no control over. I walk with a stick now. I am meant to walk with two. Some days I can't walk at all and struggle with basic things such as getting washed and dressed. It is so hard speaking out about this and even writing about it, as, well, being like this at 32 has and is still very, very hard for me to digest and accept to say the very least. A proper care pathway is so desperately needed for sufferers of people with Ehlers-Danlos Syndromes and hypermobility spectrum disorders because currently the pathway was fragmented at best and quite frankly terrible. Even counselling wasn't offered and we have so much to deal with its overwhelming to say the least. If we had a proper care pathway people would be diagnosed earlier instead of being sent for individual problems to be dealt with such as referral for knee problem, referral for back problem and so on. When it's fragmented it's not picked up quickly enough leading to us suffering more and for longer and this in turn was a bigger burden on the NHS. Like anything it needs to start from the top, recognition is key so if our council, MPs etc get to know about us and our conditions then we can finally make some progress.

- I've been asking for EDS to be considered and investigations made for several years, with no success and very little support from anywhere within the NHS. A common response is, "oh you're a bit bendy, yeah?". Which conveniently ignores the various other symptoms that have spanned the last 20 years and seen me ushered into various consultants, wards, doctors, surgeries, nurses, specialists, prescriptions all while trying to alleviate a single symptom while my health declines further. I can't help but feel the weight of all the unanswered questions and failed medications is more disabling than an actual diagnosis would be.
- My friend has been recently diagnosed with EDS but has suffered for years. She has a self-managed Hickman line. She has had a dreadful time with her GP getting relevant drugs, bloods, equipment to manage her line. Her treatment was covered by several consultants and primary care did not seem to grasp the nature of the condition and the need for support and review. She was accused of being on drugs because of her (sometimes bizarre) presentation such as tics and clumsiness. I have witnessed the poor care and treatment she has suffered and it is not acceptable.

The Chair thanked the representatives from Ehlers-Danlos Teesside for their excellent and highly informative presentation.

During the discussion that followed the following points were made:-

• Members were excited by the support group's ambition to have a centre of excellence developed in Middlesbrough.
• The point was made that a number of Centre's of Excellence had been developed in other parts of the UK for conditions such as Brecets Syndrome, which was much rarer than EDS, at which patients were able to be assessed by an appropriate multidisciplinary team in a single visit. CCG's from throughout the UK referred their patients to these well-established Centre's of Excellence.
• STCCG advised that although the ambition was admirable the development of a Centre of Excellence was not an initiative ST CCG could currently commit to.
• It was clear from the evidence presented that although there was an awareness and acknowledgment of EDS amongst Health Professionals and treatment options available the appropriate pathway was not being followed. There appeared to be no co-ordinated support to identify the condition early enough and therefore despite IAPT, Physio and OT services being available they were not accessible.
• STCCG advised that it could commit to working with Ehlers-Danlos Teesside on looking at the services currently commissioned and improving access to those services.

• The GP representative accepted that many patients with EDS had been misdiagnosed and there was a need to support GP's in looking at the patterns presented to identify the condition.
• An issue in respect of access to the post-natal ward at JCUH for wheelchair uses was also raised and it was suggested that the changes needed would be simple to implement (eliminate the step and change one room into a wet room).
• Access to appropriate needles from GP's was raised as a further issue.

AGREED as follows:-

a) That the contact details for Ehlers-Danlos Teesside be passed to ST CCG and further conversations initiated between ST CCG and ST NHS FT in respect of the suggested actions put forward.
b) That an update be provided to the panel on progress in six months' time.

19/16 **BREAST RADIOLOGY DIAGNOSTIC SERVICES IN SOUTH TEES**

The Director of Commissioning, Strategy and Delivery was in attendance to provide an update in respect of Breast Radiology Diagnostic Services in South Tees.

The panel was advised that currently a team of senior management and clinicians from South Tees FT; North Tees FT and CDDFT had been meeting on a monthly basis to consider all of the options available and the interdependencies of the options on future service delivery. Data had been examined on the number of referrals going through the service from all three trusts to identify what pressures other models would place on existing services if another model was to be implemented. It was advised that in order to inform decision making on a future model, the following was being taken into consideration:-

- national shortage of radiologists
- age profile of current radiologists (retire and returns)
- recruitment difficulties within the geographical area.
- alternative workforce implemented, however, there is 5 year training programme which still requires consultant radiologist mentorship
- Innovation from other services
- interdependencies and flexibility for supporting other aspects of the service. screening service, i.e. the breast screening service

The establishment of a hub and spoke model remained the aspiration. The panel was advised that an pre-engagement exercise was scheduled to take place from1st October until the end of December 2019 in an effort to gather public, patient and staff views during a listening exercise to inform a case for change and develop proposed models prior to any formal consultation taking place. Key stakeholders would include; Patients, carers, members of the public, staff and clinicians, GP's, Breast Cancer Support Groups, VCS, Healthwatch and the Northern Cancer Alliance.

The Care Group Manager at North Tees NHS FT was also in attendance at the meeting to provide an update in respect of a Symptomatic Breast Clinic patients DNA survey. In terms of background it was advised that patient experience surveys completed had demonstrated that patients attending the breast symptomatic service at North Tees & Hartlepool NHS Trust were highly satisfied with the service. However, concerns were raised that there was a higher rate of did not attend (DNA) patients from the Middlesbrough area. It was therefore agreed that a study would be undertaken to contact patients within TS1, TS2, TS3, TS6 post code areas to understand why the patient DNA'd their original appointment.

It was stated that the purpose of the study was to understand why patients DNA'd, and find out if further improvements could be made to improve the service recognising that the provision of a local service was not achievable at present due to workforce constraints.

A questionnaire was formulated in conjunction with panel members and it was agreed the patients who had tecorded as a DNA would be contacted by telephone to find out the reasons why they had not attended. The number of patients who were recorded as did not attend their

appointment between 1 December 2018 to 31 May 2019 was 32.

The findings of the survey were presented and in response it was advised that the following actions would now be taken:-

• Investigation of the potential for the current reminder service to be extended to include the 2 week rule / breast symptomatic patients.
• Continue to improve communication with patients through appointment letters / accurate recording of cancellations etc.
• Work in conjunction with CCG colleagues regarding the interface between primary and secondary care when a patient was recorded as a DNA.
• Review of communication with patients regarding how they could rearrange their appointment.
• The Trust would continue to look at alternative digital technologies to improve communication and reminder services in conjunction with the great north care record.

AGREED as follows:-

a) That the panel be involved in the pre-engagement process.
b) That personal impact statements of those in receipt of breast cancer diagnosis / treatment be collected by ST CCG as part of the pre-engagement process and presented to the panel.
c) That the panel be kept abreast of any interim developments.

19/17 **OSB UPDATE**

The Chair provided a verbal update in relation to matters considered by the Overview and Scrutiny Board on 16 July 2019.