

27 July 2022

Dr C Shepherd
Medical Adviser
ME Association

Dear Dr Shepherd

ME/CFS referral service in North Cumbria

Further to your open letter which has been published on your website for the attention of the CEO of North Cumbria Integrated NHS Care NHS Foundation Trust, we write to offer detailed information on our service.

My colleagues are very keen to meet with you and have the opportunity to assure you of the high quality service that we are delivering.

I am sure you are aware that the Trust is not commissioned to diagnose or deliver the medical management of ME and CFS as this sits with primary care and with the region's specialist team in the Royal Victoria Infirmary (RVI) in Newcastle upon Tyne, however, we do see patients that have been diagnosed with CFS or ME and accept referrals for patients who are under the care of medical colleagues. We do not decline referrals of patients who are in the care of other pathways and work in parallel with other medical teams to provide an integrated service to meet the whole needs of the patient.

The service, which was commissioned by the CCG did not include provision of a domiciliary service to patients with ME or CFS and whilst we are unable to provide ongoing home based treatment, we do offer a domiciliary assessment if appropriate. Over the past six years, the following has been offered by the Trust:

- support to seek regional residential assessment and treatment, for example at the Yorkshire inpatient fatigue service
- outpatient care after the inpatient episode is complete
- virtual input to patients who are bed bound to help them to improve their knowledge and understanding of their condition

The service is commissioned for individuals over the age of 18 and medical care for children with CFS or ME is delivered through both the local paediatric and regional paediatric team at the RVI. The Trust accepts patients from this service at transition age for the PPSS MDT service.

Since 2016 we have made best endeavours to work with the CCG and regional teams to offer the PPSS service to children under 18 which requires a specialist team who can liaise with education and other services. This work is ongoing and appropriate support from the ME Association and Action for ME to try and establish a service for under 18s would be welcomed.

The Trust's PPSS service offers services to patients with a range of diagnoses due to feedback relating to previous diagnostic specific services which was that patients with complex presentations and more than one diagnosis ie ME or CFS and Fibromyalgia or ME or CFS and long Covid, were excluded from services. The emphasis of our service therefore is to see the whole person and to tailor care to individual patients based on:

- their symptoms
- goals
- values

Service users are offered regular opportunities for review and feedback and the majority have provided a rating of good or very good. All feedback received is used to improve and enhance the pathway of care.

The accompanying table illustrates how the PPSS service offers care throughout the pathway which is consistent with the core principles of NICE Guidance NG206.

As with any service provided, there is room for improvement and we accept that not all patients find the service as helpful as others. Where this is the case, we endeavour to further understand how this can be improved for that individual and how services can be accessed which are more tailored to their needs.

My colleagues from the service will be in touch shortly to invite you to join a meeting with our senior clinicians from the PPSS services and our commissioners but in the meantime if you have any further queries please don't hesitate to contact me.

Yours sincerely

A handwritten signature in blue ink that reads "L. Simpson".

Lyn Simpson
Chief Executive Officer

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