

Briefing for Carers Week 2020

Engaging with patients and carers as agents for change has been pivotal to the Charity, Tees Valley Durham and North Yorkshire Neurological Alliance (working name Neuro Key) aims and impact since 2006. We deliver multi-neuro peer support to include carers to ensure people have access to informed support and information to help the partnership of care for people with a neurological disorder. We facilitate an education programme for Teesside, Durham and Sunderland Universities to reduce skills gaps, improving professional knowledge about symptoms and neurological care needs through the lived experiences of both patients and carers.

Our work is centred in the ethos of medical humanities to improve the psychosocial understanding of life with a neurological disability. We add participatory voice to strategic initiatives as stakeholders for neuro-relevant National Institute for Clinical Excellence (NICE) guidelines, contributing to NICE on Adult Carers with parent and kinship carers contributing to our submission for the NICE guidelines on Foetal Alcohol Spectrum Disorder.

Impact of Covid-19

Head of Operations, Jo Cole is a core member of the NE regional stakeholder disability network and has been working to direct local experiences to Cabinet Office and DEFRA, particularly on vulnerable people accessing food and pharmacy. From the affiliation with the national Neurological Alliance, Neuro Key has contributed data for the submission to the Women and Equalities Committee on the impact of Covid-19 and particularly, raised issues about the heavy burden placed on hidden carers.

We have highlighted three key priorities for resolution;

1. Delays to or shortages of regular prescription medication such as liquid paracetamol for people who are peg-fed and how to shield vulnerable partners
2. Cancellation of NHS secondary or tertiary outpatient appointments impacting on ability to care for people with deteriorating conditions without guidance
3. The effect of isolation and social distancing on the mental health and wellbeing of people with neurological conditions leading to unreasonable expectations being placed on unpaid carers

Some carers have health difficulties or co-morbidities but have taken on more responsibilities during the COVID-19 pandemic, queuing for long periods at the supermarket and pharmacy, in addition to their caring duties to shield loved ones.

They are physically and mentally exhausted.

Although carers have potentially exposed themselves to greater risk, there has been a huge disconnect between people receiving the 'high risk' letters and how carers have remained hidden and isolated without pragmatic support. Not every carer claims carer's allowance or has been furloughed from their employment.

Post-lockdown

Some issues that have arisen in recent weeks;

- The discussion around 'Do Not Resuscitate' orders and ad hoc telephone calls from strangers has caused considerable anxiety and adversely affected the psychological wellbeing of carers of people with progressive neurological conditions and even led to them not seeking help for fear of the consequences
- For parent or kinship carers, the reduction of support for people with neuro-developmental conditions has dramatically increased fear about the impact and potential consequences logistically, financially and emotionally on children, young adults, their families and carers in the future
- The effects of the Covid-19 crisis must be rigorously analysed and lessons learnt about exactly who is vulnerable, who has protected characteristics and the impact on caregivers must be included in strategic thinking
- There has been no coordination between primary and acute NHS services with people told by their GP they are fine to leave the house when already in receipt of a letter from their Consultant saying they are high risk or people with several co-morbidities having to repeatedly lobby their GP to scrutinise their medical records. This has caused considerable fear.

Chronically sick and disabled people should neither be made to feel second class citizens in the welfare, health and care system nor should carers shoulder the burden of a fragmented public health system.

In the event of another crisis, we need a better understanding of what local populations actually look like, not solely represented by those on a database in receipt of social care services. There must be coordinated data sets and communication chains to establish the needs of chronically sick and disabled people alongside the needs of the caregiver, not simply geared to assumption.

We have been talking about prevention of crisis for far too long and now have an opportunity post-Covid-19 to achieve something better.