NEURO KEY
An Alliance supporting people
with neurological conditions

CARERS FROM DIVERSE COMMUNITIES

Final Project Report

Contents

Foreword

Through Advocacy, information and support, we offer an asset based approach that builds formal and informal coping strategies between the caregiver and the cared-for to improve knowledge and prevent harm from crisis. Since inception, we have established reciprocal and referring relationships with a range of agencies and disciplines to get appropriate expertise quickly for people living with a neurological condition. We improve professional understanding of the common threads between rare and prevalent neurological conditions and how people manage complex socioeconomic roles along with the long-term caregiving role.

The World Health Organisation (WHO, 2012) reported that neurological conditions were the leading cause of disability in the UK equating to 1/3 the burden of all diseases and representing more than heart disease, cancer and diabetes combined. The WHO considered neurological disorders were seriously underestimated, largely defined by mortality rates, not disability rates. A Public Health England (PHE) 2018 report proved that life expectancy for people with a neurological disability has been decreasing since 2001. Over the past 25 years, the burden of neurological disorders has increased substantially without the necessary service capacity and infrastructure needed to manage demand. There has been no quantifiable improvement to services for neurological patient outcomes since 2005.

With just 11% of the neuro-client group having a care plan (Neurological Alliance 2016) there is increasing recognition of the burden on caregivers and that reducing risk of crisis and improving outcomes cannot rely on the actions of health and allied professionals alone. By enabling patients and caregivers to take part in research or deliver lived experience seminars, we directly improve the self-awareness of students to increase what they learn and comprehend both patient and caregiver needs. We promote strategic surveys and consultations to place emphasis on the day-to-day reality of caring for someone with a neuro-disability. We support people to lead the operational direction of the Charity to advocate for themselves, their caregivers, their families and their peers.

As core members of the Middlesbrough Carers Partnership, we foster collaborative working partnerships to sustain a high customer service focus. We close the gaps in local knowledge to encourage creative problem-solving and efficiencies by reducing risk and crisis. We strive for excellence with agreed standards and outcomes for the Carers Strategy.

NEURO KEY

May 2019

1. Project Aims

- Analyse the barriers that stop carers from identifying themselves to mainstream services
- Deliver outcomes for at least 23 carers through advocacy, information and support

The project has been delivered through the Neuro Exchange Information hub at the Bridge Care Centre, Middlesbrough, outreach through visiting peer support groups, liaison with 3 representatives of national Charities and staff from the Specialist Occupational Therapist Community Neurological Rehabilitation team. We conducted home visits to interview carers for the narratives that have been published as a learning resource.

We received referrals through the website contact form, telephone, word of mouth, published flyers and Facebook.

2. Project Findings

The Barriers

2.1 There is a tenable lack of knowledge about neurological need which profoundly impacts on the caregiver, spouse, partner or family members. Lack of information is isolating and people do not know who to go to when they only have clinical support once or twice a year. They are constantly reminded of the vulnerability of their situation which increases the fear about how they manage physically and economically in the future.

> ‘Support groups are not my cup of tea, I would end up apologising all the time’

2.2 Public sector skill gaps are a significant issue where lack of proper listening skill was regularly quoted by carers. They reported that they could visibly see pre-conceived ideas leading discussions which increased their fear and loneliness. Carers realise everyone is time pressured or capacity cannot meet demand but they just want something meaningful and thoughtful when they need support. There is a sense of hopelessness about engaging outside the home or family.

2.3 Carers feel they should be able to get understanding from professionals but are not getting the results they need to carry out the caregiving role as effectively as they want.

2.4 Public services do not recognise the dual issues of being both a patient and a caregiver – you can be one or the other but not both. Carers can be disabled or have ill-health too and their impairments are not necessarily age-related. Carers generally blamed austerity but also lack of understanding.

2.5 Pressure from the caring role, tiredness or forgetfulness is not treated very patiently by the public and again a range of ‘judgements’ actively prevent people from securing what they need. Universally, the carers that were interviewed felt that the messages from public service personnel were a real hindrance to them, reduced not helped confidence, reduced not helped problem-solving, increased, not relieved stress to steer good quality care plans.

> One carer had a heart attack due to the stress involved in caring for her husband’s life-limiting diagnosis and even her GP did not know she was a carer.

2.6 Primary care came in for criticism because not only do GP’s have little awareness of neurological conditions but carers felt they should do more to recognise that appropriately timed dual assessments for older married couples would save a lot of anxiety and stress. Couples look after each other. Even in general discussion about services, couples had a tenable fear about being split up and sometimes denied the actual context of needs to stay hidden. Stories about crisis episodes meant their worst fears were realised.

2.7 During the Project, 80% of carers reported that they wished they had got help sooner which would not have impacted on the own health so much. They felt asking for help would bring scrutiny on their ability to cope.

2.8 There is no recognition of the signs of mental health distress when the carer cannot cope. Again, this issue of mental distress restricted access to timely, suitable, pragmatic support. 7 caregivers highlighted that a Care home was being used as a threat to reduce the costs of Continuing

Health Care (CHC) and or Personal Health Budgets (PHB). Of the carers interviewed, there was an unequivocal agreement that there was absolutely no support for independent living and attitudes needed to be more about quality of life and less about the burden of cost.

‘Every single thing now is the least possible. It makes you feel like you are really the bottom of the heap and you feel so depressed”.

2.9 Parent carers fare particularly badly when the young person leaves school. There is no continuance of care planning, no coordination between services and no understanding that neuro-developmental conditions are not ‘cured’ the day the young person leaves school.

‘We need empathy and practical solutions, not cold bloodied blame or absolution of responsibility’

The feedback

2.10 The question of whether carers thought they were hidden or registered elicited two main responses, confusion over what would count as a registered carer and where was there that made their caring role ‘official’? Just 8 carers interviewed received carers allowance but did not proactively engage with a carers’ service. Only 3 carers had an emergency card but had never used it.

2.11 There was a general feeling that there was a lack of an overall picture of what help might be able to support them and the person that they care for. Carers felt that any help that they had received had been found ‘by chance’. They heard about services from other people or by talking to other carers at their support group for people with neurological conditions rather than professionals.

2.12 Despite a range of neurological conditions having deteriorating mobility problems no one had discussed with them how to get a wheelchair. A carer had to source a wheelchair themselves because no-one had been available to advise them. They did not have a social worker and the GP did not know.

2.14 Male caregivers reported that the most difficult part of the caring role was not being able to go to partners for help and to talk things through. There was a grief process that men found difficult, that they did not want to upset their wives by appearing foolish. They felt the loss of the ability to turn to the person they were closest to for help very sharply whereas, although more resolute in dealing with problems, female carers missed having people to talk to who understood the symptoms of more rare conditions.

2.15 Parent carers of young people with neuro-developmental conditions expressed a need for their own support because they could not establish a ‘new normal’. Their expectations could not be the same as other parents who sent children off to further education or employment and had achieved a level of independence for themselves. Parents realised they became overprotective, which their children resented.

2.16 The overriding skill every caregiver appreciated was a non-judgemental attitude from Health and Social care professionals. Again, unequivocal agreement that there was a specific ‘path of least resistance’ that was followed to ensure carers had as little information as possible in case it cost money. This very specifically applied to equipment, wheelchairs and timely home adaptations but carers felt these situations could be handled differently and not make them feel as if they were asking for too much. Even carers with stable income felt they did not receive a customer service just asking for information.

2.17 There were 3 caregivers who would welcome the opportunity to understand more about care home placements, particularly for respite care.

‘I don’t know how to have MS so I need people around me and my husband who do’

3. Outputs

3.1 Published 1,000 Flyers	January 9th 2019
3.2 Conducted interviews with 38 caregivers	February to May 2019
3.3 Delivered two monitoring reports	January 31st & March 28th 2019
3.4 Open Day event	March 28th 2019
3.5 Delivered 5 'lived experience' seminars	February to April 2019
3.6 Published 200 Diverse Carers booklets	May 28th 2019
3.7 Delivered the final Project report	June 3rd 2019

4. Outcomes

4.1 Project delivery;

- We have recruited 2 carers for our research reference group
- We interviewed and collated feedback about the caregiving route for 6 parent carers to build resilience and improve their coping skills
- We provided advice, guidance and support for 3 people whose caring role is coming to an end through end-of life care
- We have improved the interaction of outcomes for people with a neurological condition working with 22 caregivers to reduce the stress of the caring role, improved financial security for Council tax rebate, welfare benefits support or understanding terminology for Continuing Health Care (CHC)
- We have interviewed, transcribed and assembled 4 carers narratives for a Diverse Carers Open Door learning resource
- Attending a 'lived experience' seminar, 1 student informed that they were a caregiver for a parent with a neurological condition but were 'hidden'
- The cohort includes interviews and feedback with 5 male carers

4.2 Carers Strategy;

- Improved engagement with 38 carers to offer appropriate information and nurture self-management skills - Strategy Outcomes 2, 4, 8 and 9
- Improved our peer support and carers' network by 20% to befriend and support other carers - Strategy Outcomes 2 and 4
- Increased access to emotional support particularly for 10 isolated carers of people with rare conditions - Strategy Outcomes 2, 3, 4 and 7
- Raise the profile of welfare benefits, personal budgets, CHC, council tax rebates or direct payments to 38 carers - Strategy Outcomes 1, 3, 4 and 7
- Project delivery - Strategy Outcomes 2,4,7, 8, 9,10,11,12

5. Added Value

From June 2019

5.1 We are registered stakeholders for the NICE guidelines development for Carers: provision of support for adult carers

5.2 We are registered stakeholders for the NICE guidelines development for Foetal Alcohol Spectrum Disorder (FASD)

5.3 A former volunteer, a parent carer has been supported to apply, be interviewed and recruited to the NICE steering group to develop guidance for People with learning disabilities and severe complex needs

5.4 We have been invited to work collaboratively with Teesside Hospice to improve understanding of rarer conditions and care pathways for carers

6. Acknowledgements

We wanted to acknowledge that two people, a caregiver and a cared-for died during the delivery of this project and we were extremely grateful for their family's inclusion, continued support and feedback.

Since April 2019, the application process for a PHB has been withdrawn unless CHC is already in place. This placed significant stress on three carers who engaged with this Project to specifically access information to make an application for a person they cared for who had significant unmet health needs.

The following neurological conditions are represented in feedback, questionnaire responses, interviews and narratives from an age group aged 42 to 79 years;

Acquired Brain Injury
Autistic Spectrum Disorder
Brain tumour
Cerebral Palsy
Chronic Pain
Epilepsy
Foetal Alcohol Spectrum Disorder
Guillain-Barre syndrome
Huntington's disease
Learning Disability
Multiple Sclerosis
Progressive Supranuclear Palsy
Tourette's syndrome
Trigeminal Neuralgia

> "Finding help, information and support depends which lifeboat you jump into… then you know you are all in the same place and try and keep each other afloat!"

Recommendations

- Value the caregiver contribution by;

a. Recognising the impact of co-producing a care pathway to reduce stress and relationship breakdown
b. Reducing focus on 'client' or 'recipient of a service' and be more approachable to sharing expertise and long term problem-solving
c. Have open and honest discussions to manage expectation and promote freedom of choice in decision-making

- Strengthen preventative models of care to address the level of unmet need for emotional or psychological support

- Address the lack of continuity between services and personnel. There is widespread fragmentation of communication chains and thereby, relevant information becomes lost, homogenised and unsuitable or not timely

- Construct transition pathways in the school leaving year to provide access to or signpost to mental health and peer support for both the parents and the young person when managing a range of neuro-development conditions such as Tourette's, ASD, Sensory disorder or Foetal Alcohol Spectrum Disorder

- Mitigate the gulf between rhetoric and reality. There is a widening gap between the bureaucracy of the commissioning specifications and lived experience which deeply impacts on caregivers, not only from their own perspective but managing the frustration of the person they care for.

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YOU CARE.

Notes

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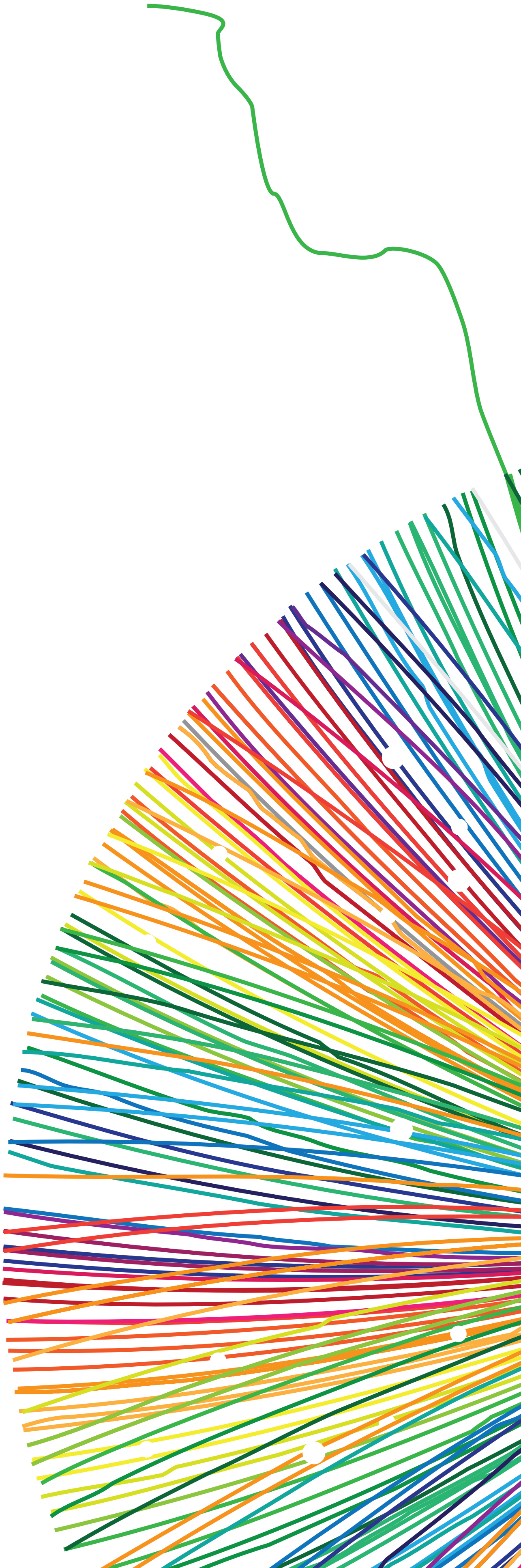

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