NEURO KEY
An Alliance supporting people
with neurological conditions

DIVERSE CARERS

‘Unlocking minds and opening doors’

Open Door series by Neuro Key

Contents

Foreword

Since inception Neuro Key, the working name of the Charity, Tees Valley, Durham and North Yorkshire Neurological Alliance, has harnessed lived experience as an educational tool to improve service delivery and professional understanding of not only the common threads between neurological conditions but also the complexities of the caregiving role. From enabling patients and caregivers to take part in research, deliver lived experience seminars, making sure people can respond to surveys and consultations or supporting people to lead the operational direction of the Charity, we are passionate about our social purpose.

We promote common objectives across all neurological conditions and in-so-doing, offer activity for people themselves to share and learn from each other. We concentrate on the value of lived experience to professional knowledge and the contribution to the evidence base to improve understanding and care in the future. By supporting people to be more confident in knowledge sharing and cooperation across social divides, we sustain a neuro-informed community to improve self-management, neuro-literacy and social capital.

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

Our **Open Door** series of booklets has been developed to acknowledge the challenges of living with a neurological condition that is misunderstood, subject to media-driven or political myths and is neither prevalent nor the focus of publicity campaigns. The following stories are all real life narratives of caregiving experiences of supporting people with neurological disability.

We have adopted fictional names to protect their identities.

NEURO KEY

May 2019

Anthony's Story

I left my job as an account manager in 2011 aged just 46 to care for my mam who has Progressive Supranuclear Palsy (PSP), a rare neurological condition with secondary dementia. I have a sister who does not drive so could not help much, I am 54 now.

My journey as a male, full-time caregiver began when my mam fell and broke her hip and needed help with reduced mobility. I first became aware of Continuing Healthcare then. The ravages of PSP caused more mobility issues and stiffness and she needed help with basic things like eating as her muscles seized up. Mam used to go to a day centre and we did a range of activities together. In 2018, it became clear that mam needed a palliative care pathway after she became bedbound. I decided to take care of her as a care home would have been a huge cost and I would have been there all the time helping her anyway. I now have carers in every day to keep mam healthy and free of infections though I am in control of her care plan. I also installed CCTV in her room so I am aware of her needs all the time.

I am lucky in one sense to be able to leave my job and manage financially. I had a good job, savings and I will be allowed to draw down my work pension at 55. The catalyst to me leaving work and becoming a full-time caregiver was a focus on the pros and cons. I worked 60-70 hours a week and did give having some kind of sabbatical, a year out, some thought but my job dominated my life. I was stressed and running around like the proverbial headless chicken. I knew a sabbatical would give me a taste of another side of life but in the end, I chose to leave work altogether. I do not miss work now!

My decision not to put mum in a care home was based on the fact that I could give her personalised attention that I knew no-one else would give and her safety was a real concern to me. Let us be candid here, if we really have a choice, how many people would willingly go into a care home? I understand all the issues about dementia and the stress on families but my mum is no trouble, maybe because she cannot communicate properly. She is not in pain and has no meds but she has had a catheter for about a year now. Her problems are associated with things like difficulty in swallowing, choking on phlegm and bed sores.

People used to have about a 5-yr life expectancy with PSP and cause of death is usually pneumonia.

I have brilliant paid carers that come by, two assistants come 4 times a day to see to mam's personal care needs and check or change her catheter bag and keep an eye on infection control by changing dressings for bed sores. I have a good airflow mattress for mam and an Occupational Therapist from the council came to assess the sores and put in training. I prepare all her meals and feed her, try and turn her to reduce the pressure on bed sores and see to all her laundry needs. The clearest issue for people with PSP is around food. The lack of taste sensation, how do you judge the necessary calorie intake when someone is bed-bound and struggles to eat, what is 'enough'? I have been lucky to have input from Speech and Language personnel who gave advice and mam is on a Category 6 soft food diet. When I cook meals, I eat the same thing as mam and just pulp her portion.

The best thing about all this is the multi-disciplinary team around mam where everyone is on the same page and working in her best interest.

The best thing about all this is the multi-disciplinary team around mam where everyone is on the same page and working in her best interest. We do not have a social worker. All mam's equipment needs have been taken care of through Occupational Therapy and I have been involved in the decision-making and able to make choices.

I never see the GP about mam because they generally do not have a clue about PSP. I have lost count of the number of district nurses I have seen. Mam used to have physio but that could not continue as the stiffness took hold. I have no expectation about who knows anything about PSP. I am happy to educate them and lead the PSP group so that people gain confidence from knowledge and knowing other people are in the same boat.

Although I am a full-time caregiver, I can have a 2-hr sitting service through the criteria from my Carers Assessment. Although I had to find this out for myself, I also get Carers Allowance which protects my National Insurance contributions for my State pension. I get out and socialise with my friends, play squash, golf and go swimming. I can go to the cinema because mum is no longer mobile and we have no risk of her falling. I can rely on the CCTV and check her regularly. I guess the only downside for me was that holidays used to be important to me because of the stress of the job. I stay philosophical that mam is on an end-of-life route and I can hopefully look forward to a holiday in the future.

> Waiting for decisions and things to happen is difficult when you are in the middle of a crisis.

I have had power of attorney for about 10 years but even then had to go and look myself. There is a real need for information, advice and guidance but mainly, I wish professional people would be more understanding and see things from your perspective. Even if you know nothing about PSP, sharing and learning from each other is vital. Waiting for decisions and things to happen is difficult when you are in the middle of a crisis. Quick telephone messages, notes or updates from people on developments or delays go a long way to you feeling more confident and you know where you are at. Some days do become overwhelming in the beginning. You do need someone to help you in digestible, bite-sized chunks of information that you can deal with. It helped me to keep a diary too. You never realise the changes that occur and you are able to explain worries to people who need to know and can use their professional instinct to react or reassure. Now, we have an extended PSP community and we are quite close-knit. The nature of PSP means we lose people but believe we have honestly done our best.

Sadly, my mam passed away as my story was being written. It is probably a blessing as she didn't have much quality of life over recent months. I will continue to be part of the PSP community because I feel sure that personal guidance from someone who has lived a carer life for some years should come before the internet and good old Google.

Christina's story

I am a caregiver for my husband who was diagnosed with Secondary Progressive Multiple Sclerosis (MS) in March 2000. MS is a particularly hard disease for people to understand when asking for support as a carer. Firstly, you do not know what or who to ask and secondly, you never know what you need in time to make a difference. You sometimes do not recognise when there is a general deterioration such as when my husband can manage tasks and sometimes when he cannot. There is no manual we can turn to for guidance, everyone is different. This can differ in a matter of hours or occur several times and then you feel you may have reached a new stage. The difference is the level of fatigue and how he can manage activity safely without incident. Even when he has managed something, the fatigue washes over him and is immense. The overwhelming tiredness is hidden to most people but is the biggest of struggles for my husband.

> Firstly, you do not know what or who to ask and secondly, you never know what you need in time to make a difference

My husband works part-time. I am not employed but I do volunteer for something I am interested in. The employer, NHS health professionals, Social services and the Department of Work and Pensions (DWP) all ask what he can manage. A simple task can sometimes mean he must sleep for a couple of hours afterwards. Through fear of appearing to not be truthful, we feel obliged to say he can manage most things. You can't ask for help on an ad hoc, on demand kind of basis. There is no universal understanding of what life looks like, in my opinion very few people have the skill to get what having MS really means. This is my struggle as a wife, a mother and a carer for someone with MS.

We may find that one morning my husband cannot get up and get dressed without help, but another day he can. Nothing can be taken for granted. A simple urinary tract infection (UTI), common for people with MS, has completely knocked him immobile in the past, bed bound and unable to even sit up in bed. The immune system reacts badly to viruses and infections when you have MS. Something like a UTI or simple cold can severely affect him and on occasions has landed him in hospital. One thing people do not take into account is the impact on mental health when your body no longer reacts the way it used to or you need it to. When my husband falls over because his legs simply give way without warning, it is a major issue which results in a bruised body and mind. Again, the physical injury may be seen but the hidden mental injury impacts on everyday life for everyone in the family. I try to protect my children from seeing their dad deteriorate or not handle what is happening to him.

His confidence goes too and he withdraws from family life. We have to treat every day like it is the worst to try and prevent accidents and control the fatigue, but every day is not the worst. As the carer, I have had to take on most household tasks to prevent the complications or a relapse in my husband. Because of this, I feel very isolated and cut off. I feel I always need to be available, even when my husband is not at home, on hand for every eventuality. The spontaneity of my life has completely gone as a caregiver.

As a service veteran, my husband was used to being very self-sufficient, determined and organised. The MS has reduced his capacity to be like this, he is forgetful and physically impaired. He finds it frustrating and I must be vigilant. Simple things as humans we take for granted like enjoying food, represent a hazard for my husband. Swallowing and choking have been an issue as the relevant nerves are damaged by the MS and cannot relay the correct messages to his throat. I feel extremely guilty and worried if this happens when I am not there.

the physical injury may be seen but the hidden mental injury impacts on everyday life

When my husband is going through a bad spell, being a mother takes a back seat. This really impacts on my ability to cope, particularly balancing the needs of my own mental health. Again, it is the overwhelming guilt feeling that washes over you and you can find it so hard thinking straight or being motivated to get things done. Trying just to ‘manage’ things on the ok days then having to step up and do everything on the bad days makes me feel like I neglect our children. I am especially aware of how the youngest misses out.

I know I have been told before to ask for help, but when I have asked there doesn’t seem to be anything out there that can get to grips with what life really looks like. MS is a never ending condition that cannot be fixed with a tablet or a massage. I have engaged with specific services before, I was offered a pamper day once, which was lovely. But, I would have much rather been offered time for someone to come and cut the grass or do the ironing, something practical that can free me to be a mother a bit more or just be me.

My husband also suffers with PTSD. This too makes me want to be about for him as you cannot rely on anything or know when someone will crash. His mental health impacts hugely on his physical wellbeing too. Jumping roles from parent, wife and carer has taken its toll on me. I feel forgotten and extremely guilty if I want something. I have sleep problems and worry that I have not done something or I worry about the next UTI or if or when my husband has a fall. This is our normal routine that people do not seem to understand. I cannot engage with regular meetings or group activities because I may not be able to go for weeks.

The outside world can make the struggle harder. People have become so much more judgmental. I recognise it is lack of understanding or awareness but it can be very hurtful when you are simply trying to do your best for your family. If you park in a disabled bay, people stand and stare, waiting to see if you’re disabled enough. The current attitude to disabled people in general is very poor and comes from this idea that the disabled are a burden or simply lying. My husband served his country and cannot help having MS or PTSD. You do feel like you are making excuses for needing a disabled parking spot but people’s attitudes are so degrading and humiliating. We have been discriminated against but our ability to challenge has left us exhausted because we have had to counteract attitudes as well as actions for so long. It would be a constant and never-ending battle to explain the issues about MS. Friends sometimes comment, ‘he looks fab today’. I do get that they are trying to be helpful but also, people only see him on his good days when he is out and about. They do not see my husband on the bad days when we are housebound and feeling like we are definitely not managing. I go through life feeling like I have to justify what we do or why we do something. Although my role as a caregiver is largely hidden, it involves having eyes in the back of my head and a contingency for everything.

they see their parents alternate between physical and mental exhaustion

Reading back through this, the biggest thing that strikes me is the guilt, guilt at not always being available for my children. They see their parents alternate between physical and mental exhaustion and sometimes we cannot be there for them. I also have a feeling of failure when my husband has a bad spell, guilt if an accident has happened, like I could have done something different or better or been more aware.

It’s exhausting carrying that around all the time.

Trevor’s story

My wife and I have just discovered we have been parent carers for over 45years since one of our children was diagnosed with severe epilepsy. The teenage years were spent with them out of the home area and the child missed a great deal of schooling because of seizures. A brain tumour was diagnosed and following surgery, we seem to have arrived at where we are today in the blink of an eye, looking after a 49year person with a mental capability of a young child. I say just discovered but I have long since questioned where I fit in to the situation as just plain old ‘dad’. I have the same worries as my wife but have usually taken a back step and sort of hovered. I help make decisions but being of an older generation, always felt my wife knew best when it came to caring for our children. I have since realised that I too have been caring because of the additional needs of our adult child and to support my wife in what needs doing.

> I say just discovered but I have long since questioned where I fit in to the situation as just plain old ‘dad’.

As age has crept over us, we are not just parent carers now. We are also patients with our own set of ailments and needs. The pace of life has centred on our disabled offspring, raising other children and when things happen, like any parent you just get on with it. These days we are not just ‘getting on with it’ as our own health needs and tiredness are affecting the time we have to not only take care of each other but also, the person who depends on us for everything.

Apart from all the usual medical care, we have not had any help from anyone, not even a social worker. We were both employed so did not qualify for extra allowances and were too busy day-to-day to think of attending things like groups or support meetings. We had nearly retired before we even knew there was such a thing as Carers Services but there was not much available that was really of any use. We attended an epilepsy support group, a Branch of a national Charity and through people there, managed to get some independent living for our child. It was a hard thing to do but we knew it was the right decision and it gave us just a little independence for ourselves.

One of the single biggest problems in our lives has been about other people’s perceptions and people acting on pre-conceived ideas, not getting their facts straight. As parents and appointees we have to see to all the financial responsibilities for our child including welfare benefits and allowances to help with disability. Luckily we have had help because the experience has been terrifying, a mine field, confusing and took ages. No-one seems to understand about how a person can ‘look’ normal but managing their acute vulnerability is a full-time job. It is a complete mystery to me why our adult child with a mental age of a seven year old has to be questioned about their capacity for work because that is what the Government want. How does anyone benefit from that? It made me feel inadequate that I could not help my own child. The system is very different now and you really need to know your way round. Perhaps we are complacent but you kind of expect the system to be there for you rather than you have to fight the system to get what you or your dependent is entitled to. Nowadays, that is a regular worry for people. The genuine disabled do not seem to have rights any more.

> One of the single biggest problems in our lives has been about other people’s perceptions and people acting on pre-conceived ideas, not getting their facts straight.

you never have a minute to think about doing something for yourself, you should be 'doing' for the person you care for.

Lately, I have experienced a sense of loss and feel quite isolated and lonely. My wife has stopped driving following some surgery and I needed to take care of her. I now have to do all the driving. I do worry about a time when I can't. I still do a lot for our child but we are coordinating more help from outside the family which has made a huge difference to how we plan and get physical work done, basic things like gardening and washing windows. May seem silly but I will be 80 soon and can't do it. I feel we should have had more help years ago which would have meant less of a worry now. It is not just about money but the practicalities of living where you never have a minute to think about doing something for yourself, you should be 'doing' for the person you care for. We must also take into account just who we let in to our circle of help because our child is so very vulnerable.

However, I am feeling that having been on the margins for a lot of years that I want a bit of life. We have never been able to make spontaneous decisions because we have always had to take the welfare of our child into account. We have barely had a holiday without having to take them too. We have had most of our lives turning about, swopping roles as and when and as with all families, curing the problems you are faced with because there is always more problems waiting round the corner.

We talk all the time about what happens when something happens to us. Our eldest child will be working likely until they are nearly 70 so will it be fair to say look after your sibling when we are gone? We have fought long and hard for independent living, not an institution but are really fearful. Again, where is the guidance, the advice, the support for you to make decisions that can help with your fears? I am not sure public services really understand how weak you feel. It is not just about the helplessness of the person you look after. Our lives seem to have been about the life-jigsaw with an edge bit missing.

Fred’s story

Our lives had been what you would call normal until teatime one day in April 2015 when my wife suddenly had difficulty getting out of her chair. She held on to furniture to move into the kitchen to get a tin open but could not hold it to open it. I took her to A&E and they decided the difficulty was probably a trapped nerve in the lumbar area. “Go home, take paracetamol and return tomorrow if concerned”…… My wife was a dead weight by this time and could hardly move at all. To get out of the car, up one step and into bed took us 2 hours. By 2am, she could not even move in bed and I called an ambulance. Paramedics played ‘push me, pull you’ and in the end my wife flew off the bed and onto the floor. It took three of us to get her into an ambulance chair. We arrived at hospital where we sat for a while until my wife had a CT scan and one of the on-call Doctors thought it may be Guillain-Barré Syndrome (GBS). That diagnosis was confirmed later that morning a rare, serious autoimmune-led neurological disorder that attacks cells in the nervous system.

By this time, the only functioning part of my wife was her eyes. She was transferred to an ICU ward and was given a course of intravenous gamma globulin (ivig) and subsequently Plasma exchange, neither of which gave any indication of being beneficial. She had to have a tracheotomy after a week in hospital which was in place for six months.

She was in hospital sixteen months including 4 months in ICU, 4 months in HDU plus rehabilitation. This was a very distressing time being apart. We were fortunate, that we had both retired and I was able to spend as much time with her as I did.

Belatedly, Social services became involved, although to be fair once assigned we had a very good social worker who started the ball rolling with discussions on adaptations that would be needed at home, including ramped access, although we would not be able to receive any financial help. This was due to the fact that we had both worked full time and had private pensions which took us over the finance limits. The local council, the ‘staying put agency’ were willing to act as project managers for all the house modifications. Although having project experience, I had no knowledge of specific disability requirements. My wife had no ability to stand or walk and she would need hoist transfers for any movement from bed to wheelchair and or bathing/toileting. A bath was out of the question for my wife so the bathroom was converted to a wet room which meant removal of the bath. This had been beneficial to me as I suffer with back problems. Some of the adaptations were not necessarily the right thing in our case, in the longer term. Although getting my wife showered would not be too difficult, getting her dry would be a nightmare. She would have to be showered in a commode chair whilst in a sling and then transferred back to bed for drying. My wife now has a bed bath daily which, although not the same as showering or bathing is the easiest solution.

Before my wife’s discharge from hospital, I realised we needed a vehicle suitable for a wheelchair. I duly rolled up to a garage and in my naivety, thought I could access a Motability vehicle. However, my wife was 68 by this time and not eligible for the Motability scheme. The implication seems to be that once you are over 65 you have no need of private transport.

I made enquiries at Citizens Advice about allowances for carers but we were not eligible. When I got the adapted vehicle, I had to fill out an on-line application for a blue badge. That was so frustrating because they do not allow for anything other than tick box. The form asked whether the applicant could walk and allowed for a “no” answer but in the next page asked how far could the applicant walk.

We have help seven days a week from professional paid carers, but Carer Companies do tend to employ very young staff, obviously they are cheaper. We have lost count of the paid carers we have seen who have been less than competent despite their training. Some of them have not shown a willingness to adapt and learn and seem far too young to embrace their role. The training does not always result in competent carers and the younger people sometimes see the job as temporary and are not interested in customer care. One company we had were not careful with catheter bags and used to spill them regularly on change over. This was an example of being trained but not being competent.

The Neuro-Physio on the ward realised my wife would never walk again but it upset me that more could have been done before to see if she could walk before she broke her legs.

My wife is a dead weight and cannot help herself. I can get her up in the morning and to bed at night, with difficulty, but I am always in attendance for the paid carers to ensure my wife has the care needed. I deal with her bladder irrigation at night. What took a good length of time to sort out was the incontinence service because the GBS knocked out the nerves to the bladder meaning there is no muscle strength. We had to pay which did not seem right. Bypassing of the catheters was causing regular UTI's and my wife needed antibiotics. One time this interfered with the statins she had to take and she became very ill. It is these kinds of things we rely on for good professional knowledge to help us through.

One evening, having been out for a meal and returning home, my wife came out of her wheelchair whilst I was driving round a corner at low speed and her legs folded underneath her. She broke both ankles, both legs and endured seven more weeks in hospital. We did not know before this but she was also diagnosed with osteoporosis. She was discharged from hospital with assistance from Continuing Healthcare (CHC)

The Neuro-Physio on the ward realised my wife would never walk again but it upset me that more could have been done before to see if she could walk before she broke her legs. I felt an earlier CHC review could have scoped some activity to help my wife. So, after this, we moved into the telecare world with an alarm, carer's card and the Emergency carer's card. My wife was in brace and plaster for nearly 18 months but we did not dare use the adapted vehicle to go out during this time as the potential for damage to her was too risky. When my wife was in hospital, I did not have to think about anything like that but once she was home, I felt responsible. I needed to be on high alert all the time which I realised was very draining. You carry on out of love without thinking but I am not a ditherer. I am methodical and even go shopping at speed to make constructive use of time.

I read a book about a chap who had GBS but he did not portray the real hardship, to be honest, his account seemed a bit blasé. But, I could relate to the problems his wife had as the first port of call. I had retired so we were not time pressured but due to changes in the sensory nerves caused by the GBS my wife could not cope with sudden changes, things suddenly happening or sudden noise. If she has a split second to see that something is going to happen or that makes a noise like dropping something, she is fine but obviously the damage to nerves makes noise very hard on her.

I did not realise that I needed support at first from the Carers Centre but in January 2018 sought help from the Carers Service. I felt I could not grieve for our lost life because I had so much to do but eventually with help from the Occupational Therapist, I asked about someone to talk to and started to accept that what I was feeling was a form of grief for the loss of our previous "normal life".

Now, trying to get some kind of normality is dependent on us not trying to return to how our lives were before. We have a new normal that we have to get on with. I can leave my wife for a while but certainly would not entertain going off for three or four hours. We see friends and they are a source of huge support and comfort. Neither of us is keen to use “support groups”. We are better off and feel more comfortable being part of familiar places and people in small groups. Personally, our marriage was always very strong but if it was possible, it has become stronger. I do recognise something like this could break a marriage but we have always been adaptable and have always had a willingness to adapt that I think has helped us achieve what we do today. We are partners in this journey.

I must admit, I do not enjoy being ‘the carer’ and don’t really want to be but it comes to understanding the power of love and that things cannot remain the same. We used to have dancing lessons and one day the teacher was off sick. Another teacher took us and claimed she had never had such a lesson like ours before because we were so easy going with each other. We have felt fortunate that the GBS did not strike 30-years sooner because we have led the life we wanted to lead, we volunteered too and were always happy to holiday in the UK. However, now we need things like ceiling hoists and trying to find an accessible, disabled-friendly hotel with a ceiling hoist in Scotland has been impossible. When places advertise as disabled-friendly, I am not sure they really understand what it means. Usually, doorways will not be wide enough or there are no ramps or they have gravel or worse, potholes in the car parks. There are places for self-catering but it becomes a chore similar to home and as the carer, my wife wants me (and so do I!) to still have some time off to enjoy the moment.

> Even now I get emotional talking about our early days, almost tearful. I have never actually had a good cry and eventually found someone to talk to.

We see the fabulous neurologist every 8-9 months and neurosciences overlaps with Rehabilitation every six months. Currently, our list of input includes Neuro-physiotherapy, Urology, Botulinum Toxin injections to help with bladder problems, Rheumatology and Endocrinology for toe care and pain relief. May seem strange but the GBS is disintegrating my wife’s nails and she must have a general anaesthetic and specific procedure because of the problems. The too-ing and fro-ing from clinic appointments, the aftercare of treatments plus the routine for prescriptions and my days are spoken for.

We have concluded that Information for the disabled is not always easily accessible and we have had conversations about what we could do better and go out and find what we need. We wish we had known more about the reality of the wet-room before we had the work done and obviously, our naivety about the Motability Car Scheme.

Even now I get emotional talking about our early days, almost tearful. I have never actually had a good cry and eventually found someone to talk to. The hardest thing is coming to terms with just how dramatically our lifestyle has changed. We loved just going walking but obviously my wife cannot. I can still get out and about. My back problem benefits from light exercise, but it is that kind of adjustment that does not give the same enjoyment. We have to make a point of not trying to replicate what we used to do, rather keep positive about the new reality and start afresh with my wife’s disability and wheelchair and see what we can achieve.

The power of faith, friends and love has kept us going. Before the GBS struck we both thought we knew how much we were loved by our friends from both inside and outside of our church. We have since realised how much more love was out there waiting to be given.

Learning outcomes

	Be able to;	Relevant for
1	Identify the range of complex needs for both patient and caregiver and the suitability of assessment criteria	Primary care - GP's and staff Occupational and Vocational Therapists NHS personnel Social Workers Hospital discharge teams Mental Health teams Voluntary sector
2	Identify condition variations and caregiver coping skills	Primary care - GP's and staff NHS personnel Social Workers Hospital discharge teams Mental Health teams Voluntary sector
3	Configure cooperative multi-disciplinary care pathways	Primary care - GP's and staff Social Workers Occupational and Vocational Therapists Hospital discharge teams Mental Health teams Voluntary sector
4	Identify the support needs of caregivers and address the communication needs	Primary care - GP's and staff Occupational and Vocational Therapists Social Workers Voluntary sector
5	Develop awareness of local community referral pathways and cycles of communication for peer support	Primary care - GP's and staff Social Workers Care support assistants Voluntary Sector
6	Construct a co-produced care plan with regular review to recognise deterioration or palliative care needs	Parent, partner or family of caregivers Primary care organisations Secondary Care organisations Mental Health teams Voluntary Sector
7	Establish condition-specific awareness training	Primary care - GP's and staff Hospital discharge teams Mental Health teams Social Workers Care support assistants

What can we learn from these narratives?

How can services respond more appropriately?

Are the needs of caregivers taken into account?

Acknowledgements

The Diverse Carers addition to our Open Door series aims to bring a sense of real life to underpin organisational, national and local Carers Strategies. With a tenable skill vacuum and very fragmented care pathways for the people they care for, caregivers feel isolated from the information they need.

We are grateful for the collaboration with Gemma O'Connor from PSP Association and the Specialist Occupational Therapist Community Neurological Rehabilitation team for South Tees Hospitals NHS Foundation Trust.

We hope these narratives can provide inspiration to support caregivers and raise the profile of caring responsibilities to the wider community.

The production of this booklet has been made possible through a grant from Middlesbrough Voluntary Development Agency in support of objectives of the Middlesbrough Carers Partnership working to deliver the Middlesbrough Carers Strategy.

Further information available from

Neuro Key
Acklam Green Centre
Stainsby Road
Middlesbrough TS5 4JS
T: 01642 641825
E: admin@na-tvdny.org.uk
W: www.na-tvdny.org.uk

PSP Association
Margaret Powell House
415a Midsummer Blvd
Milton Keynes MK9 3BN
T: 01327 322410
W: www.pspassociation.org.uk

MS Society
372 Edgware Road
London NW2 6ND
T: 020 8438 0700
W: www.mssociety.org.uk

www.gaincharity.org.uk - written by neurologists with an interest in GBS

www.nhs.uk/conditions/guillain-barre-syndrome

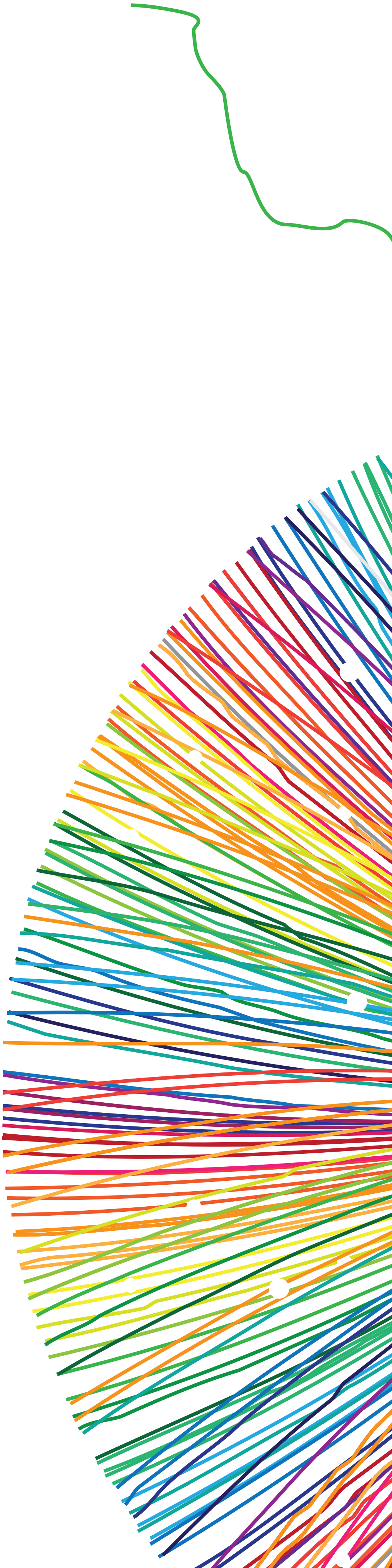
Notes

NEURO KEY

An Alliance supporting people
with neurological conditions

Our Open Door series is collectively created to share our expertise and ultimately, benefit the whole neuro community. However, we need to sustain this Charity. If this resource has been useful for you, we would appreciate a donation to help keep the work going.

Scan the QR code with a smartphone and go to the donation page on our website.



Tees Valley Durham and North
Yorkshire Neurological Alliance
Registered Charity No: 1119043

Design by www.nickballdesign.co.uk