

Tees Valley, Durham and North Yorkshire
Neurological Alliance

10 year
Impact
Report



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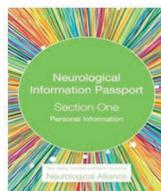
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Summary

Tees Valley, Durham and North Yorkshire
Neurological Alliance

5,400 Neuro bulletins
delivered every year
Bulletins

2,400 Neuro Passports
working to support
personalised care and self
management



Distributed
1,200 Prospectus
5,500 Directories
600 Carers Posters
500 Pain group flyers



2 Carers Week events
11 Forums and Networks
6 Consultations
4 National surveys
6 Case studies presented
to Dept of Health and
NHS England

TVDNY INFOGRAPHIC

1,475 people received **Advocacy, Information or Signposting 2014/5**

Enabled participants on **4** PhD
research projects

Provided **18** medical student
placements

Delivered **4** seminars to **105**
medical students



Invest **£35,000** a year to influence
strategic development in region



Won **6/6** ESA or DLA appeals
Navigate Health and Social care
Advocacy to achieve 4 Personal
Health Budgets
Innovative Peer Supporter to access
Personal Health Budget process

36 people in our service user and
caregiver groups delivered peer
support, information, identified local
need or responded to strategic plans



www.na-tvdny.org.uk

Since inception in May 2005, the Tees Valley, Durham and North Yorkshire Neurological Alliance (TVDNY) has believed in and worked to, a two-sides-of-the-coin approach.

By including experiences of people who use neurological and allied services in research, with first year medical students and at Networks and Forums we not only raise the value of that experience, but we present a positive motivation for service improvements rather than dwelling on historical blame. The Charity made a commitment to promote a person centred environment from scratch, to avoid inaccessible add-on or quick-fix approaches that have resulted in people living with neurological conditions becoming more marginalised because of the competing priorities within the welfare, health and social care budgets.

The strategic environment calls for a fundamental shift from care-done-to to a collaborative partnership between patient, caregiver and service. TVDNY has provided a strong focus for better access to advocacy, information, advice and support but, it takes time to encourage self-management and translate technical jargon into control, choice and improved outcomes. By promoting better mental health and wellbeing for people with neurological conditions, we also support caregivers to be equal partners in the life-long journey of neurological conditions, injuries and impairments.

Forward - Founding Chair

Glenys Marriott

Chair 2005

Chair Cumbria Neurological Alliance

When I became Chair of the Board for South Tees Hospitals Trust in 2004, I knew that it included a large neurosciences service. Having been involved for a number of years in reviewing and commissioning neurological services, I had instigated the start of a neurological alliance in Greater Manchester. It had been hugely successful in supporting the development of services and I aimed to develop one to cover the patch served by the Trust, across South Durham, Teesside and North Yorkshire. The recent loss of my sister, Cathy to motor neurone disease also fuelled for me the need to enhance the care on offer and to ensure it was timely, integrated and appropriate.

The first meeting to gauge support was April 2005, at James Cook University Hospital, Middlesbrough when over 100 people turned out to debate the advantages of such an approach.

Some key people volunteered to form a steering group which then met regularly from May 2005, in the hospital. I was pleased to gain agreement with the Chairman of the Strategic Health Authority to have the development of the group included in my own objectives and saw it as an opportunity to not only raise the profile of neurological conditions under the terms of the National Service Framework 2005-2010) but also to take the trust outside its walls to gain more understanding of the longer term conditions that patients experienced.

The first steering group went on to form TVDNY which is now well known as an Advocacy, Information and Signposting charity campaigning to improve the lives of people living with any neurological condition. Over the last 10 years its members have worked tirelessly with local NHS organisations, local, regional and national Charities, networks and forums to ensure it maintains up-to-date information on the services available in the region. It has become known nationally as innovative and at the forefront of researching ways to enhance the lives of its members. Its work in training new generations of clinicians and offering community placements has ensured that they graduate with a real understanding of the challenges facing their patients.

Having seen the successes it has achieved I was minded a year ago to start the Cumbria Neurological Alliance and am delighted once more to be working alongside TVDNY as part of the Strategic Clinical Network.

I hope we shall have a long and fruitful relationship supporting our clients.

Forward - Current Chair

David Mudd

Chair 2015

TVDNY Neurological Alliance

An emergent truism over recent years is that voluntary and charitable organisations are stepping into the gap left by shrinking statutory services. Charities, such as TVDNY Neurological Alliance, are providing services once the remit of the modern welfare state, local authorities and health and social care services. This raises important questions. To what extent can charities be expected to fill in the gaps in provision? How do we look at the balance of service provision? What is the precise role of the not for profit sector in the absence of some statutory provision?

I believe that the answers to these questions are contained within the TVDNY Neurological Alliances' Strategic Plan 2015-18. In the context of the plan, I see our role as multi-functional: Influencing policy and practice, providing support, advocacy and representation and extending our educational role.

If people living with neurological conditions are to receive the quality and level of care and support they need, it is essential that care commissioners, commissioners of service, providers and regulators know more about neurological conditions. They also need to understand the relationship between the impact on the individual and their families and the components that need to be in place for the provision of equitable and consistent policies and care practices.

We have a crucial role as a community resource. This often includes easing the tensions that sometimes exist in the relationships between people working in and people using care services.

Through our robust University links we contribute to contemporary thinking and scholarship. We utilise our technical skills of research to contribute to the evidence base and we have a key role in educational programme development and delivery.

I believe that our strategic plan includes the vision, the ideas and practical solutions to enable a future for people living with neurological conditions to live in an inclusive society, as equal citizens and with full and enforceable civil rights.

A set of dedicated, driven, talented and friendly people make up the Trustees of TVDNY Neurological Alliance and together with our extremely well organised, hardworking, passionate and resolute Head of Operations, we will achieve our vision, aims and objectives to improve care and consideration for people living with or caring for someone with a neurological condition.

Background

Tees Valley, Durham and North Yorkshire Neurological Alliance, a registered Charity known as TVDNY, is celebrating 10 years of operation throughout 2015 with events and this impact report on the work of the Charity.

TVDNY was formed to support improvements to services under the terms of the National Service Frameworks (NSF) for Long Term Neurological Conditions (2005 - 2015)¹. A North East Neurosciences Network was initiated in 2009, comprising any professional or voluntary sector representative with an interest in improving services for people with neurological conditions. In 2008, TVDNY was the first regional Neurological Alliance in England to secure a service level agreement with Primary Care Trusts for funding to support an Information and Signposting service. TVDNY also supported the emerging Northern Neurological Alliance and began to develop joint work streams. In 2009, TVDNY appointed a Regional Coordinator who was the third employee in England under the banner of a Neurological Alliance.

Under the auspices of the Neuroscience Network, a Workforce Innovation Programme (WIP) was devised to improve equity of access to skill and expertise in neurological conditions through senior NHS staff mentoring staff interested in learning about neurological conditions. In 2010, widespread redundancies cost the region a significant share of NHS professional knowledge about care for people with neurological conditions. The change from Primary Care Trust to Clinical Commissioning Group in 2013 caused further upheaval to communication networks. The NSF disappeared and in 2013, the Northern England Strategic Clinical Network for Mental Health, Dementia and Neurological Conditions replaced the Neurosciences Network.

In the UK, 2% of people live with a neurological condition². With a population of 661,600 in the Tees Valley, there would be 13,232 people living with a neurological condition. Despite National Audit Office³ and Public Accounts Committee⁴ reports highlighting care for neurological conditions, developments have stagnated from 2012 with a tangible lack of service development or awareness of neurological need.

Now, just 14.7% of CCG's in England have assessed local costs relating to the provision of neurology services, rendering the neurological community an increasingly marginalised and isolated group of people⁵. Neurological conditions have lagged behind development of other condition areas and are mostly unpreventable and lifelong.

The growth of this client group will continue. Reducing risk and improving outcomes cannot rely on national policy or health professionals alone. Individuals living or caring for someone with a chronic long term neurological condition must balance choice with more self-directed action but, people need information and support to be equipped with the skills to do so.

Our Members

TVDNY membership has been drawn from individuals living with or caring for someone with a neurological condition, Independent Rehabilitation providers such as Keiro and Voyage, academic staff from Teesside University and representatives from social care, national, regional and local Charities.

TVDNY has brought a sense of solidarity between organisations that support people living with neurological conditions, working together to highlight the commonalities between conditions, problem-solve at a grass roots level and provide expertise and impetus to statutory sector initiatives.

Headway

“Headway Teesside has been involved with TVDNY from its beginnings, as we could always see the value in neurological charities banding together and having a louder voice as a result. There has never been a lack of ambition at TVDNY and I have always found it to be a useful resource. I am very pleased that the organisation is continuing to develop and grow after 10 years. I would like to offer my very best wishes to everyone involved in the charity for its next 10 years.”

Ben Townsend

Trustee of Headway Teesside

Partner in Stewarts Law LLP

Tourettes Action

“Thank you so much for all your help on Teesside, most invaluable for us to set up a new support network in your area.”

Julie Collier

Groups Manager

ADDER

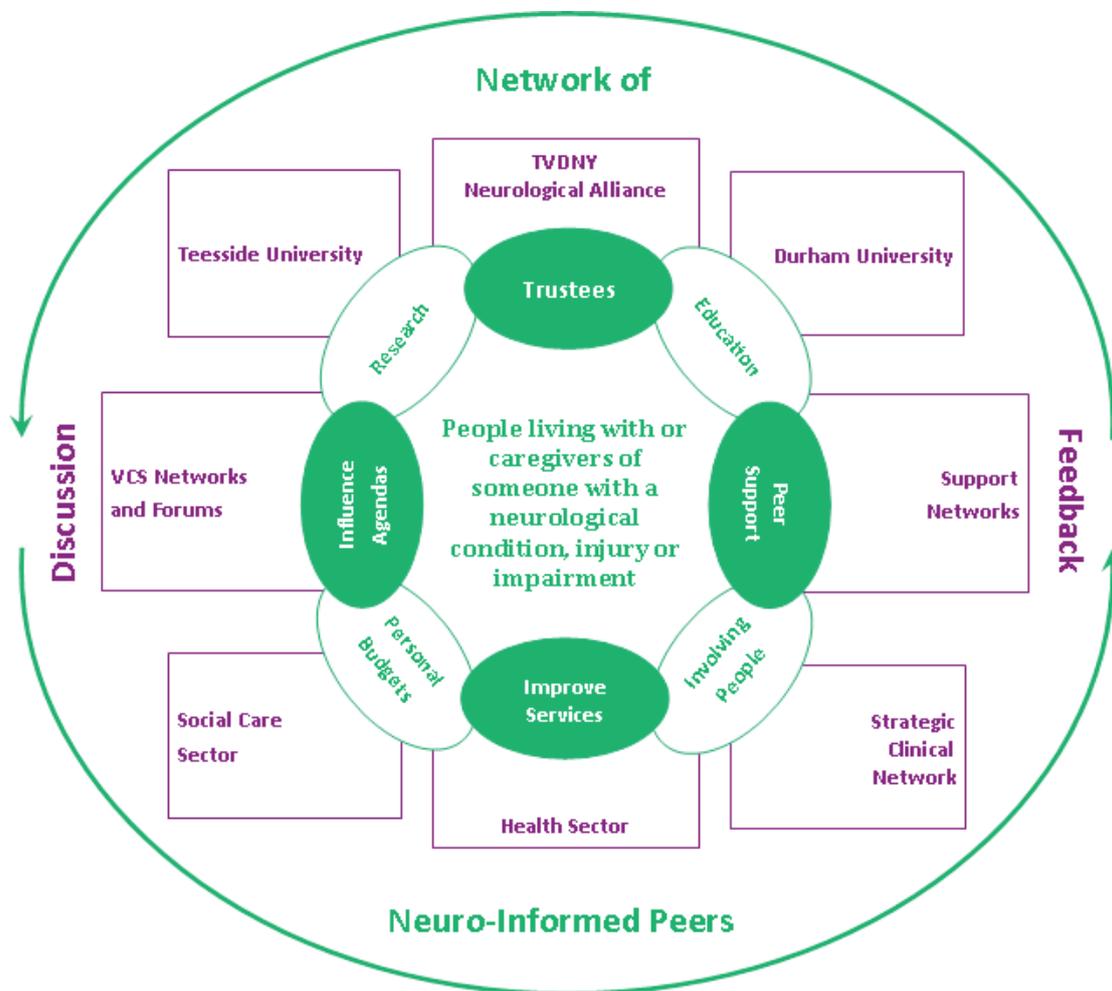
“Action for Dystonia, Diagnosis, Education and Research is one of the founder members of TVDNY, believing neuro Charities have a louder, stronger collective voice working together. Working in the North East over the past 10yrs, much has been achieved but the next 10 years will need vision and determination to meet the needs of people with neuro conditions. So, thank you to the past and may we look forward to 2025 with true purpose and vigour.”

Verona Butler

President

A.D.D.E.R

Strategic Impetus



Model of Operation The Model of Operation is a graphic representation of how the work function follows the objectives of the Charity.

TVDNY Aims;

1. To create and sustain an environment where no one will face a neurological condition alone
2. To create and sustain an environment where people with neurological conditions can engage as equal partners and make their views known
3. To be a leading credible channel of communication, influence and support between people with neurological conditions, commissioners and service providers
4. To be a collaborative partnership to improve local services for people affected by neurological conditions

External Environment

Formal Partnerships 2008- 2013

TVDNY has become an integral part of a distinctive neuro community in the region to provide benefit for service users and caregivers by working collaboratively with 3rd sector, statutory and independent agencies, adding value to service improvement initiatives by directing service user feedback to commissioners, service improvement leads and service providers.

To April 2013, TVDNY has been represented at and provided formal partner reporting arrangements to;

- North East Neurosciences Network
- North East Neurological Partnership - NENP website
- Tees-wide Neuro Forum
- Durham Neuro Forum

Post- April 2013

The strategic environment in which TVDNY operates changed to include;

- North East Strategic Clinical Network (NESCEN)
- Involving People Forum (SCN)
- Tees-wide Neuro Forum
- Care Act Reference group - Middlesbrough Voluntary Development Agency
- Strategy and Development - Evolution - Darlington

Since inception, TVDNY has brokered and enabled the co-production of improvements to services and outcomes by professionals, service users and caregivers. The Charity involves individuals to connect with the neuro community and the broader society, improving self-management skills and reducing the isolation people experience when they have been diagnosed with a neurological condition.

TVDNY has ensured people living with neurological conditions are a vital and integral part of the Charity to harness first-hand experience as a core driver to improve service delivery and outcomes. The Charity is committed to the principle of at least 50% of Trustee Board members being people who live with or care for someone with a neurological condition.

- In 2007, three people from ten Trustees lived with or cared for someone with a neurological condition
- In 2015, seven people from twelve Trustees live with or care for someone with a neurological condition

Combining with this excellent team, strategic work and publications promote common purpose across different neurological conditions, disciplines and agencies.

Charity representatives advocate for and influence appropriate service design and delivery and foster a regional network of neuro-informed peers.

The Charity delivers an Advocacy, Information and Signposting service. People with neurological conditions have a real voice with the Charity. Through publications, events, strategic Forums, Networks and volunteers, TVDNY works to strengthen communication routines, problem solve and close some of the gaps that prevent people accessing good information.

- In 2014/5, TVDNY delivered Advocacy, Information or Signposting to 1,475 service users, caregivers, NHS and allied professionals, independent organisations, PHB projects and regional and national Charity representatives

Engagement and Involvement

TVDNY demonstrates a positive, asset-based approach to promote lived experiences as constructive drivers for improvements to services and well-being. Additional projects the Charity delivers are derived from the neurological community and we respond to unmet need and the challenges people experience.

The Charity offers resources to strengthen the factors that support physical and mental wellbeing whilst managing a neurological condition. By safeguarding people against crisis through peer support, timely information or improved condition literacy, the Charity improves the knowledge of the whole neuro community.

Introduced in 2011, the TVDNY service user reference group called FRIENDS, (Friends or Forum/ Reference/ Information/ Education/ Neurological Conditions/ Discussion/ Services) was initiated to respond to the agenda and work streams of the Tees-wide Neuro Forum under the auspices of the Neuroscience Network. The group meets 6 times a year and comprises people with different neurological conditions such as Multiple Sclerosis, Parkinson's, Tourette's syndrome, Neuro-muscular disorders or Brain Hemorrhage and ME/CFS.

- This multi-neuro group is the only one of its kind in England.

In 2012/3, the Charity delivered a project for the Middlesbrough Carers Grants Fund – Innovation and Good Practice, managed by Middlesbrough Voluntary Development Agency (MVDA) on behalf of the Middlesbrough Carers Partnership.

- *“The work delivered through this grant was deemed to be of a high level, demonstrating added value in a number of areas and contributing to wider developments associated with improving outcomes for carers and the people they care for.”*
(Mark Davis - MVDA)

Also in 2012, TVDNY became involved with a group for people living with chronic pain, chronic fatigue syndrome and 4 or more other health conditions, co-morbidities who meet every month. Members hear from guest speakers on subjects of their choice, participate in a 360° cycle of communication from becoming Trustees of the Charity, as participants in research, delivering a seminar to medical students, responding to regional and national strategic initiatives or distributing information to their own support networks.

- In 2015, two people are involved in both groups.

Through these mechanisms, we prepare people with condition literacy, improve communication skills to build confidence and reduce isolation by accessing social opportunities such as peer support or volunteering options.

The community of neuro-informed peers has been developed through multiagency, multidisciplinary engagement with reciprocal and referring collaboration with representatives of local and national Charities working in the region, NHS and allied personnel, students and academic staff from Tees and Durham Universities.

Education

Since 2008, TVDNY has offered 19 community placements for first year medical students from Durham University, Queens's Campus, Stockton on Tees to spend 60 hours across a calendar year to improve knowledge about neurological conditions.

Aim

To advance education on service-user perspectives of life with a neurological condition

Objectives

- Gain an holistic overview and understanding of how people living with a neurological condition manage their lives
- Improve communication skills
- Raise awareness of what Charities offer and how they operate
- Learn about local service structures that campaign, support or influence service development e.g., Neurological Alliance, Strategic Clinical Network, Neuro Forums, Carers organisations
- Gain insight to the common threads between neurological conditions

The Charity Head of Operations covers an induction programme with a comprehensive information pack and enables the students to attend TVDNY Trustee meetings to understand how a charity works.

Comprising a broad educational experience, visits are organised to the Botulinum Toxin clinics to talk to people with Dystonia, access to people with ABI at the Headway Teesside drop-in, the MS Therapy Centre, the Spinal Injuries Unit at James Cook University Hospital, Rehabilitation service provider

and shadow a social worker on home assessments. There are also opportunities to attend Carers centres, events, Forums or shadow the strategic work of the Head of Operations if interest and the timetable allows. Students are supported throughout the time with regular communication and up-dated on newly published material.

Seminar

The Charity has delivered four annual seminars to 105 medical students during Additional Clinical Experience Week (ACE) at Durham University, Queen's Campus - 'What happens when a neurological condition drops in'. TVDNY facilitate the seminar but 4 people living with different neurological conditions deliver individual briefings on their experiences. Partners, family members and sometimes children are all very much involved in the care of someone with a neurological condition and the influence and needs of caregivers is not generally recognised.

Students begin to understand the words of one lady with Parkinson's disease who told her husband, 'We're in this together'

Feedback from Seminars

"I really enjoyed the personal accounts, found them very informative and useful. It helped me gain a greater understanding of the psychological impact of neurological conditions."

"Patients perspectives - says it all - this has been really good."

Feedback from placement

"Wonderful placement to be on - would do it all over again if I could!"

"I did not imagine I would learn so much from a community placement. Everything possible is done to make sure we get maximum benefit from the time and that has had a huge impact on my future."

"Undertaking this placement has been hugely beneficial for me. Neurology is something which always interested me hence why I wanted to undertake my placement with TVDNY. A year ago I had very little knowledge and understanding about neurological conditions and the impact they have on individuals. I believe as result of undertaking the placement, this has changed".

Research

Across the Charity geography there are approximately 36,000 people living with a neurological condition but there is a dearth of research exploring the experience of living with a neurological condition and how services could improve. In 2007/8 TVDNY conducted a small pilot project, funded by the former Durham Primary Care Trust, whereby people with 3 different neurological conditions kept a regular diary.

The project aimed to examine what it is like to live with a neurological condition in the region and how neurological services could be developed in the future.

A subsequent bid was made to National Institute for Health Research, Research for Patient Benefit to fund a follow-on Project to map patient journeys and explore the viability of a generic baseline approach to Neurological Services. Whilst the bid was unsuccessful, several issues were raised about evidence-based practice, appropriate service frameworks and how to influence service design and delivery.

Working with academic staff from Teesside University since 2009, the Charity has supported five graduate prizes for evidence-based practice to improve the care of people with neurological conditions, socio-cultural factors preventing employment- an occupational injustice, practice of 'constraint' rehabilitation after Stroke, pain management, living with Tourette's and the lived occupation experiences of mothers and young adults who attend a specialist Autistic Spectrum Disorder day service.

The University recommends a piece of work to Trustees, subject to approval the student is awarded a £200 prize at Graduation.

TVDNY has enabled members of the former Middlesbrough Epilepsy Support group to develop an Epilepsy Award, form an awards panel and invite applications. The Charity presented a £350 prize to a student from Teesside University for research on the experience of mothers with epilepsy and their partners.

Through working in close partnership with students from the Schools of Health and Social Care and Social Sciences, Business and Law, TVDNY has supported service users and caregivers to engage as research participants on four PhD projects, people living with acquired brain injury in rural communities, access to psychological support for people with neurological conditions, psychosocial aspects of life with epilepsy and early intervention for managing chronic pain.

TVDNY recommends suitable subjects for study based on reported gaps in service delivery made by service users and caregivers. With the work undertaken to date, it is hoped there will be some clear benchmarks to establish appropriately designed services to meet the future needs of this marginalised group of people.

Strategic engagement and collaborative working

Neurological Alliance

TVDNY is an affiliate member of the national Neurological Alliance and has contributed to surveys, consultations, policy development, initiating and developing the Regional Neurological Alliance (RNA) Network northern and southern hubs.

“TVDNY has been central in raising the profile of neurological conditions for over 10 years. Their work on the neurological directory and passport has provided commissioners with essential tools for understanding more about the needs of those regional neurological alliances, their work with the North East Strategic Clinical Network has been vital in shaping the strategic direction which will improve neurology care in the area.

As well as working hard locally, TVDNY has also supported the national initiatives of the Neurological Alliance by promoting the recent patient experience survey through their network in the North East; responding to and providing case studies for consultation responses to the Department of Health and by advising on the best way to approach regional influencing.

Finally, we must acknowledge the hard work and dedication of the Head of Operations. TVDNY would have had limited success without her. Her passion for improving neurology services and service user outcomes knows no bounds.”

Arlene Wilkie

Chief Executive

The Neurological Alliance

Middlesbrough Voluntary Development Agency

“Since inception, TVDNY Neurological Alliance has been proactive in a wide range of local planning and partnership forums - providing a voice for individuals with and caregivers of neurological conditions as well as promoting the needs of marginalised communities and the position of the voluntary sector as collaborative partners with the statutory sector. The Head of Operations has played a key role as a VCS representative in Health and Social Care Partnership meetings, Health and Well-being Forum and former Middlesbrough Community Network, contributing to disability issues on behalf of the wider sector, the Carers Strategy and addressing some key issues facing services in Middlesbrough.”

Mark Davis

Strategic Development Manager MVDA

Northern England Strategic Clinical Networks



Northern England
Strategic Clinical Networks

TVDNY Contribution to the Northern England Strategic Clinical Networks

The Tees Valley, Durham and North Yorkshire Neurological Alliance have made a valuable and important contribution to a number of Strategic Clinical Network projects and events.

Most recently, TVDNY has contributed to the development of a workbook aimed at providers and commissioners on shifting towards a culture of supported self-management when working with people with neurological conditions. This has been done through TVDNY's input into a local forum, which includes links with Cumbria Neurological Alliance and the group has been instrumental in bringing a service-user perspective to the project.

TVDNY have also supported a number of Networks events, including the launch of the Parity of Esteem agenda. TVDNY had a specific role in this around raising awareness of personal health budgets, linked with their ongoing work on this subject.

TVDNY are active members of our 'Patient and Public Voice' Engagement Bank.

Prior to the establishment of NHS England and the Mental Health, Dementia and Neurological Conditions Network, TVDNY made a significant contribution to the work of the North East Neurosciences Network.

Claire Braid

Network Delivery Lead

Suzanne Thompson

Network Manager

Workforce Innovations Programme (WIP)

TVDNY was woven into the fabric of this programme as a member of the North East Neurosciences Network and the WIP Steering Group. It was a key partner in establishing the project vision with a clear focus on improving outcomes for and with people living with a long term neurological condition.

As a specialist source of expert knowledge, information and invaluable experience, the Charity was an active and expert collaborator throughout the developing, delivering and reporting processes. TVDNY kept people's voices at the heart of the WIP decisions and actions.

Tees-wide Neuro Forum

"The Tees-wide Neuro Forum was formed as the Teesside local provider division under the auspices of the North East Neurosciences Network. The Forum comprises a range of professionals from different disciplines in health from both primary and secondary care, social care, the voluntary sector and commissioners. Members have a common interest in developing services for people living in Teesside with neurological disability.

The Tees-wide Neuro Forum has always put the

patients and their views at the heart of any service development. The Charity, TVDNY Neurological Alliance has been involved with the Tees-wide Neuro Forum from the outset, creating a service user forum to work collaboratively with the health professionals and offer an insight into patient perspectives. TVDNY involvement has formed an integral part of driving changes forward in local service delivery for people with neurological condition".

Serena Hartley, Co-Chair

Gearing Up for Personal Health Budgets - Round 1 Feedback

"Your experiences with the CCGs reflect the experience of some of the other 'Gearing Up' organisations in that the progress is slow but moving forward. I was particularly interested in your reflections on how to develop Personal Health Budgets (PHB) and their role in the self-management agenda. I would agree that there is room for this as we move to the expansion of PHBs beyond Continuing Health Care. The development of

your work with volunteer peer support is innovative and links with some work that I have been involved with in CSV looking at the role of volunteers in offering support around PHBs. Your report helps to shape and shed light on the growing role of voluntary sector organisations in working with PHBs in a rich variety of ways".

Alix Crawford, Personal Health Budgets Delivery Team, NHS England

Publications

In 2006, TVDNY published a tri-fold leaflet to place at events and GP surgeries. In 2015, TVDNY has a range of publications;

- Website - www.na-tvdny.org.uk
- TVDNY developed a new website in 2013 when the Neurosciences Network and Neurological Partnership (NENP) ceased to exist.
- Neuro Bulletin - a bi-monthly round up of local, regional and national news relevant to personnel who support and people living with neurological conditions received by over 900 people.
- Neuro Information Passport - a directory and booklets to promote understanding
- FRIENDS postcards - promotes the FRIENDS group
- Pain Management Group leaflet - promotes the pain friendship group
- Jargon Buster - published on-line to reduce the confusion of acronyms
- PHB Booklet - an information resource to raise awareness of personal health budgets
- Prospectus - a graphic to highlight the work of the Charity
- Banner stands - visuals to promote the Charity

The Neuro Information Passport

The Neuro Information Passport is a flagship product, designed by the FRIENDS group to support decision-making, discharge processes and access to information. Consistent reports about the lack of information post-diagnosis led to people not understanding their condition. The Passport has stimulated a growing recognition of how each condition fits in to the wider community of 324 neurological conditions.

The Directory part of the Passport has been produced since 2008, considered the marque of good practice by the national Neurological Alliance in 2009. We improve the Directory every 18months by consulting with service users and professionals to keep information up-to-date and relevant.

In 2012, discussions about other condition passports at a FRIENDS meeting led to members agreeing to develop one of their own. Over one year, the 2 booklets were formatted, an election was held for delegates to vote on the design of the wallet at conference 2013 and 400 copies of the Neuro Information Passport were published.

The Neuro Information Passport was launched on June 14th 2013 with a panel comprising, TVDNY Patron, Tom Blenkinsop MP for Middlesbrough South, Andy McDonald MP for Middlesbrough, Chair of the South Tees CCG, Henry Waters, Director for Public Health, Edward Kunonga and the lead for Tees Healthwatch, Jane Hartley who answered questions from people living with neurological conditions.

- The Passport was considered 'excellent' from feedback at conference 2013
- In February 2014, the Northern Acquired Brain Injury Forum (NABIF) members considered the Neuro Information Passport as 'absolutely marvelous'.

A stamped addressed postcard was included in the Neuro Passport to seek feedback - 38 postcards were received to March 2014.

- The Passport scored either marks of 4 = useful to me or 5 = very useful to anyone.

Neuro Information Passport Dissemination

In January 2014, members of the Northern Strategic Clinical Network for Mental Health, Dementia and Neurological Conditions were asked to provide some feedback on the Neuro Passport.

- 'We need this rolled out across the region'
- A social worker commented 'it was the most comprehensive tool' to help her support her clients
- 'The passport makes a significant contribution to the understanding of the bigger neurological picture'.

In August 2014, the national Myasthenia Gravis Charity, MyAware became a TVDNY member to distribute the Passport to their client group.

The Neuro Passport is being distributed at James Cook University Hospital in Neurology outpatients, through the Neuro-physio teams, Neuro-oncology and the Movement Disorder clinics at Darlington Memorial Hospital and Bishop Auckland.

Sanctuary Housing Association is distributing the Passport to their clients with Dementia and a training session has been delivered to the staff.

- In 2014, the Charity included Acute Rehabilitation services and Myotonic Dystrophy in the Directory following suggestions from NHS staff and a caregiver.
- In March 2015, a lecturer from Sunderland University signposted students to the TVDNY website to download the directory and passport booklets.

- In April 2015, an MSc student requested copies of the Neuro Passport to conduct an evaluation as a service improvement tool.
- In May 2015, a Care organisation in Durham requested the Passport for the first time for their client group, people with learning disabilities.
- Following a presentation, a Tweet from CPFT research 27.01.15 - "*@NA_TVDNY like the Jargon Buster and neurological information passport, the latter being very useful when people visit their doctor/hospital*".

Influencing through Events

In January 2011, the Charity held the first Appreciative Inquiry workshop, to respond to the South Tees review on rehabilitation services and gather 'User-led Perspectives in using Rehabilitation Services'. The outcomes from this workshop

formed a business case for Rehabilitation services and guided the principles for TVDNY core work that continue to exist in 2015. Participants were asked to highlight the positives and negatives of their experiences.

The Positives	The Negatives
The co-operation between the occupational therapist, the specialist nurse and the physiotherapist	Hydrotherapy is limited or no access Everyone is tied to targets – not us and what we need!
Support groups are important	Access to information
Talking to people with the same condition	Only find out about 'things' by word-of-mouth
Lifestyle	Access to in-patient rehab is very difficult
The future	Only have short-term access to physio
Facilitated access to other professionals	Difficulty of accessing services when working full-time
Use of community gyms after hospital-based rehab	Not always told about this
Simple is best	Media and political pressures to make choices but does not say what they are
My home life is 80% better following discharge with aids provided	Orthotics Department not very good
Rest of team were great	OT not very good at all
Felt very supported once I actually started the course	Courses not offered at diagnosis

Participants were asked to score priorities on the issue they felt most strongly about. The top 4 priorities for service structure were;

1. Specialist Nurse posts are vital and must stay
2. Information on access to support services and groups and specialist health professionals
3. Opportunities to share experiences with peers
4. Creating public awareness and education

There was consensus amongst participants that therapeutic routines should be for the life course of the condition and not dependent on having to deteriorate or experience difficulty before people could re-engage with a rehabilitation service. There was also consensus that the term rehabilitation did

not apply to people who needed life-long help.

As a result of this workshop, TVDNY lobbied the Tees-wide Neuro Forum members about the potential for regular exercise classes. A group was established at Billingham Forum, Stockton on Tees with the Occupational Therapists training leisure centre staff. The group is oversubscribed, members forgo on other opportunities to maintain their place.

In 2015, TVDNY promote access to regular exercise to stimulate use of Personal Health Budgets and are assisting a service user group to write a business plan.

Conferences

The Charity launched by conference in November 2006 and committed to a routine of bi-annual conferences to adopt the issues raised on the day into core work the following year. Hitherto not seen before, TVDNY established a multi-agency marketplace for conferences which offered any voluntary organisation supporting people with neurological conditions, a window on regional initiatives to encourage collaborative working partnerships.

With funding from the six Primary Care Trusts in the geography along with delegate fees for people working in the voluntary or statutory sector, the Charity offered free places to anyone living with or caring for someone with a neurological condition.

Over the course of four conferences, TVDNY reached more people and consistently improved the number of service users and caregivers attending the event;

- 2006 - 18% delegates were service users
- 2008 - 32% delegates were service users
- 2010 - 45% delegates were service users and caregivers
- 2013 - 51% delegates were service users and caregivers



Andy McDonald, formerly with Thompson's Law, now MP for Middlesbrough presenting the graduate prize to James Hart in 2010. Thompson's Law sponsored the prize of £200.

“People do not listen *and* understand”

“I wish they would remember that mobility is the ability to STAY mobile”

Conference 2010

In November 2010, the early and dramatic snowfall caused blizzards which blocked the roads across the region but did not deter people from attending.

Speakers delivered motivating presentations, highlighted what is achievable, whether putting research into action or living life to the full or managing with a personal budget. At every Conference, TVDNY has supported the winner of the graduate prize to deliver an abstract of their work and receive their prize.

Four key outcomes from the Conference 2010 highlighted;

1. Therapy or rehabilitation was seen as a repair function not as part of a maintenance programme with little understanding in the system of how a person can need therapy as part of a continuous pathway and still be employed.
2. A continued myth is that a person is deemed to be 'fit enough' with therapeutic interventions - sometimes causing the loss of benefit.
3. Consensus and dismay about the continued negativity and discrimination on reasonable adjustments which still occur in the world of work.
4. A call for good practice to be highlighted more so we create better quality models, particularly the 'who, where and what' to working partnerships to achieve better outcomes for people.



Graham Ogilvie the cartoonist, recorded comments in artwork during the afternoon session.

Graham is a popular addition to events and the drawings are inspired by discussions about how to manage a long term neurological condition and stay in employment, the personalisation agenda.

He also recorded the frustrations in the health and social care marketplace on the homogenised myths about conditions made by professionals.

TVDNY purchased 3 cartoons from the day to use for publicity.

Conference 2013

The Conference offered speakers from Healthwatch, Personal Health Budgets and the Strategic Clinical Network to explore the new environment and present a portal for good quality information. Delegates were offered a vote on the design of Neuro Information Passport and a multi-agency marketplace offered a wide range of information from a variety of voluntary sector and independent organisations.

Tom Blenkinsop MP attended.



Butler Prize

The 2014 graduate prize for excellence in evidence-based practice was awarded to Leanne Oates for her work; 'To explore and interpret the lived occupation experiences of mothers and young adults who attend a specialist Autistic Spectrum Disorder day service'.

Leanne graduated from Teesside University with an MSc Occupational Therapy and received her prize of £200 in November 2014. Trustees, Stephanie Kiliņç

and Claire Brewis co-ordinated nominations from Teesside University and assessed applications based on the potential impact on changes to professional practice.

The prize was re-named in 2012 to The Butler prize in recognition of the work of Dr 'Ginger' Butler, a co-founder and former Chair of the Charity who died in April 2012.

Branding



TVDNY launched the new branding at Conference 2013 which was very well received. The branding is a circle of multi-coloured strands to represent the numerous neurological conditions with the strands representing neurons in the brain. The white dots and single strand represent the structural, biochemical or electrical malfunctioning in the brain or spinal cord which results in a neurological condition.

Advocacy

Feedback from the Conference 2013 on Welfare reform, disability awareness and personal budgets has informed development of TVDNY services.

TVDNY established an advocacy routine for people in welfare benefit tribunals, winning six cases for appeals against removing Disability Living Allowance (DLA) and Employment Support Allowance with two cases remaining the same for appeals to increase DLA.

The Charity became grant holders for NHS England to 'Gear up' for Personal Health Budgets (PHB) and in 2015, became a mentoring organisation for round 2 grant holders. TVDNY has provided advocacy for

four people to achieve a PHB with another 2 two people engaging with the process. TVDNY has developed a new booklet with In-Control to provide better quality, local information.

As part of the PHB project, with a memorandum of understanding with Tees-wide Clinical Commissioning Group's, TVDNY has recruited and trained a Peer Supporter. A volunteer maintaining a PHB supports a person waiting to access the PHB process to translate technical terminology and guide on how to configure suitable outcomes.

Information and Signposting

Since 2011, TVDNY has lobbied for a neuro category on the Joint Strategic Needs Assessment (JSNA), lodging a report in 2012. Whilst the JSNA steering group believe issues may be resolved in other categories, there is no importance placed on fast track procedures, the needs of long term deterioration of conditions and wheelchair services cannot react to immediate need. Service users and carers need service providers to work together across Health and Social Care to provide a joined up, seamless journey post diagnosis of a neurological condition.

Whilst Local Authority targets are based on the number of DLA claimants, equity of access to information or peer support is obscured for those who cannot claim DLA or for those people at the start of their condition pathway and not regarded as having critical needs. Consistent, skilled support and information, particularly for rare conditions at this stage is vital to a person's ability to manage in the longer term.

Communication markers

TVDNY has hosted or taken part in 18 Carers Week events and 6 Brain Awareness week events to outline the Charity information and advocacy functions.

Annually, TVDNY has representation on 10 or more local or regional Forums and Networks adapting to the needs of service users and caregivers and the issues they raise.

In ten years, the Charity has been involved in 32 Consultations, 10 national surveys, 6 service evaluation panels, asked to speak at 12 events or answered requests for comments on strategic initiatives to keep 'neuro' on agendas and improve the profile of patient perspectives.

In 2014/15 TVDNY has had 3 articles published;

1. School of Health and Social Care Newsletter - Teesside University
2. Evening Gazette - promotion of 10th anniversary and the coffee morning
3. Community Placement Newsletter - Durham University - placement and 10th anniversary

The first 360° cycle-of-communication took place in March 2009 when Information distributed by TVDNY returned to TVDNY via the Neurosciences Network and Tees-wide Neuro Forum. The information reached a multi-agency audience of 62 people.

Stewart's Law hosted the first website for TVDNY. In 2008, a student on community placement created the name of the forming joint website with the Northern Neurological Alliance - Northern Areas Neurological Alliances, known as NANA. The website achieved 97,404 hits in 2009/10.

TVDNY initiated a partnership agreement with the Neurosciences Network and the North East Neurological Partnership - NENP - was created to improve equity of information for NHS and allied professionals and share good practice. The NENP site hosted the Evidence Portal for the Workforce Innovation Programme and created a link with the website Patient Opinion until the Network ceased.

TVDNY took the opportunity to develop a new website and www.na-tvdny.org.uk was created to improve access to information resources such as the Neuro Information Passport. In autumn 2015, a secure on-line forum is being created as an information exchange to strengthen access to other opportunities for support.

TVDNY receives information from or engages with 85 local, regional and national organisations to generate and sustain a flow of good information to improve service user and caregiver outcomes and promote personal experiences as drivers for change.

From an evaluation of TVDNY in March 2015 by service users and caregivers, 90% of respondents rated the Charity as 'Excellent' and 10% as 'Good'.

Service Success

In 2009, the single biggest barrier for people with neurological conditions was poor quality and inconsistent information. Coupled with regional inequalities of access and with a lack of support for caregivers, people felt labelled and marginalised by the needs of their condition.

Reported success factors for TVDNY now include;

- Explicit person centred approach
- Understanding and commitment to appropriate outcomes
- Trustworthy, flexible and reliable
- Extensive knowledge of neurological need in the wider community
- Influencing change

Customer satisfaction

- *"I did not know you existed until I saw the website, glad I made contact".*
- *"I was at my wits end until I met you. I was offered time and skill which helped me understand the situation I was in and what to do in the future. Thank you!"*
- *"It has been a long and traumatic time. Hopefully I can settle down now, once again many thanks. I would not have managed without you".*
- *"After I contacted TVDNY, I immediately felt a huge relief. I had someone who would listen to me, support me and most of all someone who was articulate and willing to get the CCG to act! My grandfather was able to continue to live at home, a war veteran who has seen some horrible things during the war and his wish has been to continue to live at home not to go into a care home. Not only has TVDNY helped my grandfather but it has also helped me! My physical and mental health was being adversely affected by the stress I was enduring. I actually ended up being admitted to hospital. Thanks to Jo's perseverance, expert knowledge and understanding we got there! Jo really has understood the difficulties I faced and her empathetic non-judgemental attitude really helped me get through this in one piece".*
- *"I wanted to thank you for your time and for your knowledge and experience. And most of all, thank you for taking the time to not only listen but to offer some constructive help. That has been so sadly lacking in the last two years".*
- *"What incredible work you have been doing over the years. I love your approach and the level of care you have given the work. Thanks so much for your support and insights".*
- *"You go the extra mile where most cannot be bothered and I could not be more grateful for your support".*
- *"The saying 'I know a man who can' - well you are that person, you help and know other people who can too. I had given up because services understand so little and I've learnt more from speaking to you than anyone else".*
- *"You always have your finger on the pulse and the bigger picture!"*

Neuro-Exchange Tees Valley

A new Information hub is being established with a Service Level Agreement (SLA) adopted between member organisations and Keiro Ltd, Gateway Centre, Middle Haven, Middlesbrough.

The Neuro-Exchange Tees Valley brings together representatives, staff or volunteers who work under the auspices of any organisation supporting a person living with or a person caring for someone with a neurological condition, injury or impairment.

With the aim of providing a collective commitment to resource a Neurological Information Hub, the Neuro-Exchange will deliver an Information and Signposting service to raise awareness of neurological conditions, the impact on individuals, their families and caregivers and inform or influence commissioners and service providers about neurological need.

- The Neuro-Exchange will open in July 2015.

The Future

The Charity has built a network for engagement to offer a consistent, informative service brokering a sharing and learning environment between people who use the services and the people who deliver them. The Charity believes in nurturing shared common values to guide multi-agency collaboration and deliver lasting improvements for service user and caregiver outcomes.

Looking ahead;

- TVDNY Vice-Chair chairs the Advisory Group for the 6-year MIND lottery funded Ageing Better Project in Middlesbrough
- TVDNY is represented on the VCS reference group to assist Middlesbrough Borough Council consider the implications of the Care Act (2014)
- TVDNY is represented on the Strategy Group held by Evolution Darlington to coordinate information and resources on Health and Social Care Initiatives

- TVDNY is represented on the Executive Board for Healthwatch Middlesbrough
- TVDNY to sustain commitment to NHS England and the PHB programme

It is critical to well-being that people living with or who care for someone with a neurological condition, injury or impairment can access right time and place information, equipment and skilled expertise to support choice for the next steps for a life-long condition.

A robust, community-based support framework is essential to access good information, peer support, advocacy and sometimes, just a listening ear. These are important factors to build resilience and problem-solving and encourage self-management and co-production of care pathways closer to home.

References

- 1 National Service Framework for Long Term Neurological Conditions - Department of Health - March 2005

- 2 European Neuropsychopharmacology Report - European Brain Council - Cost of Disorders of the Brain - October 2011

- 3 NAO - Services for people with neurological conditions - Department of Health - December 2011

- 4 House of Commons PAC - Review of services for people with Neurological Conditions - March 2012

- 5 Neurological Alliance - The Invisible Patients: Revealing the state of Neurology Services - January 2015

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