

# **‘Top Ten Tips for NHS Staff’**

and

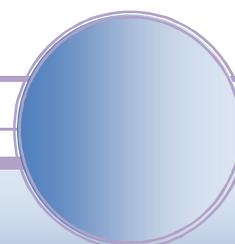
# **‘Practical Things that would make a difference’**

**Report and Summary  
from**

**‘Your opportunity to influence change’**

**Conference and Workshop  
organised by Carers Together and  
Hampshire Neurological Alliance**

Report issued August 2014



**Carers Network Event  
held on 13 November 2013**

**Organised by Carers Together and Hampshire Neurological Alliance**  
for carers and people with long term neurological conditions living in  
Hampshire, Isle of Wight, Portsmouth and Southampton

**Report prepared by Carers Together  
February 2014**

**Final Report issued  
August 2014**

**Grateful thanks go to:**

**The 140 participants who attended and made it a worthwhile event**

**The facilitators who gave their time to lead discussions and take notes**

**The excellent speakers:**

**Scott Durairaj Head of Patient Experience - NHS England**

**Lucy Sutton Associate Director NHS England (Wessex)**

**Gill Duncan Director of Adult Services Hampshire**

**Annette Scivier Carer, wife, mother and GP from the Isle of Wight**

***“No decision about me without me”***

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*‘Anyone with a disability, long term health condition or illness is a person first.*

*Planning and support for any person should be holistic and person-centred and mean a person’s needs are met as an individual and as someone with a disability, long term health condition or illness’*

*‘A carer is a person first. Planning and support for any carer should be holistic, person-centred and mean a carer’s needs are met as an individual and as a carer’*

## 'Your opportunity to influence change'

Network Day on 14 November 2013

### Summary

This report reflects the range of contributions made by participants during the Network Day. Participants in the workshops came from Hampshire, Portsmouth, Southampton and the Isle of Wight and brought a wide range of experience, personal expertise, skills and knowledge.

It is a record of patient/carer preferred choice and recommendations and, although mainly qualitative, it represents the experience and knowledge of people who use services. Their experiences are important and should be listened to, taken into account and not dismissed without consideration.

The day was attended by 140 people

- 112 carers and people with long term health conditions
- 28 professionals of whom 12 were also carers.

There were four presentations, two in the morning and two in the afternoon

Presentation 1 - NHS England - Focus on Patient Experience

Presentation 2 - Wessex Clinical Senate & Strategic Clinical networks - Changes to the NHS, how you can be involved and influence

Presentation 3 - Carer, wife, mother and GP - Finding a pathway through services on a journey with Huntington's

Presentation 4 - Adult Services in Hampshire - Integration - Putting people at the heart of health and social care

#### **Neurological Information Booklet**

There was an opportunity to hear about the new Neurological Information Booklet being developed by Hampshire Neurological Alliance and give feedback and comments.

At lunch time - there were good opportunities for networking.

There were two workshops

Workshop 1 in the morning

- What are the top 10 things NHS staff could do to improve the experience of people with long term neurological conditions?
- What are the top 10 things NHS staff could do to improve the experience of carers?

Workshop 2 in the afternoon

- *What practical things would make a difference for people with long term health conditions and their carers?*

#### **The Results**

The results are shown in 'Top Ten Tips for NHS Staff' and 'Practical things that would make a difference' for people with long term health conditions and their carers (page 17).

*'All people are service users'*

*Not just users of health and social  
care services, but a range of  
services in the community  
including:*

*police*

*ambulance*

*fire service*

*housing*

*leisure services*

*libraries*

*shops*

*transport*

*village / community halls*

*waste disposal*

*and many others.....*

## Background to the Network Day



Carers Network Meetings have been running each year since 1995 when carers in the area realised that they needed to be independent and proactive if they were to have any choice or control over their own lives.

It was also recognised that reports and consultations undertaken by statutory organisations (commissioners and providers) and voluntary and private sector organisations often reflect the result that they want to achieve rather than the reality of carers wishes, needs and experiences.

The Network Days are led and organised by carers. They provide an opportunity for carers in Hampshire, Portsmouth and Southampton to meet, share information and knowledge, discuss current issues important to them and take part in local consultations.

The organisation and management of health and social care services changes continually. This may be as a result of a change in government, new Acts of Parliament, different strategies, plans, procedures, practices, processes and protocols. Statutory Organisations may close down or develop, reorganise or entrench, separate or merge on a regular basis. The change can mean that the support carers need is often changed or stopped at the whim of national government proposals and/or local decisions by statutory bodies. Where does this leave the individual or carer?

The Carers Network includes carers from the three areas because at different intervals they have been managed separately, joined together, and then again managed separately. Services for carers have been dragged in different directions at different times depending on current government and local government trends, legislation or political direction. Add to this the vested interests of large providers - and carers find they are often offered what commissioners and providers want to provide rather than given real individual choice.

The twice yearly Carers Network Events are planned to reflect any current proposals and trends of the day, to keep carers up to date and to give them an opportunity to comment on proposals and influence the outcomes.

One of the main objectives of Network Days is to listen to carers, hear their views and provide a comfortable environment for them to relax, meet other carers, network together and share their experiences, skills and knowledge.

**In November 2013** it was agreed to work with the Hampshire Neurological Alliance to provide a joint network day for carers and people with long term neurological conditions in Hampshire, Portsmouth, Southampton and the Isle of Wight. It was felt that this different perspective was particularly relevant because of:

- the changes in the NHS from April 2013
- the greater emphasis on listening to patient experiences
- the move towards service integration and working around the needs of people, their carers and families
- the need to look at what information would make a difference.

### Background information references 2013

**Making integrated out-of-hospital care a reality** - This report from the NHS Confederation discusses the foundations for integrated care for adults, children and young people, with a focus on implementing out-of-hospital care, and connecting primary, community and social care. It highlights key evidence and draws on learning from partners across health and social care.

**General Practice and the Integration of Care: An RCGP Policy Report** - The Royal College of General Practitioners champions integration of care as crucial to patient-centred practice, seeking approaches that improve patient care and experience as well as being efficient and effective. Integration of care is about placing patients at the centre of the design and delivery of care. It leads to better outcomes for patients, safer services and improved patient experience, and can also act as an enabler of more cost effective care.

**Integrated Care: Our Shared Commitment** - This framework on integration, agreed by 12 national partners, sets out how local areas can use existing structures e.g. Health and Wellbeing Boards to bring together local authorities, NHS, public health, care and support providers, education, housing services and others to further the steps towards integration.

**Better Care Fund** - The Better Care Fund (previously referred to as the Integration Transformation Fund) was announced in June as part of the 2013 Spending Round. It provides an opportunity to transform local services so that people are provided with better integrated care and support. It encompasses a substantial level of funding to help local areas manage pressures and improve long term sustainability. The Fund will be an important enabler to take the integration agenda forward at scale and pace, acting as a significant catalyst for change. It provides an opportunity to improve the lives of some of the most vulnerable people in our society, giving them control, placing them at the centre of their own care and support, and, in doing so, providing them with a better service and better quality of life.

The Fund will support **the aim of providing people with the right care, in the right place, at the right time**, including a significant expansion of care in community settings. This will build on the work Clinical Commissioning Groups (CCGs) and councils are already doing, e.g. through Community Budgets, through work with the Public Service Transformation Network, and on understanding patient/service user experience.

#### **National Voices – A narrative for person centred coordinated care**

National Voices developed, with its members, a set of **principles for integrated care** which put patients and service users at the heart of care. The principles state that integrated care must:

- be organised around the needs of individuals (person-centred)
- focus always on the goal of benefiting service users
- be evaluated by its outcomes, especially those which service users themselves report
- include community and voluntary sector contributions
- be fully inclusive of all communities in the locality
- be designed together with the users of services and their carers
- deliver a new deal for people with long term conditions
- respond to carers as well as the people they are caring for
- be driven forwards by the commissioners
- be encouraged through incentives
- aim to achieve public and social value, not just to save money
- last over time and be allowed to experiment

**The Public Services (Social Value) Act 2012** The Public Services (Social Value) Act 2012 received Royal Assent on 8 March 2012. It was brought fully into force by commencement order on 31 January 2013. From that date the operative provisions of the Act will apply and commissioners / procurers must follow the Act and take it into account when considering procurements of certain types of services contracts and framework agreements. The Act requires commissioners to consider the economic, environmental and social benefits of their approaches to procurement before the process starts. They also have to consider whether they should consult on the issues.

**The White Paper - Caring for our future: reforming care and support - July 2012.** Its purpose was that the focus of care and support will be to promote people's independence, connections and wellbeing by enabling them to prevent and postpone the need for care and support. Also to transform people's experience of care and support, putting them in control and ensuring that services respond to what they want.

## Network Day – 14 November 2013

**The draft Care and Support bill published July 2012** (Now called the Care Bill) will be the most fundamental reform of social care law in over 60 years. Key messages:

- The new statute will be clearer, fairer, and built around the needs and goals of the people. It will empower people to take control over their care and support and to understand their entitlements.
- For the first time, the Bill gives a positive message about what care and support is for. The wellbeing principle and focus on individuals' needs and outcomes creates a defining purpose for care and support.
- It is an historic step forward in relation to carers, with new rights to public support, putting them on the same footing as the people they care for.

**Carers and Personalisation: improving outcomes** (published November 2010) was developed from information gathered through 3 national events held in 2009 & by the Department of Health Carers and Personalisation reference group. Its purpose was to provide clear guidance on how services / support to carers could better reflect the principles underpinning public services reform instigated by **Putting People First** (HM Government, 2007; reinforced by the government in its **Vision for Adult Social Care Capable Communities and Active Citizens** and its White Paper **Equity and Excellence: Liberating the NHS**. See: [www.gov.uk/government/publications/personalising-services-and-support-for-carers](http://www.gov.uk/government/publications/personalising-services-and-support-for-carers)

**Think Local Act Personal (TLAP)** The work instigated by Putting People First is now being taken forward by the **Think Local Act Personal Partnership**, and through initiatives such as the Personal Health Budgets Programme in the NHS and the Right to Control Trailblazers programme.

[www.thinklocalactpersonal.org.uk](http://www.thinklocalactpersonal.org.uk) [www.personalhealthbudgets.dh.gov.uk](http://www.personalhealthbudgets.dh.gov.uk)  
<http://odi.dwp.gov.uk/odi-projects/right-to-control-trailblazers.php>

**Making it Real: Marking Progress towards personalised, community-based support:** a publicly declared commitment to improving the way older and disabled adults experience care and support.

**Think Local Act Personal (TLAP) - Carers and Personalisation: emerging practice** is a series of web pages on the TLAP website which contain a large number of examples from around England (some used in Carers and Personalisation: improving outcomes): [www.thinklocalactpersonal.org.uk/Browse/Carer](http://www.thinklocalactpersonal.org.uk/Browse/Carer)

### **5 Key principles from Carers and Personalisation: improving outcomes**

- Recognise the expertise of, and work in genuine partnership with, carers at all levels of service design and delivery
- Enable carers to design and direct their own support, have access to direct payments and be engaged in the support plan of the person they care for and their assessment where appropriate
- Wherever possible, establish whole family approaches that ensure there is integrated support planning that benefits everyone involved
- Fully recognise the differing social and emotional impacts of providing support to another person and that these do not necessarily correlate to the number of hours spent, or the tasks undertaken, in providing care
- Develop a range of support options/opportunities to match the diverse needs of carers (including those who do not choose to identify themselves as carers) and outcomes they wish to achieve in their lives

**Common Assessment Framework for Adults (CAFA) 2009 – 2012** The primary purpose of CAFA was to establish a common process for collecting, disseminating, recording and sharing information between local individuals and professionals. **Challenging** - because the partners (health, social care and voluntary organisations, service users and carers) needed to work together to achieve the same end. It was not easy, simple or straightforward and everyone did not all suddenly agree on the plan, process and the actual task. **Different** - because, during the course of the project, it became clear that everyone was working from a totally different viewpoint, needed to change individual and corporate views and to see things from the service user and carer perspective - person-centred.

**Say it Once** - the partnership has developed a website where documents produced during the programme to support individuals to be independent and take actions for themselves will be available after the project ends. These include a Personal Profile, Personal Plan and Advance Care Plan. See: [www.sayitonce.info](http://www.sayitonce.info)

**The Power of Information - DH Information Strategy** - The Strategy set a 10-year vision - quality information for quality care - and some early actions. It sets a framework for local innovation, not a national directive. Getting the right information to the right people at the right time (in a form they can understand, engage with and contribute to) will help individuals take control of their own care, improve self-management, shared decision making, and give more informed choices. There will be detailed implementation plans from DH, NHS England and Public Health England.

**Quote from a service user:**

As service users and carers it is easy to spot three kinds of professional from all parts of health and social care including commissioners and providers:

- those who care but think they know best
- those who listen but only enact what they agree with and
- those who engage with service users on an equal footing, using expertise on both sides to co-design services and achieve better outcomes.

## Organisation of the Network Day

In November 2013 the day was organised into three sessions - morning, lunchtime and afternoon and the main areas for discussion were:

- **How to improve the NHS experience of people with long term neurological conditions?**
- **How to improve the NHS experience of carers?**
- **What practical things would make a difference for people with long term health conditions and their carers?**

### Morning Session

In the morning there were two presentations and a single theme workshop.

#### Presentations

1. **“What are we at the NHS England Patient Experience team going to do? How are we going to address service quality and how are we going to make patient experience count?”**  
*Scott Durairaj, Head of Patient Experience - Mental Health and Learning Disability Nursing Directorate NHS England*
2. **“Changes to the NHS, how you can be involved and have influence”**  
*Lucy Sutton, Associate Director for Clinical Senate and Strategic Network NHS England (Wessex)*

#### Workshop 1

- What are the top 10 things NHS staff could do to improve the experience of people with long term neurological conditions?
- What are the top 10 things NHS staff could do to improve the experience of carers?

### Lunch Time Networking

There was an opportunity for informal networking during the lunch hour.

### Afternoon Session

In the afternoon there were two presentations and a single theme workshop.

#### Presentations

- 3 **“Finding a pathway through services - on a journey with Huntington’s Disease”** *Annette Scivier - carer, wife, mother and GP*
- 4 **“Integration - putting people at the heart of health and social care”**  
*Gill Duncan Director of Adult Services Hampshire*

#### Workshop 2

- *What practical things would make a difference for people with long term health conditions and their carers?*

## Presentations

### 1. Presentation 1 - NHS England - Focus on Patient Experience

Introduction to the National Support team, their aspirations for Patient Experience, their ambitions for improvement:

- How they can make patient experience count and how the ambitions will make a difference for patients:
- How they are going to address service quality and make plans to make improvements

#### **NHS England Mission:**

The NHS must be more responsive to the needs and wishes of the public, all of whom will use its services at some point in their lives.

Ambitions and priorities:

- Work in collaboration to identify key issues and effective solutions
- Lead debates
- Set a level of ambition for the quality of care for patients/carers
- Develop a breadth of subject matter expertise
- Provide a framework to ensure consistency in improving patient experience
- Support provision of external support to commissioners/NHS providers when required
- Support the Call to Action and a longer term strategy for the NHS, such as ensuring the experience of patients / carers informs the narrative on what patients/carers want from future services and contributing to and/or leading debate on key issues
- Ensure focus on pockets of poor quality care, whether services or underserved populations - monitoring progress

### 2. Presentation 2 - Wessex Clinical Senate & Strategic Clinical Networks

#### **Changes to the NHS, how you can be involved and influence**

Background to the NHS reorganisation

- NHS England is the 'new' body overseeing the commissioning of health care in England (£96bn budget). It has:
  - 4 Regional Teams
  - 27 Area Teams
  - 12 Clinical Senates and Strategic Clinical Networks
  - NHS England (Wessex)
  - Population 2.8 million
  - Third most populous area of England
  - 5% of NHS England budget (4.8bn)

## Network Day – 14 November 2013

- 9 Clinical Commissioning Groups (CCGs).
- 7 Local Authorities
- 17 District Councils
- 9 hospitals (6 Foundation Trusts & 3 NHS Trusts)
- 324 GP Practices

- Clinical Senate

The new commissioning system is designed to give clinicians the best opportunities to plan and pay for the most appropriate and effective health services for services for their local populations.

This local focus, supported by an NHS structure that has clinicians at every level, aims to improve the health outcomes that matter most to patients. Clinical Senates play a unique role in the commissioning system by providing strategic clinical advice and leadership across a broad geographical area to CCGs, HWBs and the NHS Commissioning Board.

Clinical Senates are not focused on a particular condition - they take a broader, strategic view on the totality of healthcare within a particular geographical area, e.g. providing a strategic overview of major service change.

They are non-statutory advisory bodies with no executive authority or legal obligations and therefore need to work collaboratively with commissioning organisations.

The type of strategic advice and leadership Clinical Senates are able to provide includes:

- engaging with statutory commissioners, such as CCGs and the NHS CB to identify aspects of health care where there is potential to improve outcomes/value.
- providing advice about the areas for inquiry or collaboration, and the areas for further analysis of current evidence and practice
- promoting and supporting the sharing of innovation and good ideas
- mediating for their population about the implementation of best practice, what is acceptable variation and the potential for improvement with AHSNs for a specific part of the country. Based on evidence and clinical expertise, they will be able to assist in providing the public profile on service changes
- providing clinical leadership and credibility. Understanding the reasons why clinical services are achieving current clinical outcomes and advising when there is potential for improvement through significant reconfiguration of services
- taking a proactive role in promoting and overseeing major service change, for example advising on the complex and challenging issues that may arise from service reconfiguration within their areas
- linking clinical expertise with local knowledge such as advising on clinical pathways when there is lack of consensus in the local health system
- engaging with clinical networks within a geographical area.

## Network Day – 14 November 2013

- Strategic Clinical Networks
  - Cancer
  - Cardiovascular (incorporating cardiac, stroke, diabetes & renal conditions)
  - Maternity & Children's Services
  - Mental health, Dementia & Neurological conditions
- Aim to
  - support large scale change across complex pathways of care, where co-ordinated, combined improvement approaches are required to overcome particular healthcare challenges.
  - work with patients, carers and members of the public to plan health care services that benefit our local population
- Domains
  - Domain 1: Preventing people from dying prematurely
  - Domain 2: Enhancing quality of life for people with long term conditions
  - Domain 3: Helping people to recover from episodes of ill health or following injury
  - Domain 4: Ensuring that people have a positive experience of care
  - Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm
- How to get involved
  - They have a vision to work with users of health care services (patients, carers and members of the public) to build a 'People Bank'.

Through recruiting a wide range of individuals with differing knowledge and experience of health care, they aim to work together to provide services that meet the needs of our local population.

Contact NHS Wessex to be involved

### 3. Presentation 3 - Carer, wife, mother and GP

#### Finding a pathway through services on a journey with Huntington's

Challenges faced by every carer in finding what is available "out there" and that Charities are just as important as professionals, and in medium rare or rare conditions carers and charities are much better equipped.

It illustrates the challenges faced by those of working age, describes a journey over many years, before and after diagnosis and the benefits of family conferences, branch meetings and peer support.

The reliance on professionals at crucial stages & the real need for partnership working.

A question posed by patients and carers at a focus group to service designers was "would you cope if you had to use your own service?"

The need to change systems and culture to be more person focused.

#### 4. Presentation 4 - Adult Services in Hampshire

##### Integration - Putting people at the heart of health and social care

Integrated working with health and community

- Pooled fund to be deployed locally on health and social care - £3.8bn nationally
- Joint plans to be agreed by Health and Wellbeing Boards and signed off by CCGs and Councils
- Plans and assurance must satisfy nationally prescribed conditions
- For Hampshire the Fund by 2015 is approximately £74.5m (not new money)

Nationally Prescribed Conditions

- Protection for social care services (rather than spending) with the definition determined locally
- Seven day working in social care to support discharge and prevent unnecessary admissions
- Better data sharing between health and social care, based on the NHS number
- Plans and targets for reducing A&E attendances and emergency admissions
- Risk sharing principles and contingency plans if targets are not met
- Agreement on consequential impacts of changes in the acute sector

Hampshire Approach

- The partners
- Adult Services
- Clinical Commissioning Groups
- Southern Health Foundation Trust
- Families and carers
- A vision statement for integration:
- Improve people's lives - through a strong focus on personalisation, community participation, choice and control and diversity and equality issues
- Quality of life, independence, self-management and control for older people, adults with long term conditions and carers
- Improve service system efficiency for service users and carers
- North Hampshire CCG - six integrated care teams:
- Focus on older people with complex needs
- Social workers linked to 4 ICTs, so far, with links back into own team
- Links to Hants Direct and Community Independence Teams

Integrated care and personalised outcomes – Quality outcomes in all care settings

- Integrated care - supporting people to remain independent in their own homes
- Housing care and support - recognising the key role of extra care and accessible housing related support
- Integrated care in a care home setting - the role of the family, care home staff and primary, community and social care

## Priorities identified on the day

### Top Ten Tips and Practical Solutions

Some of the Top Ten Tips were anticipated and similar recommendations can be found in many reports and discussions produced over a number of years and some were identified by several tables.

Most discussions and reports concentrate on formal situations and activities recognised as being part of NHS or Social Care. This includes: assessments, services, service users, patients and carers, self-management, direct payments, commissioners, providers, therapies, medication, etc. The list is long and well known to anyone who works in health and social care and /or has dealings with any health and social care professional.

So some of the Tips and Solutions, although important, brought few surprises

There was general consensus on the priority issue identified by participants on the day and people who have given feedback subsequently. This includes people with long term health conditions, carers, NHS and Social Care professionals .

### Priority Issue

The main priority identified was to look at a simple solution to a common problem:

**‘Why do so many teeth, glasses and hearing aids go missing in hospitals, hospices and residential / nursing homes?’**

**How can the cost to the NHS be reduced and the loss of care, lack of dignity and distress caused to patients be improved?’**

The issue that is raised continuously in everyday life is the apparent inability of hospitals, hospices and residential homes to look after people’s personal possessions in particular teeth, spectacles and hearing aids.

People constantly report and talk about the loss of personal possessions in any institution but in particular in hospitals, hospices and residential homes. This can be any personal possession and at any time but is often and usually when people are being moved from one ward to another at all times of the night and day.

Everyone knows about the problems e.g.

- people are moved from A&E to a ward and their possessions ‘disappear en-route’ (on or along the way) and are never found.
- people die without dignity and in distress because their teeth, glasses and/or hearing aids have been ‘lost’ in the hospital and are never found.
- sick people are in greater distress and take longer to recover or improve because they have lost their clothes, their teeth or glasses and as result they lose their sense of well-being, self-respect and dignity

How do the things disappear? Why do they disappear? What happens to them? Why isn’t there a lost property centre in each institution where any items found can go? If there is a centre, how can things such as teeth be identified and claimed?

It is made worse by the lack of concern of staff and lack of action by the institutions to find, restore or replace the items. Complicated claim forms are produced and need to be completed but they seldom bring any results. People leaving hospital often need to try to replace the items and this only after a delay, reassessment and often at a cost to the NHS.

**There could be a simple solution.**

Items such as false teeth, glasses, hearing aids could be marked at manufacture / issue with the identity of the person who owns or uses them.

This needs to be investigated and the best way of doing it identified.

It could be achieved, for example, by a competition to find a solution using modern technical methods but it needs a national commitment to start any process as well as national and local commitment to implement.

However it is achieved, the outcome would have the effect of reducing loss of dignity and distress caused to people by being unable to eat, see or hear.

It would improve wellbeing and outcomes for patients and their families and friends.

It would also save a great deal of time and resources for professionals and could make huge savings to the NHS Budget.

This is a priority to be addressed especially at a time when resources are becoming scarcer and savings are becoming essential.

The positive results would be that many patients recover more quickly, leave hospital sooner and have a greater sense of dignity and self-respect.

**Action and Improvements suggested on the day are:**

- **The Top 10 things that NHS staff could do to improve the experiences of people with long term neurological conditions**
- **The Top 10 things that NHS staff could do to improve the experiences of carers**
- **The Practical things that would make a difference for people with long term health conditions and their carers?**

**Top 10 things that NHS staff could do to improve the experience of people with long term neurological conditions?**

1	<p><b>Research into how to identify people's property and equipment</b></p> <p>To find an effective low cost way of marking all false teeth and glasses with the identity of the owner</p> <ul style="list-style-type: none"> <li>• This will:             <ul style="list-style-type: none"> <li>• help prevent loss</li> <li>• help to find the owner</li> <li>• give back dignity and respect to patients in Hospitals, Hospices and Homes</li> <li>• reduce NHS costs considerably</li> <li>• provide a far better outcome for patients &amp; carers</li> </ul> </li> <li>• Other equipment/aids issued or loaned to people should be clearly marked with the name, contact details of the place to where they should be returned so there is more chance of equipment being re-cycled - less loss, more returns.</li> </ul>
2	<p><b>Personal Information</b></p> <ul style="list-style-type: none"> <li>• Support people to make their own personal plans for action, care, circle of support, end of life care including advance care plans etc. that can be used when needed to 'feed' health or social care plans</li> <li>• Patient owned health records would mean the patient will not have to repeat themselves over &amp; over because of information governance/confidentiality issues that are misquoted/misunderstood by many.</li> </ul>
3	<p><b>Patient choice and control</b></p> <ul style="list-style-type: none"> <li>• Provide/enable independent advocates for all people, so they can make informed choices with support</li> <li>• Peer support is vital for people with long term conditions and their carers</li> <li>• Patient centred care not target centred care is vital</li> <li>• Listen to the patient - most want to work with their carer/family - health and social care professionals must assume the positive relationship first and only when there is clear evidence to the contrary - assume they have any relationship problems</li> </ul>
4	<p><b>Communication by health and social care staff</b></p> <ul style="list-style-type: none"> <li>• Health and social care staff need to:             <ul style="list-style-type: none"> <li>• Talk to patients and clients as people with individual needs and rights</li> <li>• Remember people with any condition are people first - they do not want to be identified or labelled as a condition (they may have several) but need to be treated and supported holistically as a person with a life</li> <li>• Reduce jargon and speak plain English</li> </ul> </li> <li>• NHS Personnel/Services need to communicate with each other effectively and offer a seamless service round the individual not expect people to keep repeating themselves.</li> <li>• Social care staff need to communicate with each other more effectively - make it easy for people to contact the staff members who are supposed to be working with them</li> <li>• NHS and Social Care need to work together more effectively and ensure the person has a one stop access to someone who can coordinate the services - or be enabled to do it themselves if appropriate.</li> </ul>
5	<p><b>Care Coordination</b></p> <ul style="list-style-type: none"> <li>• An appropriate care coordinator could be the individual themselves and this should be assessed together and, if appropriate, respected by all</li> <li>• Sometime a professional may be better - this should be assessed/agreed not imposed</li> </ul>

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6	<p><b>Respect and information</b></p> <p>NHS and Social Care Staff need:</p> <ul style="list-style-type: none"> <li>• to acknowledge and respect the experience and knowledge of people with long term conditions</li> <li>• to work with people to help them make informed choices - not tell them what to do</li> <li>• to give all people information, choice and control about their diagnosis, treatment and support</li> <li>• training from people with long term conditions and carers (the experts)</li> </ul> <p>People need:</p> <ul style="list-style-type: none"> <li>• an early diagnosis with good information as and when needed to understand their condition, their medication, the support needed</li> </ul>
7	<p><b>Age Discrimination</b></p> <ul style="list-style-type: none"> <li>• Ensure people get the right outcomes whether they are children, young people, adults or older people</li> <li>• Do not discriminate because of age</li> </ul>
8	<p><b>Support Therapies</b></p> <p>Access to OT, Physiotherapy &amp; other complementary services for maintenance as well as improvement of conditions - not just rehabilitation.</p>
9	<p><b>Medication</b></p> <p>General nurses in hospitals should be trained:</p> <ul style="list-style-type: none"> <li>• in the importance of giving medication on time for some conditions e.g. Parkinson's</li> <li>• in the importance of supporting people to manage their own medication in hospital</li> </ul>
10	<p><b>Transition</b></p> <p>All professionals should:</p> <ul style="list-style-type: none"> <li>• Ensure children and young people are not suddenly changed from Children's Services to Adult Services - without good effective support throughout the transition period</li> <li>• Remember better outcomes are achieved by recognising that people with long term conditions are the experts and should be encouraged and supported to self-manage their lives and services</li> <li>• Remember better outcomes are achieved by recognising the relationship between the person and their carers and working with them both whenever possible to achieve the best result</li> <li>• Remember better outcomes are often achieved by/with independent voluntary sector advocates</li> </ul>

<b>Top 10 things that NHS staff could do to improve the experience of carers?</b>	
1	<p><b>Carers Advocacy</b></p> <ul style="list-style-type: none"> <li>• Acknowledge that the carer (who may not be related) is usually the best advocate and knows the person best</li> <li>• Independent peer advocacy should be available for carers</li> </ul>
2	<p><b>Carers</b> are an asset - but must not be abused. They need to be valued and respected for their expertise and supported financially, physically and emotionally to maintain their health and wellbeing.</p>
3	<p><b>Carers Assessments</b></p> <ul style="list-style-type: none"> <li>• Carers should be offered an assessment of their needs automatically but it must be agreed and recorded separately from the person's assessment.</li> <li>• Self-assessment - carers could and should be enabled to do a self-assessment.</li> <li>• Why not use independent carer led organisations i.e. peer advocacy to support and achieve effective carers assessments rather than health or social care staff?</li> <li>• Absolutely need to focus on outcomes rather than process</li> </ul>
4	<p><b>Carers Rights</b></p> <ul style="list-style-type: none"> <li>• Professionals need to respect the rights/wishes of the carer as well as the person</li> <li>• Professionals need to talk to carers as people with individual needs and rights</li> <li>• Carers may also have health conditions and/or other personal needs and should be treated as an individual in a holistic way</li> </ul> <p>A carer has the rights to refuse to:</p> <ul style="list-style-type: none"> <li>• Be expected to be a carer</li> <li>• Accept the responsibility of being a carer</li> <li>• Undertake certain aspects of care delivery/support</li> </ul>
5	<p><b>Carers Voice</b></p> <ul style="list-style-type: none"> <li>• Listen to carers</li> <li>• Ensure the carers voice is heard at <u>EVERY</u> stage of their loved ones journey through the NHS Pathway – from A &amp; E through to Out Patients, Community and Social Care.</li> <li>• Encourage wider carers voice, networks and develop skills and knowledge</li> </ul>
6	<p><b>Communication</b></p> <ul style="list-style-type: none"> <li>• Nurses should include carers when dealing with patients in hospital and ensure three way communication is the norm not the exception</li> <li>• All professionals should: <ul style="list-style-type: none"> <li>• communicate with carers</li> <li>• treat them with respect</li> <li>• give them relevant information about the diagnosis of the person they care about</li> <li>• inform them about support available to help them/give them choice and control</li> </ul> </li> </ul>
7	<p><b>Confidentiality</b></p> <ul style="list-style-type: none"> <li>• Overcome the barrier of confidentiality</li> <li>• Information governance should be used to enable not block information sharing</li> <li>• Realistic approach to confidentiality which should involve a main carer having ALL rights to information. This should be arranged and agreed early in the patient journey</li> </ul>

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8	<b>Continuity</b> <ul style="list-style-type: none"><li>• Social work support stops when person in hospital - if it continued - it could relieve the burden on the carers and ensure better care in hospitals</li><li>• It would also improve the pathway to early discharge</li></ul>
9	<b>Professionals should identify, include and support carers:</b> <ul style="list-style-type: none"><li>• Identify the carers when someone is being diagnosed</li><li>• Provide basic information so they can support the patient and find out what they need to know when they need to know it.</li><li>• Include the carers at all points of a life limiting illness</li><li>• Include carers at all points of organisation and planning especially at end of life care</li><li>• Make carers feel welcome, included and comfortable when accompanying a person in hospital or to other health and social care appointments. Carers are often made to feel unnecessary, unwelcome and excluded even if the person wants them there</li><li>• Work with carers to find the best way to support them with information and breaks</li><li>• Offer carers a range of training and support that they can select as needed</li><li>• Give holistic family support to ensure comprehensive services</li><li>• Flexible appointments for carers should be always available</li></ul>
10	<b>Transition</b> <ul style="list-style-type: none"><li>• Ensure Young Carers and Parent Carers have effective support during transition so they are not suddenly changed from Children's Services to Adult Services without information and support</li><li>• Use good independent training facilities and facilitators - peer led training, awareness and support is particularly effective</li></ul>

<b>Practical Things that would make a difference for people with long term health conditions and their carers?</b>	
1	<p><b>Access to 7 day a week services is needed</b></p> <ul style="list-style-type: none"> <li>• Doesn't have to be everything exactly the same - but must ensure it meets real needs</li> <li>• Must be fairly local - but can be single point of access for multiple needs out of hours</li> </ul>
2	<p><b>Accessible information</b></p> <ul style="list-style-type: none"> <li>• Shared with different professionals/team by patients, service users and carers</li> <li>• Electronic so information can be shared as needed e.g. A&amp;E and neuro information.</li> <li>• Use Hampshire Health Record more effectively.</li> </ul> <p>Use the wealth of information and resources 'out there'</p>
3	<p><b>Do not re-invent the wheel</b></p> <ul style="list-style-type: none"> <li>• Every time there is a reorganisation professionals start afresh and valuable research, knowledge and action is lost</li> <li>• Professionals - please do not reinvent the wheel - find out what is there, what has already been developed and use it - wisely</li> </ul>
4	<p><b>Advocacy</b></p> <ul style="list-style-type: none"> <li>• Provision of peer advocacy not just a reliance on health and social care practitioners</li> <li>• Independent advocates of person's choice</li> <li>• Effective channels to communicate carer concerns when cared for person is in residential/nursing home</li> </ul>
5	<p><b>Appointments</b></p> <ul style="list-style-type: none"> <li>• Ensure appointments for GPs and outpatient appointments are flexible, accessible and bookable directly with choice of time and day.</li> <li>• It will: <ul style="list-style-type: none"> <li>• reduce no-shows/non-attendance</li> <li>• give better outcomes for people, carers and professionals</li> <li>• reduce waste/costs</li> </ul> </li> </ul>
6	<p><b>Assessments - information and action</b></p> <ul style="list-style-type: none"> <li>• Make forms and information about assessments easily available to patients and carers on 'Say it Once' where people can access them before doing or having an assessment with health or social care personnel</li> <li>• An assessment is not a test requiring one person to fill in the form and the other to provide the answers. It should be joint approach to finding out what is needed, what is available and how the best outcome can be achieved</li> <li>• Making the forms and guidelines available reduces time at assessment and increases opportunities for better outcomes</li> <li>• Assessment of whole family is needed not just the individual</li> <li>• Include all needs including domestic tasks, e.g. garden, housework, light bulbs.</li> </ul>
7	<p><b>Continuing Health Care</b> must be:</p> <ul style="list-style-type: none"> <li>• A clear and transparent process</li> <li>• Accessible and understandable</li> <li>• Accurate</li> <li>• Dealt with in a timely and empathetic fashion - Not delayed by red tape</li> </ul>

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8	<p><b>End of Life needs:</b></p> <ul style="list-style-type: none"> <li>• Good preparation and planning</li> <li>• Good local, independent carer-led support to deal with preparation and planning for living a positively between diagnosis and reaching the last few days and hours of life</li> <li>• Plan early and prepare effectively in partnership</li> <li>• Realistic, flexible and empathetic arrangements in the last few days/hours of life</li> </ul>
9	<p><b>Culture in Health and Care</b></p> <ul style="list-style-type: none"> <li>• Change the culture in health and social care so that co-design becomes the only way forward</li> <li>• Train staff to listen and respect patient/carer views</li> <li>• Dealing with Adult and Children's Services often feels like a battle and is extremely stressful. The carer ends up suffering and then becomes in need of services as a patient themselves</li> <li>• Every statutory organisation wants <u>to lead and be in charge</u> - so nothing really gets joined together - <u>lots of rhetoric, little positive action</u></li> </ul> <p>Why not put patients and carers in charge and listen to them?</p>
10	<p><b>Joined up services</b></p> <ul style="list-style-type: none"> <li>• Professionals must communicate better with each other and with us.</li> <li>• Poor communication between different organisations holds back the quality and speed of support and services.</li> <li>• Poor communication between organisations and carers holds back the quality and speed of support and services.</li> <li>• Dealing with different organisations, different professionals and different processes and protocols often feels like a battle.</li> </ul> <p><b>We need flexibility, swift reliable responses, individual support, good services and communication</b></p> <p><b>We get processes, procedures, protocols, delays, lack of cohesion and silence</b></p>
11	<p><b>Research</b></p> <ul style="list-style-type: none"> <li>• More medication research – involving patients and carers</li> <li>• More condition research - involving patients and carers</li> <li>• More patient and carer-led research to find out what people really want and need and how they would like it provided</li> </ul>
12	<p><b>Openness and transparency</b></p> <ul style="list-style-type: none"> <li>• Patients/carers should always receive copies of their medical and social care letters and reports - this should be the norm not the exception</li> </ul>
13	<p><b>Pathways</b></p> <ul style="list-style-type: none"> <li>• More action - fewer pathways</li> <li>• More services - fewer 'care' plans - 1 per individual not one per organisation / service</li> <li>• More choice - fewer restrictions and control</li> <li>• More support - fewer protocols</li> <li>• More flexibility - less rigidity</li> <li>• More respect - less talk of compliance</li> <li>• More dignity - less corporate attitudes</li> </ul>

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14	<p><b>Personalisation and Procurement</b></p> <ul style="list-style-type: none"> <li>• Choice and control means rethinking commissioning and procurement - so that people have a greater choice of the organisations, people and services they use and are not constrained to one contracted organisation</li> <li>• Developing the Market Place does not mean procuring one organisation to provide what they want to provide and commissioners think is needed - it means diversity, choice, small and simple as well as large and complex</li> <li>• Diversity of supply costs less to procure, run and manage and gives better choice and control to people</li> </ul>
15	<p><b>Person-centred coordinated care</b></p> <ul style="list-style-type: none"> <li>• Talk Person Centred Coordinated care not just Integration of health and social care</li> <li>• Personal care packages - practical, responsive and tailored to individual needs and holistic - not just health and social care</li> <li>• Care Packages should be agreed with the person and their carers - not provided to them by a lot of different organisations piecemeal</li> <li>• Personal Budgets/Direct Payments</li> <li>• Need wider choices</li> <li>• Direct payment to give a choice of person (consistent)</li> </ul>
16	<p><b>Prevention and early intervention</b></p> <ul style="list-style-type: none"> <li>• Look at early action to ensure self-development</li> <li>• Help people to find local solutions early</li> <li>• Help people to be independent of social care for longer</li> <li>• Use the voluntary sector and peer support to get a better outcome and reduce health and social care need</li> <li>• Encourage people to do things themselves and to build a personal circle of support</li> </ul>
17	<p><b>Resources</b></p> <ul style="list-style-type: none"> <li>• Stop money being wasted by groups and individual professionals, who neither have experience, expertise or “common sense” to solve problems</li> <li>• Ensure real consultation at all levels with patients, service users and carers.</li> </ul>
18	<p><b>Quality for the Individual</b></p> <ul style="list-style-type: none"> <li>• More emphasis on individual quality of life, less use of ‘equality’ to prevent innovation, choice and excellence</li> </ul>
19	<p><b>Short breaks</b></p> <ul style="list-style-type: none"> <li>• Imaginative</li> <li>• Innovative</li> <li>• Flexible</li> <li>• Non-medical</li> <li>• Non-registered</li> <li>• In local communities</li> <li>• Using holistic needs and allow for a range of respite from having a bath in peace to having a weekend away</li> </ul>
20	<p><b>Transport</b></p> <ul style="list-style-type: none"> <li>• More transport for social needs</li> <li>• Recruit local voluntary drivers</li> <li>• Provide small amounts of funding to help develop local social transport</li> </ul>

## Conclusion

There were a great number of ideas and suggestions made by people with long term neurological conditions and carers on the day and also in feedback and comments afterwards. They cannot all be included in this report but verbatim comments from each table can be made available on request and have been put on the website with this report.

The workshops were designed to hear the views of experts by experience and give them a voice. All these views have been recorded to support the proposed actions and activity.

The main issues identified from all the recorded notes have been collated into the 'Top Ten Tips' and 'Practical Solutions'. Participants at different tables raised a number of similar issues, concerns and recommendations. This reflected the importance of listening to individuals who use services, understanding the needs they identify and acting positively to address the apparently small issues that have a big effect e.g. loss of people's possessions with the ensuing loss of wellbeing, dignity and respect and the high cost to the NHS in both time, staff and resources. Everyone has experienced this or knows of someone who has.

The report is based on the views expressed by experts-by-experience and promotes further action to implement issues important to carers and people with long term neurological conditions.

Ten Top Tips and Practical Action Points were identified for action.

It is anticipated these will help in the development of national and local action to respond to the many issues raised in the workshops.

It was incredibly difficult to hone down all the ideas and recommendations to 'Ten Top Tips' from the many suggestions received on the day. Feedback received following the day has been incorporated, as well as the input from people, who couldn't attend but who took the opportunity to comment after the event and before this report was completed and issued.

### Action Needed

It now needs a commitment from NHS England and local health/social care professionals to consider the points raised, the solutions suggested and to ensure action is implemented appropriately to achieve an effective outcome.

Any action needs to be led and shaped by people with long term neurological conditions and carers.

This will ensure that implementation will follow the principles of co-design, coproduction and personalisation.

“Go to the people.  
Live among them.  
Learn from them  
Start with what they have.  
Build with them.  
And when the deed is done, the mission accomplished.  
Of the best leadership the people will say “We have done it ourselves.”

Lao Tzu

This statement appeared in the front of a Department of Health document  
'In the Public Interest - Developing a Strategy for Public Participation in the NHS'  
dated 1 January 1998.

Copies of this report and other papers can be found on the websites of Carers Together and Hampshire Neurological Alliance

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