**Hampshire Neurological Alliance Study Day**

in collaboration with Hampshire County Council

Monday 11th July 2016

Kings Community Church, Hedge End, SO30 4BZ

**Report and Feedback from the day**

The day was well received and enjoyed by all.

The speakers were inspiring – each different with a different personal story – each raising different key issues.

Parkinson’s UK - a personal journey Fiona Wheeler

Stroke Survival - a personal experience Karen Pritchard

Serious Head Injury - a personal experience Joy Cleightonhills

Information tables were well presented and the information sharing and networking were a strong feature of the day

Personal Planning & Say it Once were introduced to start the process of encouraging individuals to prepare, discuss and plan their own lives, starting difficult conversations with those closet to them before they need concentrated social or health care

Table discussions raised a buzz around the room and facilitators were amazing in capturing main issues

Dates for your diary - Next events 2nd November 2016 and 2nd February 2017

**Feedback on the day**

**Comments & Ideas from individual participants during the day**

* “Interactive days rather than being talked at” Work well and we learn
* Educating the people around the person who has been diagnosed with……
* The values of the service they can offer:
  + Art Therapist
  + Dance Therapist
  + Music Therapist
* Multi-disciplinary working. Improving care & support
  + Communication – how to make it happen.
* Education!!! Education!!! Education!!!
* Some people with a neuro condition want to know about what is likely to happen in the future (even if it is not nice).
* It would be better for persons living in care homes if disciplines like hospital OT & physiotherapies, SCI etc, could be routinely available without the care homes paying for it. Meaning if people are in hospital these therapies are available for “free” but if people are in care homes, this option is not readily available. I would like to see this campaigned for.
* Encourage people to become an expert in their condition.
* It would be better for patients/service users if they and charities and trusts could directly refer into hospital based services without the gatekeepers hoops which currently exist. I would like to see this campaigned for.
* Very inspiring and thought provoking to listen to first hand experiences
* Personal and family impact. Need for information and compassion for families
* From Headway – Hidden Disability challenges because people don’t look unwell and others don’t understand.
* Who is in the audience? What are their skills?
  + Social Worker, Care Managers = 5
  + Care worker = 1 or 2
  + Physio = 2
  + Vol orgs = about 6 or 7
  + OTs = about 9
  + Training = 1 or 2
  + Carers = 6 (Maybe others roles)
* Awareness!!! Awareness!!! Awareness!!!
* Get quality long-term support for the whole “family”

**Table Discussions around three questions**

* **What is working well for people with neurological conditions/carers/people working with them?**
* **What is not working well?**
  + **What will make a difference?**

**Sheets 4 & 5**

1. What is working well?

* Care is person-centred x 2
* Multi-prof meetings, e.g. in GP re GSF
* Networking events and social media
* Hospices take different cases, not just cancer
* Increasing understanding of meaningful activity for people with cognitive/physical conditions

2. What is not working well?

* Expectation of prof/stat services
* Sharing info, lack of joint working
* Geographical gaps
* Lack of awareness = people don’t access all benefits
* Limited access to care for cognitive impairment due to understanding
* Info not shared e.g. hospital & care homes (inc due to ESL)

3. What will make a difference?

* Upskill staff knowledge
* Joint health – voluntary – statutory
* Shared records system (universal)
* Help people in registered services access care/info
* Raise money to raise partnership working and focus on well-being.
* Communication to be effective and appropriate for the audience/people
* Wifi in care homes – for activity and skype (esp for younger people)

**Sheets 6, 7 & 8**

1. What is working well?

* Understanding of importance of meaningful activity. Mentally and physically. Previously viewed as a bolt-on
* Allowing people responsibility to do things. To empower staff. Meeting targets, etc. (Routine of role can limit listening/person centred approach)
* More networking opportunities now – still need to be more.
* Using networks – Southampton Voluntary Services, for example.
* CQC – using quality of life measures in their assessments (Rather than just quality of care).
* Care homes can embrace CQC – use it as an opportunity to share ideas.

2. What is not working well?

* People talk about person-centred approach – but not following through with it
* Risk Assessment culture – puts people off doing things. Fear of blame for mistakes
* Fear of failure – need to see the lessons learned and removed fear.
* CQC – demonised by some care homes – some inspectors embrace this. Feared
* Lack of communication between agencies – people repeatedly asking same questions – hospital passports – communication within hospital bad.

3. What will make a difference?

* Wifi in all care homes (cost if prohibitive) – enables far more activity, communication, etc (1 in 5 has it)
* Better communication across sector
  + Between service users, staff, etc
  + Need to communicate in plain English Language
  + Within care homes – different nationalities – affects ability to deliver – reading bottles, etc.

**Sheet 9**

1. What is working well?

* Study event is positive
* Utilising voluntary sector – for support/advice outreach roles within the community
* Listening to the person and their carers
* Timely intervention/specialist nurse
* More public awareness
* Person-centred planning
* Empowered – internet – knowledge – due to reduced services

1. What is not working well?

* Mix of neurological/LD/Older Persons Services – not successful
* Respite – lack of appropriate placements
* Long-term/Palliative care
* Not listening to the person/carers
* Reduction of services/resources
* Expectation on statutory services – remit has changed

1. What will or can make a difference? What could help you to do your job?

* Better communication between providers
* More staff/resources
* Upskilling staff to manage “common” difficulties
* People being better informed
* Joined up working with all sectors/providers
* People knowing what is “local”

**Sheet 10**

1. What is working well?

* Ground Zero – Emergency care is good
* Joint training = all training
* Hospice taking different cases with long-term conditions, Neuro conditions
* All works well IF IT IS WORKING WELL!
* Individuals – professionals. How well they are working together.
* Wellbeing and outcomes
* Tapping into new resources, Net tech, new ipads, Telecare

2. What’s not working well?

* Knowing what is out there
* Re. signpost people
* Changing people thoughts (changing the way people think)
* Health/Social Care how to access support
* Multiple systems
* Cognitive impairment. Limits access to care
* Empowering people. Not providing enough opportunity, information and advice
* Lack of consistency
* When different family members have different social work teams
* Communication!!

3. What will make a difference?

* Fully integrated health and social care
* Increase in personal health care budgets
* Choice
* More continuity
* Better communication
* Less change – less consultation
* Listen!!
* Listen to what is being said!!!
* Communication effectively with appropriate people!!!

**Sheet 11**

1. What’s going well?

* Empowering service users – person centred.
* Maximising independence.
  + Improved communication with shared assessment
  + Greater control over persons information
* Availability of information on conditions. Quality of information on conditions.
* Staff willing to work flexibly – will keep complex/progressive cases open.

1. What’s not so well?
2. a. No shared information record between health and social care

b. Lack of joint work between health and social care

1. a. Drive to discharge/close cases

b. No system to review

1. a. Failed hospital discharge

b. Lack of assessment in hospital

1. What would help?

* Client held records - ? who’s been to visit
* Money! Time! Staff!
* Shared records – even if read only
* Improved communication
* Portable electronic device for case notes
* More recognition that some people need ongoing support.

**Sheet 12**

1. Working well

* HHR
* Access to resources
* Sensory team
* Telecare
* Good GP services…time for appointments
* Specialist nurses
* Integrated Care Teams\*
  + GP white board meetings. Avoidance of hospital admissions
  + GSF meetings
* Sharing of information (electronic)
  + Not always with all teams though

1. Not so good

* Still some geographical gaps in services\*
* Not so good GP services. Lack of time and appointments
* Financial constraints
* Time for HSCPs

1. What we would like to see

* Joined up working
* People in care homes should be able to access equitable services
* Care Act means people doing things themselves if able. Lack of resources

\* Postcode Lottery Effect

**Sheet 13**

Q1: Working well

* Events like today – networking/social media
* Signposting
* Support positive carers and service users environs/groups
* Local groups are really good
* Support works well short term but at end of that time it all goes backwards
* Lack of awareness of Brain Injury and neuro conditions impacts – benefits, PIP, Adult services (A) – seems unfair

Q2: Not so good

* Unable or difficulty to access services and information
* Lack of funding impacts whole system
* GP too busy
* Lack of visual e.g. (Portsmouth info portal)
* People don’t prepare for a bad diagnosis?
* Lack of consistent referral pathways
* Personal Independence Payments (PIP) causes stress – worsens mental health
* Raise awareness

Q3: What we would like to see

* Trained advocacy with PIP particularly
* Greater understanding of how people manage the conditions
* More funding to enable greater partnership work – more funding for time to focus on well-being
* Being able, as a vol sector worker, to refer in our own right to medics/mental health etc.
* Easier referral to AS – not just safeguarding getting attention.
* More services like Portsmouth Connectors that help people get linked with services and support
* Info Sharing – using twitter, social media team at Queen Alexandra.

**Feedback as people left against three headings**

* **What made me think?**
* **Something that will stay with me**
* **Now in my toolbox**

Made me think

* Individual stories
* The age of diagnosis
* The impact of the speakers
* My life could change so much after an accident/illness

Something that will stay with me

* Hidden effect
* Individual impact
* Personal Experiences of speakers
* Joy’s presentation x 2
* The positivity of all contributors
* Talk from the heart
* Impact a disability has on the extended family
* Neurological diseases or events can affect people under 65/or working age
* Although I understand about the impact condition may have. I will not know how it feels for the individual
* How life can be turned upside down

Now in my toolbox

* More knowledge
* Accessing information
* There are huge crossovers in supporting people living with neurological conditions
* Networking
* That there is a PSP association for support
* Making new contacts to engage with
* Consider how life can be impacted on