**HNA Study Day**

**Table Notes 02 11 16**

**Table 1**

1. What have we learnt today?
   1. Telecare
      1. New devices
      2. Useful for students when leave college
      3. Range of products
      4. Red button – no landline
   2. Pain
      1. Emotional adjustment to chronic pain
      2. Support around dignity
      3. Life goals
   3. Not knowing about PSP or Friedrichs Ataxia
   4. Most interesting about personal experiences of people living with conditions
2. Well paced
   1. Lots of comfort breaks
   2. Networking opportunities good
   3. Good to get out of bubble of school and see other realities & bigger picture
   4. Excellent about PSP
   5. Hospital passport for more clients
3. What will we do differently?
   1. Emotional impact
   2. Advanced decisions
   3. Future decisions for students/length of life
   4. Taking on board psychological issues of pain
   5. Thinking about energy pie – length of meetings
   6. Hidden impacts
   7. Information about PSP to others

Feedback

- Make telecare, more accessible and available for people. Unreachable – only red button

- Good range of speakers/time slots

- Lunch was amazing!!!

Wish list

* Hospital passport for rarer conditions
* not everyone can be expected to understand
* Continuing healthcare
* Funding
* better system
* split funding
* no gaps in provisions
* Good signposting
* Accessing what people need

**Table 2**

1. What have we learnt today?
   1. PSP – had not heard of!
   2. Good to learn about PSP
   3. So many neurological conditions we don’t know about.
   4. Rachel - good support, community, friends & how she stays so positive. Very brave to talk about her life
   5. Good to learn about the advance technology re Argenti
   6. Good to learn how to manage pain. Looking at positives all of the time
2. What will we do differently?
   1. Share the information learnt today with others.
   2. How to ‘mentally’ support someone in chronic pain.
   3. Person Centred approach to people’s needs
   4. Giving people more time
3. What changes are we going to make?
   1. Make more time for people
   2. Person centred approach
   3. Spend more time with individuals
   4. Look at all services available to support diagnosis when needed

Wish list

* I wish everyone is free from illness/disease, if not I wish that early diagnosis, treatment and support is given!!
* Neurology to also become a priority to the NHS!!
* Wish people were more open minded to now visible health conditions

**Table 3**

1. What have we learnt?
   1. Emotional impact of pain
   2. Emotional responses to pain
   3. Rachel’s outlook amazing – looking forward
   4. Impact of fatigue on how people manage – might need a different ethos in care
   5. What does the person want to be able to achieve
   6. Awareness that CRT is not always the best team for some neurological conditions as short term
2. What will we do differently?
   1. Better understanding of real issues for individuals
   2. Awareness of different conditions
   3. Ask the person what they want, what they want to work towards
3. What changes will we make?
   1. Share knowledge with teams
   2. Be aware that there might be “something else going on”
   3. Strength based care…is this the same as working towards greater independence? Should we be looking at the person’s strengths e.g. they are better in the morning.
   4. Making it personal. What do they want to be able to do. ‘Light Bulb moment!!’

Wish list

* Make access to CHC easier
* We would like to see quicker diagnosis to access care
* More effective integration between health and social care. Continuity

**Table 4**

1. What have we learnt today?
   1. Learning about services i.e. clinical psychologist specialists in pain management.
   2. Strategies for self-management of conditions and put a plan in place to better manage their health and wellbeing. Changing behaviours.
   3. Strength and positive mind-set – build on strengths.
   4. Reinforce multi-disciplinary/joined up care.
   5. Information and having a diagnosis helps people to understand and be accepting.
   6. Health unlock forum.
2. What will we do differently?
   1. Joined up working. Strengthen our commitment to multi-disciplinary working.
   2. Help people to achieve their outcomes by taking small steps and planning.
   3. Giving as much information as possible and enabling people to make choices.
   4. Using specialist voluntary sector organisations more.
3. What changes are we going to make?
   1. Preventative practice – liaise with other professionals and services early on.
   2. Encourage contingency planning and advanced care planning.
   3. Linking individuals with peer support networks and enabling people to share information and experiences.

Wish list

* Health and Social care to become one organisation
* Investing in therapies will help to maintain function and wellbeing, reduced use of health and social care services needs to increase
* People having more choice and flexibility about how their care and support is delivered.

**Table 5**

1. What have we learnt?
   1. Confirmation of knowledge
   2. Refresher
   3. Rachel was inspiring
   4. Pain: look at taking things forward - positively???
   5. Finding a way forward – accepting how we are now – accepting the need to pace one self
2. What are we going to do differently?
   1. Never heard of PSP, learnt more about PSP
   2. Aware of more Argents and equipment
   3. Support people to move forward.
   4. Support for people looking backwards
   5. Ensuring colleagues are aware of chronic fatigue
3. Changes
   1. Aware of my wellbeing
   2. Stop when I need to

Wish list

* More funds to stop looking over your shoulder
* Funding for early provision
* Funding panel not questioning our professional judgement
* We are all accountable
* More funding for health and social care
* Need/funding for CHC health and social care
* CHC Funding should not be difficult to obtain

**Table 6**

1. What have we learned today?
   1. More about PSP.
   2. Importance of early/correct diagnosis.
   3. Psychology of pain.
   4. Fatigue – impact on function, mood, psychology.
2. What will we do differently?
   1. Highlighted what’s missing.
   2. Sharing information with team members.
   3. Focus on the individual – person-centred plan.
3. What changes are we going to make?
   1. Identify learning needs re Advance Care Plan.
   2. How to improve fatigue management.

Wish List

* Psychological support
* Improved partnership between health & social care
* Improved access to respite

**Table 7**

1. What have we learned today?
   1. Different neuro conditions have similar symptoms.
   2. Limited support.
   3. PSP was informative – reassured by the information.
   4. Telecare Advancement.
   5. Rachel sessions was informative. Personal reflection is very valuable.
   6. How difficult it can be to get an accurate diagnosis.
   7. Making contact with organisations.
   8. Legal perspective was valuable.
   9. Educating/re-educating.
2. What will we do differently?
   1. Enjoy life more – take each day as it comes.
   2. Take time to get it right.
   3. Increased awareness of different conditions and the needs of the individual.
   4. Use of everyday language is better understood.
   5. Link in with voluntary services with the knowledge.
3. What changes are we going to make?
   1. Circulation of presentation would be very useful at the start of the day.
   2. More education of the specific condition for front line health professionals.

Wish list

* Continuity of primary carers - GP for example.
* Easier process to access CHC Process/Funding.
* Not being “closed” to professionals.

**Table 8**

1. What have we learned today?
   1. Understanding pain better.
   2. Impact of fatigue.
   3. Letting go of what you had and changing expectations to new expectations and how to support change for the person.
   4. New conditions.
   5. CHC funding linked to PSP.
2. What will we do differently?
   1. Work differently with people to support change.
   2. Plan for achievable goals and small steps.
   3. Make sure wider conditions are identified in choking strategy.
3. What changes are we going to make?

* Integrating health and social care – how?
* Increased funding – easier
* Proactive/Prevention – link to funding
* Joint increased working with health.
* A greater awareness of conditions – signs/symptoms recognition.

Wish list

* Super agency – one assessment/one budget
* Stability in social care sector
* Increased social care funding from the government to improve outcomes for individuals
* Recruitment of staff.