

Kent Acquired Brain Injury Forum

Minutes

Wednesday 6th February 2008 at 7 pm

asb aspire llp, Horizon House, Eclipse Park, Sittingbourne Road,

Maidstone, Kent ME14 3EN

In attendance:

Mr Tanesh Bhugobaun		Raphael Medical Centre
Ms Claire Carter	Occupational Therapist	Strode Park Foundation
Ms Jan Cartmell	Service Manager	The Regard Partnership
Mrs Sophia Chung	Executive Director	S C Support & Care Services Ltd
Ms Becca Coffey	PA to Frances Pierce	Rix & Kay Solicitors LLP
Ms Sally Collins	Speech & Language Therapist	Strode Park Foundation
Ms Di Drummond	Manager	Headway Centre Tunbridge Wells & District
Mrs Ros Eastwood	Head Teacher	East Kent Health Needs Education Service
Ms Delia Elliman	Independent Case Manager	Case Management Services
Dr Gerhard Florschutz	Director	Raphael Medical Centre
Ms Karen Heath		The Prioory
Mr Keith Hutchinson	Centre Manager	Hothfield Manor Centre Acquired Brain Injury Home
Ms Anna Kartun	Trainee Solicitor	asb Law
Mr Roy Marcus	Brain Injury Case Manager	ABI Services UK Ltd
Mrs Jenny Mazur	Parent of son with ABI	
Ms Denise McKeown	Partner	McMillan-Williams
Mr Tony Merriman	Solicitor	asb Law
Ms Aggie Moreno-Lopez	Trainee Clinical Psychologist	Canterbury Christchurch University
Mrs Pam Munro	Founder and Volunteer	Headway Tunbridge Wells and District
Professor Mike Oddy	Director of Clinical Services	Brain Injury Rehabilitation Trust
Ms Frances Pierce	Partner (KABIF Chairwoman)	Rix & Kay Solicitors
Ms Julia Ross	Director of Civic Engagement	West Kent Primary Care Trust
Ms Mary Ryan	Vocational Assessment Manager / Occupational Psychologist	Royal British Legion Industries Vocational Assessment Centre
Mr Dennis Smith	President	Headway Tunbridge Wells and District

Ms Joanne Stovold	Group Care Homes Manager	Priory Neuro-rehabilitation Services
Mrs Linda Theoff	Brain Injury Case Manager	East Kent Hospitals Trust
Miss Katie White	Paralegal	Rix & Kay Solicitors

Apologies:

Mr Bruce Aitken	Principal Physiotherapist	Strode Park Foundation
Mrs Liz Bray	Head of Nursing	The Children's Trust, Tadworth
Mrs Louise Brown	Paralegal	Thomson Snell & Passmore
Mrs Lorna Buckwell	Solicitor	Thomson Snell & Passmore
Ms Nicky Coffey	Associate Director	South East Coast Specialised Commissioning Group
Ms Rikki Gandolf	South East Regional Co-ordinator	Headway UK
Mr Tony Hart	Head of Vocational Rehabilitation	Queen Elizabeth's Foundation, Brain Injury Centre
Ms Lorna Morris	Consultant Clinical Psychologist	West Kent Neuro-Rehabilitation Unit
Ms Mandy O'Brien	Brain Injury Case Manager	
Mr Julien Payne	Managing Director	Titleworth Healthcrae Ltd
Ms Patti Simonson	Head of Social Work	Royal Hospital for Neuro-disability
Mrs Jenny Stockley	Consultant Paediatric Neuropsychologist / Director	Jennifer Stockley Limited
Ms Juliette Stuart	Rise & Reability Manager	Strode Park Foundation
Miss Victoria Toy	Trainee Solicitor	Rix & Kay Solicitors
Miss Sue Ware	Independent Speech & Language Therapist	

1. Welcome and introductions

Frances Pierce welcomed all attending.

2. Approval of minutes of meeting held on 14th December 2007

The following amendments were made:

1. 2nd last paragraph just before point 7. Suggestion was made to change '*a huge number of service personnel*' to '*a number of service personnel*'. FP suggested changing it to 1 in 3 but this was not agreed.
2. Under 'Any other business' at point 10, para 7 – correction of name Tim to Tina. It was agreed to change name to Tim.

3. Matters arising from minutes of meeting held on 14th December 2007

Pam Munro mentioned that the one bed flat advertised on the website was still available. There are 8 flats in total, located in Rusthall, Tunbridge Wells. Anyone aged 18-55 with a brain injury who is interested in occupying the flat should contact Pam.

Aggie Moreno-Lopez thanked KABIF members for their assistance with her project. She had interviewed 9 candidates and was hoping a few more would come forward. She would be grateful to be contacted by any willing participants aged 12 – 21 who have a parent who sustained a moderate to severe brain injury within the last five years.

4. Neuro-Rehab Stakeholders Group and NSF update – Nicky Coffey

Nicky Coffey had hoped to be at the meeting. Her update was deferred to the next meeting.

5. Mapping exercise/website update

Tony Merriman and Chris Merriman introduced the new KABIF website and confirmed they would appreciate feedback on the site or suggestions for improvement.

KABIF's mapping committee was given a brief to fill the gaps in the mapping. The committee should encourage the PCTs and social services to get involved to help fill some gaps.

FP confirmed that there was no charge for advertising events on the forthcoming events page of the website. Anyone who knows of a forthcoming event that would be of interest to KABIF members should let her know.

On behalf of KABIF, FP thanked Chris Merriman for all his hard work to date on the website and thanked Tony Merriman and Mary Ryan who sat on the website committee for all the time they had given to help update the site.

6. Headway (Kent)

Di Drummond confirmed that Headway moved into their new centre on 9 January. The official opening will take place on 8 March.

On 21st January Headway Tunbridge Wells celebrated their 20th anniversary.

Brain Injury awareness week starts on 31st March. Di agreed to put some information together about this for the website.

Headway are also working towards getting an outreach worker for Headway Junior. This is still in the early stages but they want to develop that this year and would like to have drop in centres for youngsters.

Headway's new contact details will be forwarded to us [Milestones, 3 Culverden Park, Tunbridge Wells, Kent, TN4 9QT, telephone 01892 619001]. The email address remains the same (headwaytwells@hotmail.com).

7. Focus on young adults with ABI

KABIF's project focusing on young people, with the aim of developing a brain injury information leaflet for young people with brain injury, is still ongoing. Tony Merriman and Frances Pierce's firms will pay for the printing costs. Jenny Stockley's husband's assistance was offered to the project.

All assistance with putting together the leaflet would be much appreciated. Anyone able to help should contact Ros Eastwood or Mary Ryan.

8. PPI forum

Dennis Smith confirmed that four years ago the government set up a consumer watchdog called Patient and Public Involvement. The Government has decided to abolish PPI at the end of March 2008. In its place, LINKs (Local Involvement Networks) will be set up. PPI was NHS focussed whereas LINKs covers social services as well. Dennis said it is not yet clear exactly how LINKs will work. We shall have to watch this space!

The PCT has recently issued a draft strategic plan for the next five years, which covers a number of long-term conditions including stroke neurosciences. The wide heading of stroke neurosciences involves carrying out an audit of head injuries in Kent, Medway and South London with an aim towards a Kent-wide framework for commissioning for brain injury.

Dennis said that he is interested in getting involved in a scheme that the PCT has set up P.A.N. - Public Advisory Network and hopes to continue to be involved with the PCT, focussing particularly on long-term conditions and community services.

9. Talk by:

a. Professor Michael Oddy, “Recent Findings Regarding Recovery from Brain Injury”

Presentation topic 1: Recent findings regarding recovery from brain injury

Professor Mike Oddy’s first topic of discussion was brain plasticity. This refers to the organisation of the brain as a result of experience. The brain is constantly changing in response to experience. These events may also be factored to change an injured brain.

Changes occur in neuronal levels right down to changes in parts of the brain responsible for different types of behaviour.

Synapse means the junction between nerve fibre and dendrites and wrap into the main arm of another nerve cell. You can estimate the number of synapses by these means. The number of synapses can go up or down.

The brain is constantly changing in response to experience. Slide 4 lists examples of events which alter the cortex, such as, *inter alia*, sensory and motor experience, task learning, stress, diet, gonadal hormones.

Experiential treatments were also used to demonstrate that, once placed in complex environments, the brain grows. Rats were used in the experiment and were placed in complex housing as shown in slide 5. The experiment showed that complex environment housed rats’ brains were larger and had more connections and that they had more enhanced cognitive and motor behaviour than laboratory housed rats, but age is critical.

Complex housing and age

Complex housing has different behavioural benefits dependant on the age of the person undergoing the treatment. For example complex housing in adults (including old adults) results in increased dendritic length and increased spine density and heavier brain. On the other hand, complex housing prenatally results in decreased dendritic and increased spine density.

Also, there are sex differences in connections. Slide 7 shows a graph demonstrating female connections in the GREY areas and male connections in the BLUE areas. The implications of this are that we can expect differences in behaviour and response to treatments depending on the sex of the patient.

Different regions of the brain react differently to medication. Psychomotor stimulants all have opposite effects on the orbital cortex (the region of the brain above the eyes) compared to the frontal cortex, i.e. there is a decrease in dendritic length and / or spine density in response to psychomotor stimulants compared to an increase in frontal cortex.

Thus, the same drug can alter differently the function of different regions, much like hormones do.

Can we alter a person's experience in order to help recovery from a brain injury? Multisensory / motor / social experience induces widespread synaptic changes in the normal brain. Thus such experience should enhance synaptogenesis that will reverse strike – induced atrophy and induce synaptic growth in residual motor areas.

The result is that complex housing seems to be the treatment that stands out. Complex housing is the most powerful in stimulating functional improvement, but not if only for short periods each day.

How do we apply this to brain injured people? The best approach would be to employ intense, multidisciplinary treatments.

Summary of 'repair' treatments.

Treatments that improve functions:

- nicotine; amphetamine (conditionally)
- complex housing
- electrical brain stimulation
- exercise
- olfactory or tactile stimulation

Treatments that do not improve functions:

- diet
- COX- 2 Inhibitors (non-steroid anti-inflammatories)
- repetitive practice

Treatments that make functions worse:

- Fluoxetine (i.e. Prozac)
- social change (stress?)

Is plasticity necessarily good?
Shifting functions may interfere with other functions
One plastic change may prevent a later one

But, remember, the brain is going to change regardless of what we do.

Conclusions

Plastic changes in synaptic organisation can support functional improvement after cerebral injury.

Both pre- and post- injury experience can affect outcome from cerebral injury

A wide range of factors can influence outcome from injury

There are limits to recovery: Animals with high spontaneous recovery show little benefit from experience or chemicals

There are synergistic interactions between behavioural and pharmacological treatments

Presentation 2: Virtual Reality: Uses in neuropsychological assessment and rehabilitation

Virtual reality allows one to test the brain injury patient in a safe environment. Technological advances have allowed us to simulate virtually any real world environment from a city to a kitchen. We can now simulate the tasks people experience in their daily lives (e.g. food preparation, office skills, use of public transport).

One simulation used was the V-Store. It is a virtual fruit shop. It consists of a representation of a user in front of a conveyor belt with baskets (1-3) crossing the room. Distractions can be introduced such as light going on/off, belt speed changing, phone ringing – to increase difficulty and time pressure. This allows us to look at how participants compensated.

In Virtual reality the limitation of monitoring and recording behaviour are removed. VR ensures that test materials are of consistent quality, reduces errors and inconsistencies in administration by the clinician. Another example of how it has been used is a virtual bungalow, Morris et al (2002). the virtual bungalow was used to assess prospective memory, strategy formation and rule breaking in 35 patients following pre-frontal surgery with 35IQ –matched controls. The task was to help the owner of a 4 room bungalow move to a larger 8 room house. The brain injury patient had to collect items in specified order, remember to put ‘fragile’ notices on specified items.

Avatars (representations of human beings in technology) have been found to be a promising way of introducing a social dimension (Pertaub et al. 2002, Blascovich et al.2002)

Zalla et al, 2001 – another example used was a Virtual reality apartment consisting of a bedroom, bathroom, kitchen and living room. The task was to verbally formulate a plan to get ready for work in the morning and then use this in the virtual apartment. 7 patients with prefrontal damage were tested with 16 controls. The patients showed more action slips, omissions and failure to initiate. Controls took longer to execute the

plan than to make it and all patients spent similar amount of time on planning and executing.

Compliance and motivation levels are generally higher for VR tasks than others. VR allows tasks to resemble video games which appeals to the younger patients and generally has been seen to be more motivating for patients. Elkind et al. 2001 developed a version of the WCST which involved a virtual beach and delivering Frisbees, sodas, popsicles and beach balls to a bather under umbrellas depicting these items. Compared to the computer version of WCST it was found that VR was more difficult, interesting and enjoyable.

Conclusions

Work is only at preliminary stages of development. The theoretical advantages of VR in neuropsychological assessment have been shown to be advantageous in practice but only in small scale pilot studies.

NO VR instruments have yet been developed. Costs/ skills involved in their development hinder their development. The potential is there but needs to be realised.

Finally, Professor Oddy discussed new '*Smart Technology*'

This is technology that includes a level of intelligence, i.e. it is able to provide automatic assistance rather than simply detecting problems and calling for help.

In order to use this, one needs 1. behaviour monitoring sensors, 2. Assistive support technology, and 3. a communication link between the two.

Sensors and Support devices

Sensors are readily available and can detect movement, smoke, CO, toilet use, fridge use, bar codes, epileptic seizures. Support devices include automatic cooker shut-off valves, bath top shut-off devices that don't take control away from the user and means for providing prompts and reminders e.g. detect movement near an external door and, knowing it is an inappropriate time to go out, to prompt them with a message to that effect. E.g.: a client who was often restless at night would often wander out of his room. A wander reminder detected movement near a door during the night and replayed a message to discourage the client from going out. Discussions with him revealed that he would often wake up at night severely affected by night time anxieties and consequently he would go in search of a member of staff. He was given a voice recorder to enable him to record his concerns and he would then replay them to a member of staff in the morning.

Questions for Professor Mike Oddy

1. Regarding the statement that diet does not have any effect on head injury...what research showed this?

Professor Oddy: Research says there is no direct effect on the brain as a result of diet. Exercise does do the brain good. But there is always scope for more research.

2. Endocrin system

Frances Pierce asked whether there was a deficit in the body's possibility to produce hormones where a brain injury has occurred?

Professor Oddy: The brain does have an effect on hormones. There is an endocrinologist at Hurstwood Park and we are looking at him to do research in this area.

b. Julia Ross Director of Civic Engagement- West Kent PCT “Creating an NHS fit for the future”

Julia Ross explained that her role is to try and build dialogue with the public to enable change.

First of all, the NHS is changing. the technology is changing, the medical practice is changing and it is expensive and need to engage groups like KABIF to find out how to prioritise.

The workforce is changing. NHS is looking at specialist centres. What that means is that, a specialist centre may not be set up in Maidstone, it may only happen in Medway.

An issue of concern for the NHS is how to keep ongoing intervention for brain injury victims.

A recent survey of 24,000 patients across Surry and Sussex, showed that the NHS has a long way to go to developing into a satisfactory medical service. Some results from the survey included:

- 1 in 5 patients felt in control
- 1/3 thought that staff actually listened
- 15% thought that health and social care worked together as a team
- Majority were unhappy with NHS

Fit for the Future

It is a long term improvement plan. The aim is to provide long term financially sustainable services and long term clinically sustainable services. At the end of this financial year, the NHS Trust will break even.

The Vision

The vision is to keep people healthier at home for longer and to provide access to those that need it.

A specialised Services review is being undertaken. This is commissioner led and consists of pan-Kent & Medway work programmes.

Long Term Conditions

A long term conditions strategy is in place.

Supported self –care strategy

Whole Systems Demonstrator – project with West Kent PCT. This is about using very rigorous tests using telecare and telehealth and then fed through to the Matron (West Kent).

NHS want to push telecare as one of the key treatments

Care Call

This is another initiative. It is a proactive telephone outreach service.

- this is dependent on person's level of risk and will work with that individual
- this is also based on motivational interviewing

Carers support is another important initiative for NHS.

Neurosciences

Head Injuries Unit

A head injuries Unit audit across Kent & South East London has just been started.

NHS is in process of developing a commission to review neuro-rehab.

NHS is very busy with national stroke strategy at the moment.

They are also setting up a citizens panel in the form of the Health Advisory Network. The aim is to get public input as much as possible.

Strategic Commissioning Plan / Operating Plan

- - the aim of this plan is to align the money with the vision!

Website address: www.westkentpct.nhs.uk

Questions for Julia:

Where is the information for the audit coming from?

- public's views
- Public Health Analysis
- Nicky Coffey is working on it

Frances Pierce said that an audit ought also to take those that do not even see the GP into account – the undiagnosed.

Will auditors also be looking at young children? – Yes

What about those who are airlifted to London and not Kent hospitals. We need to repatriate as many as possible from London and these should also be considered in the audit.

10. Any Other Business

a. Brighton & Hove ABI Co-ordinator

Mike Hope is leaving his post in Brighton and relocating to Suffolk. His post is under threat but Francis Lacy-Scott and Gerry from Hurstwood Park and SABIF are working hard to save it. There is rumour of a possibility that there may be a coordinated post within East Kent. The post may just be Social Services funded.

b. Greg Clark

Greg Clark has joined the All Party Parliamentary Group for ABI as well as KABIF. Frances Pierce suggested getting four MPs together for a lunch, who can then go to the Minister with specific problems in this county.

c. Next Meeting

The next meeting will be a networking event. Frances Pierce asked all those attending to please bring leaflets, information and goodies promoting their respective organisation and to be prepared to talk for a few minutes about their organisation.

d. Forthcoming Events

Jan Cartmell mentioned the BISWG conference in Cardiff on 24th April 2008, which would cover mental health and brain injury.

Gerhard Florschutz mentioned that The Raphael Medical Centre were holding a conference on 2nd May 2008.

e. NSF

Julia Ross confirmed she was appointing someone to lead the NSF process, she will let KABIF have their details in due course.

The meeting concluded at 8.50 pm.