Bristol Aquarium - Saturday 28th April

Summary of the day

The day was introduced by Anna Panton, Childhood Stroke Project Manager for the Stroke Association. Anna offers a Childhood Stroke Support Service for families affected by stroke in childhood. The service offers information, advice and support for families – and more details are available on the Stroke Association website.

The day was co-facilitated by Renée Wallen, parent of a childhood stroke survivor. She runs a Facebook group for parents and carers – My child had a stroke.

My experience of stroke in childhood

Siân Slee opened the day by talking about her personal experiences of stroke in childhood.
What’s new in childhood stroke?

Dr Andrew Mallick, Paediatric Neurologist from Bristol Children’s Hospital talked about childhood stroke and new areas of clinical and research activity.

A full set of his slides can be found at the end of this summary.

Therapy and Rehabilitation after stroke in childhood

Lisa Hutchens, Physiotherapist and Helen Cullimore, Speech & Language Therapist from Bristol Children’s Hospital talked about the aims of therapy and rehabilitation with children affected by stroke.

They reviewed the 2017 Childhood Stroke Guidelines in relation to therapy and rehabilitation, and shared examples of how young people affected by strokes had been involved in feeding back on services and planning and preparing information about their support needs when returning to school.

A full set of their slides can be found at the end of this summary.
Thriving in the educational system after stroke

Dr Siân Rees, from the SHIPS Project, talked about the type of difficulties children might experience in school after an acquired brain injury. She described how special educational support might be offered in school settings, and how parents can work in partnership with teachers. She talked through some of the strategies and approaches that might be helpful for children after an acquired brain injury.

A full set of her slides can be found at the end of this summary.

During the discussion after this session parents mentioned a number of services and websites they have found supportive when working with schools and understanding special educational needs provision:

- Child Brain Injury Trust
- Brain Injury Hub
- HemiHelp
- Supportive Parents
- Disabled children: a legal handbook – covers education and social care

One of the authors of the handbook is Luke Clements, and he has his own website which includes a range of useful downloadable resources.

For families in the South West Watkins Solicitors specialise in educational law, offer access to events, and include seminars on their website.
Psychological aspects of stroke in childhood

Dr Ingram Wright, Neuropsychologist from Bristol Children’s Hospital talked about the role of psychology after stroke in childhood, how to access services, and the types of approach that might be supportive to children, young people and families.

A full set of his slides can be found at the end of this summary.

During the discussion after this session parents talked about the impact of stroke on the wider family and siblings. One parent referenced an organisation/website she has found helpful in offering sibling support:

SIBS
Young Sibs
Managing transitions and changes after brain injury

Dr Karen Cundy, the Children’s Trust and Nicola Shearan, parent – talked about managing transitions and changes after stroke in childhood. They discussed the many changes and adjustments families have to adapt to – coming home from hospital, going to school, accessing different types of therapy and rehabilitation – and how families can plan and prepare for these.

Nicola described the journey of her son Ollie, and how they have managed some of the transitions and changes he has had to work through since his stroke. A full set of their slides can be found at the end of this summary.

Information stands and resources provided by:

Brain Injury Hub
Child Brain Injury Trust
Contact
HemiChat
SHIPS Project
Stroke Association/Evelina London Childhood Stroke Project
Supportive Parents

Thank you to everyone who supported the day.

We the Curious provided free tickets to the museum and the aquarium for children and young people who attended on the day – we would like to thank them for their support of the event.
Childhood Stroke
What's New?
Andrew Mallick
Research Activity
Results: 1 to 20 of 35

1. Mechanical thrombectomy for acute stroke in childhood: how much does restricted diffusion matter?
   Ladner TR, He L, Jordan LC, Cooper C, Froehler MT, Mocco J.
   PMID: 25406473 [PubMed - as supplied by publisher]
   Related citations

2. Mechanical thrombectomy for acute stroke in childhood: how much does restricted diffusion matter?
   Ladner TR, He L, Jordan LC, Cooper C, Froehler MT, Mocco J.
   PMID: 25391820 [PubMed - In process]
   Related citations

   Marecos C, Gunny R, Robinson R, Ganesan V.
   PMID: 25223401 [PubMed - Indexed for MEDLINE]
   Related citations

4. Experience of mechanical thrombectomy for paediatric arterial ischaemic stroke.
   Bodey C, Goddard T, Patankar T, Childs AM, Ferrie C, McCullagh H, Pysden K.
   PMID: 25135471 [PubMed - In process]
   Related citations

5. The prospects and predicaments of intravenous rt-PA in childhood ischemic stroke.
   Behrouz R.
   PMID: 24491039 [PubMed - Indexed for MEDLINE]
   Related citations
Search: stroke AND children
International Paediatric Stroke Study

Aiming for 12,000 children by 2020
What to Study
Outcomes following childhood arterial ischaemic stroke: A Delphi Consensus on what parents want from future research

Hannah Edwards a, Melissa Dunlop a, Andrew Mallick b, Finbar O'Callaghan c,*

a University of Bristol, Paediatric Neurology Department, Level 6 Education Centre, Upper Maudlin Street, Bristol BS2 8AE, UK
b University Hospitals Bristol NHS Foundation Trust, Bristol Children's Hospital, Paediatric Neurology Department, Level 6 Education Centre, Upper Maudlin Street, Bristol BS2 8AE, UK
c University College London, UCL – Institute of Child Health, Neurosciences Unit, 4-5 Long Yard, London WC1N 3LU, UK
Planning interventional trials in childhood arterial ischaemic stroke using a Delphi consensus process

MAJA STEINLIN¹ | FINBAR O’CALLAGHAN² | MARK T MACKAY³

¹ University Children’s Hospital Bern, University Bern, Bern, Switzerland. ² Great Ormond Street Children’s Hospital, London, UK. ³ Royal Children’s Hospital, Murdoch Research Institute, Parkville, Melbourne, Vic, Australia.

Correspondence to Maja Steinlin at University Children’s Hospital, Neurupaeidiatrics, Inselspital, Freiburgstrasse 31, 3010 Bern, Switzerland. E-mail: maja.steinlin@insel.ch

This article is commented on by Elkind on page 672 of this issue.
Incidence Rates

How many children affected

Huge variation

40 fold difference between studies

Japan 1991 - 0.2 per 100,000 per year
France 1995 - 7.9 per 100,000 per year
New, Better Studies

Incidence per 100,000 per year:

USA (2009) - 1.3
Denmark (2011) - 1.3
UK (2014) - 1.6
UK Data

12 million children (under 16yr)

AIS incidence 1.6
= 200 children per year

All stroke incidence 2.8
= 340 children per year
Age-specific incidence rates

Age

<1yr  1-5yr  6-10yr  11-15yr

Incidence per 100,000 per year

7
6
5
4
3
2
1
Why
100 "Risk Factors"

Little evidence of causality

Many factors are common in childhood
Arteriopathy

Abnormalities of the arteries
Arteriopathy

Acute / acquired
Chronic / inherent

Transient Cerebral Arteriopathy
Arterial Dissection
Infection and Stroke

Case-control studies

- Hills 2012 – minor infection 4 weeks prior to AIS
  OR = 4.6

- Thomas 2014 – Chickenpox in 6 months prior to AIS
  OR = 4.1

- Fullerton 2015 – infection in 1 week prior to AIS
  OR = 6.3

- Fullerton 2015 – Under vaccinated vs full vaccinated
  OR = 8.2
Which Infections?

Fullerton 2016/2017:
VZV
HSV
CMV
EBV
Parvovirus
Abnormal strains of viruses?

Abnormal response to infection?
Accumulation of abnormal metabolites:
- GLA (Fabry's disease)
- Homocysteinuria

External elastic lamina
- Internal elastic lamina
  - ELN
  - ABCC6-calcification of elastin fibres

Vascular smooth muscle cells
- ACTA2, pericentrin, NF1

Vascular basement membrane
- COL4A1

Abnormal response to endothelial injury:
- SAMHD1, GLUT10, ATP7A, NF1

Abnormal vascular homoeostasis:
- NOTCH signalling pathway: NOTCH3, JAG1
- TGFβ pathway: HTRA1, SLC2A10
Endothelial TLR4 and the microbiome drive cerebral cavernous malformations

Alan T. Tang¹, Jaesung P. Choi², Jonathan J. Kotzin³,⁴, Yiqing Yang¹, Courtney C. Hong¹, Nicholas Hobson⁵, Romuald Girard⁵, Hussein A. Zeineddine⁵, Rhonda Lightle⁵, Thomas Moore⁵, Ying Cao⁵, Robert Shenkar⁵, Mei Chen¹, Patricia Mericko¹, Jisheng Yang¹, Li Li¹, Ceylan Tanes⁶, Dmytro Kobuley⁴,⁷, Urmo Võsa⁸, Kevin J. Whitehead⁹, Dean Y. Li⁹, Lude Franke⁸, Blaine Hart¹⁰, Markus Schwaninger¹¹, Jorge Henao-Mejia³,⁴,¹², Leslie Morrison¹⁰, Helen Kim¹³, Issam A. Awad⁵, Xiangjian Zheng²,¹⁴,¹⁵ & Mark L. Kahn¹
Guidelines
WHEN STROKE STRIKES, ACT F.A.S.T.

FACE.
Has their face fallen on one side? Can they smile?

ARMS.
Can they raise both arms and keep them there?

SPEECH.
Is their speech slurred?

TIME.
Time to call 999 if you see any single one of these signs.
STROKES CAN HAPPEN AT ANY AGE

Pediatric stroke can happen in infants, children and even before birth.

PERINATAL STROKE
Last few months of pregnancy to 1-month-old

Risk Factors
The cause in most perinatal strokes remains unknown.
Risk factors that could lead to stroke include:
- Congenital heart disease
- Disorders of the placenta
- Blood clotting disorders
- Infections (e.g. Meningitis)

Warning
Signs of a perinatal stroke may go unrecognized for months or years because the signs can be subtle.

Newborns:
Seizures may be an early sign:
- Repetitive twitching of face, arm or leg
- Apnea (pauses in breathing) associated with staring

Developing Children:
- Decreased movement or weakness on one side of the body
- Showing a hand preference, or consistently reaching out with only one hand before 1 year of age

Time is Brain at Any Age

Newborns: Quick recognition → Prompt medical evaluation and treatment
Babies: Early diagnosis → Rehabilitation treatment can start while a young brain is still developing

CHILDHOOD STROKE
1-month-old to 18 years

Risk Factors
Risk factors in children ≠ Risk factors in older adults
Risk factors for children include:
- Congenital heart disease
- Diseases affecting the brain’s arteries
- Infections affecting the brain or other organs

No previous risk factor is identified in about half of childhood stroke cases.

Warning
Signs are often missed in children because there is a lack of awareness that strokes can happen in this age group.

F.A.S.T.
Face Drooping Arm Weakness Speech Difficulty Time to Call 911

Additional Signs in Children Include:
- Severe sudden headache, especially with vomiting and sleepiness
- Weakness or numbness on one side of the body
- Difficulty speaking or understanding others
- Vision loss or double vision
- Severe dizziness or loss of coordination
- New-onset of seizures usually on one side of the body

Don’t delay!
Prompt diagnosis and treatment of stroke in children is as critical as it is in adults.

Learn more at:
lapediatricstroke.org
StrokeAssociation.org

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1/3 childhood AIS missed on CT

Mallick 2014 - Average (median) time from symptoms to diagnosis 24.3 hours

Marceos 2015 - None of 107 children eligible for thrombolysis (6 hour window)
Important Questions

Antiplatelet vs Anticogulation
Both AP and AC?
Duration of therapy?
Role of antibiotics / antivirals?
Role of immunomodulation?
Role of thrombolysis / thrombectomy?
Rehabilitation?
Paediatric Arteriopathy Steroid Aspirin Project (PASTA)
Hot Topic
Rehabilitation and Therapy

Lisa Hutchens, Physiotherapist
Helen Cullimore, Speech and Language Therapist

Bristol Royal Hospital for Children

Rehabilitation service Bristol Children's Hospital.
South West Stroke conference April 2018
The evolving team

- Young person & family
- Occupational Therapy
- Discharge Planning Coordinator
- Speech & Language Therapy
- Medical & Nursing Teams
- Physiotherapy
- Audiology
- Play Therapy
- Neuropsychology
- Ophthalmology
- Music Therapy
- Hospital School

Rehabilitation service Bristol Children's Hospital. South West Stroke conference April 2018
Aim of presentation

<table>
<thead>
<tr>
<th>Overview</th>
<th>Overview of 2017 stroke guidelines with regard to rehabilitation</th>
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</thead>
<tbody>
<tr>
<td>Review</td>
<td>Review of Bristol Rehabilitation service in line with recommendations</td>
</tr>
<tr>
<td>Input</td>
<td>Input from the stars of stroke rehabilitation- the children!</td>
</tr>
</tbody>
</table>
Overview of guidelines

....Rehabilitation

Assessment

Implementation of guidelines

Principles of rehabilitation

Needs of the family during planning of care/rehabilitation

Specific rehabilitation interventions

Rehabilitation service Bristol Children's Hospital. South West Stroke conference April 2018
Principles of rehabilitation

• Difficult to give clinicians recommendations regarding ‘optimal rehabilitation’ approaches and long term management due to lack of evidence.
• Stroke outcome research does suggest the impact of childhood stroke and family concerns, changes over time.
• Current adult research suggests more therapy improves outcome and recovery within in 1st 6 months, in children dose and timing is still being researched.
• Group agreed that although desirable difficult to prescribe a set time and frequency across all ages and abilities.
• Time and frequency should be at a pace to achieve rehabilitation goals.
Key principles

- Individualised approach
- Child and family centered process & goal setting
- Positive collaborative working
- Hollistic MDT working
- Practise of frequent goal directed purposeful activities
- Access to wider service
- Address all child’s health
- Use of outcome measures to address/identify change
- SMART goals, meaningful and relevant to child.
- Support the child and family in adjusting to changed ability and circumstances
Using guidelines throughout patient journey..
Guidelines in practice...

Acute phase..

Guideline

- ‘Withhold oral feeding until the swallow safety has been established’

- ‘Assess the communication, information and support needs of the parents/carers, family and child/young person during early functional assessment.’

- ‘Provide clinical assessment of a child's body structures and functions and activities by members of the relevant multidisciplinary team’

- Individual therapies should compliment each other to maximise functional skills

- ‘Undertake at least weekly multidisciplinary review of abilities and rehabilitation needs during the inpatient stay’

Evidence

- Initial Joint working/joint sessions.

- Most of the time, SALT ax is requested prior to oral feeding.

- Communication assessment and advice is provided in acute phase, involving family and personal interests and needs.

- Early referrals are made to MDT neurorehabilitation team and to services such as Ophthalmology, Audiology, orthopaedics etc

- Therapists work jointly and incorporate goals from other therapies where possible.

- Children / young people due to come to neurorehabilitation, are discussed at weekly ‘intake’ meeting with MDT.

Rehabilitation service Bristol Children's Hospital.
South West Stroke conference April 2018
Guidelines in practice... inpatient rehabilitation phase..

**Guideline**

- ‘Avoid delay before commencing baseline assessment of functioning’
- Consider splinting and medical management of disorders of muscle tone, BoNTA in combination with other active treatments
- ‘Goal Attainment Scaling may assist with identifying individual targets for Intervention and evaluating outcome’
- ‘Identify a named key worker or key point of contact for families, who will remain a key point of contact through transfer from hospital to community...’

**Evidence**

- Measurable assessments are used at earliest opportunity.
- Inreach working with spasticity management therapy and medical teams, including movement disorder teams.
- Goal Setting Meetings are held every 2-4 weeks, starting sometimes in acute phase. These are captured using ‘Goal Attainment Scaling’
- Our Discharge Planning Coordinator remains the key point of contact from admission to post discharge.

Rehabilitation service Bristol Children's Hospital.
South West Stroke conference April 2018
Guidelines in practice... inpatient rehabilitation phase.

Guideline

- ‘Provide access to VF with a Specialist Paediatric Team.’
- ‘Offer referral to AAC services where children and young people have significantly impaired language understanding and/or expressive/speech...’
- ‘Be aware that children and young people who have apparently unaffected language skills may have high level language processing difficulties that will impact on educational performance, communication and socialisation/social participation.

Evidence

- Videofluoroscopy is available on site where needed and neurorehabilitation SALT would attend clinic and support.
- Referral is made to Augmentative and Alternative Communication (AAC) services where needed.
- High level language and person / family /MDT reports are given as much, sometimes more importance than standard language tests when assessing subtle changes to communication which can impact on life.

Rehabilitation service Bristol Children's Hospital.
South West Stroke conference April 2018
### Guidelines in practice...
transition to community phase..

**Guideline**

- ‘Ensure regular, effective collaboration and communication between the child. Young person and family and health, education and Social Care professionals throughout the child’s schooling.’

- ‘The creation of a long term condition passport can support information sharing and reduce repetition’

- ‘Ensure Health and Education professionals have access to information about child stroke’

**Evidence**

- Intermediate and final discharge planning meetings held with all community team invited. Post discharge meetings, readmission for review and follow up clinics used.

- Self advocacy DVD, ‘Tip card’, wrist band, passport, made with child / young person if they wish to disseminate information and avoid repetition / questions.

- CBIT representative offers visit to school for staff and pupils to explain nature of ABI.
“Within the context of current NHS these guidelines are aspirational and will require additional financial, workforce and organizational resources at both local and national levels”

“The organisation in secondary and tertiary services varies from hospital to hospital and so the guidelines encourage to identify and exploit specialist services with clinical expertise”
From an Expert...

Cons:
Therapists: Lisa, Helen, Rebecca and all the Therapists have to remember we are all different, with different strategies and different coping mechanisms and so on and so forth...

The Nurses: It’s not my, the Therapists or my Mother’s job to get me prepared it’s the nurses job. But then again that’s just my opinion.

Physio: Yes people shouldn’t get bad habits, but personally people do things for a reason, usually. Again that’s just my opinion.

Pros:
Therapists: They do their jobs and don’t slack off, they may go over time but pants, don’t complain.

The Nurses: they always stay bubbly and fun even though stressed. Not much ever brings them down.

Physios: Everyone always has their spirits high and are able to make jokes even when the going gets tough.
Southwest and nationally

- Rehabilitation within acute hospital/protecting beds
- Staffing
- Equipment & resources
- Location for families
- variation in service provision
- Step down services
- Social services resources
Resource dependent improvements

- Increase Inpatient rehab staffing (therapy and nursing) to National rehabilitation standards Outreach service
- Easier access to bespoke equipment
- Follow up MDT clinics Outreach service
- Additional social worker support
- Environmental improvements
- Raise awareness of ABI rehabilitation and assist transition to community

Rehabilitation service Bristol Children's Hospital.
South West Stroke conference April 2018
Non resource improvements

- Managing expectations throughout process.
- Improve use of QOL outcomes
- Implement user feedback questionnaires - patients/ families and community services
- Address areas where communication can be improved with child/ family & between services and teams
- Access charitable support mechanisms earlier
- Ensure EHCP personnel are appropriately updated/ signposted.
We are still learning...

- Formal assessment is not always the right or most important way of telling us how a young person is functioning.
- Lots of face to face therapy time is not always the answer to progress and improving quality of life.
- We must not hide ‘take home’ message in piles of information.
- Power of Parental/sibling & family engagement cannot be underestimated.

- It is always right to strive for what a young person needs regardless of resource limitations
- It is always right to listen to the young person and family.
- It is always right to stay involved for the long term, transferring to adult services where needed.
- Key therapist can help consistency in support/understanding in communication process.
- Rehabilitation is a 24 hour process.

Rehabilitation service Bristol Children's Hospital.
South West Stroke conference April 2018
Self-Advocacy Film....
When we listen we learn!

........Any questions?

Rehabilitation service Bristol Children's Hospital.
South West Stroke conference April 2018
Thriving in the educational system after stroke

Dr Siân Rees
PhD, MA (Ed) BMus PGCE
AdvDip (Special Needs)
Schools today
Who's who?

• Head
• Head of Year
• SENCo or SENDCo
• Teacher
• Teaching assistant
• LSA Learning support
• TA or HLTA
• Learning mentor
• Inclusion Worker
What schools do

• teaching and learning
  - Filling a bucket/ blank sheet
  - Helping a pupil grow/ acorns
  - Delivering the curriculum

• inclusion
  - Mixed ability classes vs sets
  - Whole class teaching
  - Differentiation
  - Removing vs In-class

• inspections
  - Evidenced learning
  - Meeting targets
    » Termly targets
    » Public exams
On return to school

- Student looks fine
- Relief at new milestone reached
- Student thinks they are back to normal
- Previous learning accessible
- Effects of ABI are patchy (Swiss cheese effect)
- 'New learning is very difficult' - careful teaching is necessary
Common Problems on return

- Concentration and fatigue
- Lack of self-awareness
- Missing underlying skills
  - Noticing and perception, attention skills
  - Expressive and receptive language
  - Organisational skills, including planning and choosing
  - Other executive skills
- Unknown ground rules
- Lack of empathy
Provision for pupils with additional needs

• 1:1 support
• IEP
• Targeted/Top up funding
• Statement of special educational need
• Education Health and Social Care Plan
Common Issues after ABI
Attention

Different kinds of attention are needed in the classroom

• Switching attention
• Sustained attention
• Focused attention
• Divided attention

Multi tasking is a major issue - teachers need to consider what they are teaching and control other aspects

Rees SA(2016) Pay attention please: issues of classroom attention after ABI
Attention cycle

Rees, S.A. (2015 awaiting publication in JORSEN) Where have they all gone? Classroom attention patterns after Acquired Brain Injury
Rehearsal - Thinking aloud

1. Planning and monitoring
2. Action as rehearsal
3. Giving permission
4. Internally persuasive
5. Going underground
Rehearsal - Thinking allowed

- Think aloud; repeat the instructions to themselves, read the question again, set their own rules, monitor understanding
- Narrative helps with impulse control
- Addressed inwards - don’t break the thought - Adults must learn to be quiet!
- ‘Don’t know’ is a request for space - Give time and space
- Analytical thinking through authentic questions

The PEDER principle

- **Point out** - focus attention
- **Explain** - label
- **Demonstrate** - visual & enactive
- **Encourage** - success orientated
- **Repeat** - little & often
• chunking,
• reducing options,
• directing attention,
• marking features,
• demonstrating
  Bruner 1978

• strategic learning
• learning strategies
  Butler 1998
Scaffold the building or buttresses

Support and Interventions

In class
- Attention focus
- Note taking
- Reminders
- Encouragement
- Removal from unsuitable lesson structures
- Advocate
- Necessary breaks
- Supervision for safety

Programmes
- Skill specific/Lifeboats
- Age and stage dependent
- Counselling/awareness
- In-house/external
What can I do as a parent?

Help him/her accept help
• Be aware
• Be accepting
• Like herself
• Be prepared to be different
Make friends with the teacher(s)
Case Studies
Felicity suffered a stroke soon after birth. She is now in Y3 but so far had not made much progress with reading. She can recognise some keywords on good days but not on others. She knows most of her letter sounds, but muddles them with the letter names when trying to use them to sound out. She can not blend the sounds together. Her reports note that she has a very much shortened working memory. Her attention span is very short and she frequently reverses symbols when copying.

• Which reading strategies may help Felicity?
• What skills should we ensure are in place?
• How could we support her in class lessons?
• What can you do at home?
Brandon suffered a stroke aged 2 yrs 6 months. As a result he has upper limb weakness, with altered sensation on the right side. He attends a mainstream primary school full-time and will transfer to a secondary school next September. Brandon finds it difficult to let go of playground issues and has a deep sense of justice. He finds it difficult to delay reward or resolutions of issues. His academic achievements are roughly on track for his age, reading being a little better and writing not so good.

Brandon’s written work is limited in scope, and can be repetitive. The maths task on which he gave up was one where he had to ‘explain’.

Brandon often finds himself in a position where he has annoyed others, through what he has said or done, but also because his ‘fidgeting’ disturbs them. He also reacts to certain triggers, such as comments about his handwriting.

- How can we help Brandon?
- What should we tell the secondary school?
Nigel suffered a stroke following a bout of chicken pox. He has just moved into KS3. Nigel appears happy, occupied and well-adjusted to his new setting. He can find friends to work with and other pupils are happy to work with him. However he was very careful to follow a routine at the start of each class, and can get anxious when things do not happen the way he imagines.

- Homework takes a long time and he does not always know what to do. Sometimes his friends alert him to homework tasks which he has not written in his planner. His teachers remind him to write in his planner.

- In most classes Nigel was seated advantageously, however sometimes he sits with his back to the teacher and he focuses on his book rather than on her?

- What should we do about this?
- Is this important?
- What can parents do to help?
Psychological aspects of stroke in childhood

Ingram Wright
Consultant Paediatric Neuropsychologist
UH Bristol

Honorary Senior Lecturer
University of Bristol
What do psychologists do?

- Support for young people and families in hospital
- Advice about reintegration to home and school life
- Support for transitions in development, school and home life
- Advice regarding diagnosis and management of specific difficulties

![Diagram showing categories: Behavioural, Emotional, Cognitive, Social]
# How do I access psychology support for my child?

<table>
<thead>
<tr>
<th><strong>Educational Psychology</strong> – access via EHCP assessment / SEND tribunal</th>
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<td>• Referral by SENCO at school</td>
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<table>
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<tr>
<th><strong>Clinical Psychologist in District General Hospital</strong></th>
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<tr>
<td>• Referral by community or hospital based paediatrician</td>
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<tr>
<th><strong>Psychologist / practitioner in Mental Health Team</strong></th>
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<tr>
<td>• Referral via paediatrician or GP</td>
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<tr>
<th><strong>Neuropsychologist in Regional Neurosciences Centre</strong></th>
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<tr>
<td>• Referral via hospital based paediatrician or neurologist</td>
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<tr>
<th><strong>Support from Charities / Access to self help literature and advice</strong></th>
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<tr>
<td>• Stroke Association, Hemihelp, Epilepsy Action</td>
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A child psychologist’s toolkit:

- Knowledge of brain development
- Functional skill development
- Linkage between skills
- Plasticity (resilience of the child’s brain)
- Vulnerability
- Implications of early vs. late stroke
Immature commitment to function

Flexibility in left/right brain organisation

Brain areas committed to specific functions

Functional localisation and commitment
Injury to the brain often results in a network of cognitive difficulties.

Specific problems with memory, language, movement are common.

How are a child’s cognitive abilities organised in development?
Improvement in functioning following acquired brain injury in childhood

Age effects on ABI – Anderson et al, Brain, 2004, 127, 2608-2620; Age effects on TBI – Ewing-Cobbs, Developmental Neuropsychology, 2003, 24, 669-704
What influences development after childhood stroke?

Pre injury
- Age
- Gender
- Pre-existing stressors
- Psychosocial reserve & resources

Post Injury
- Resources – jobs, relationships, engagement with services
- Beliefs about stroke
Children showing an *increase* in IQ

Children showing an *decrease* in IQ
How should we intervene to support children following childhood stroke?

What are your needs?

What are your child’s needs?
Meeting rehabilitation needs

Specific interventions
Restitution of function
Discrete cognitive interventions

General interventions
Environmental changes

Family integrity / Educational support
Recognition that child deserves / needs support
Mindset for change (hopefulness / optimism)

• Hidden/disguised cognitive deficits
• Repair vs. compensatory strategies
• Limited evidence for direct benefit of cognitive rehabilitation
Managing behaviour
Thinking about the past and future

Psychological Inflexibility

Grappling with painful thoughts

Thoughtless action
Being “present” connected

Psychological flexibility

Open up

Do what matters

The Reality Slap
How to Find Fulfilment When Life Hurts

Dr Russ Harris
Author of the International Bestseller The Happiness Trap
Questions and discussion
Transition points following childhood stroke

Brain Injury Community Service

28th April 2018

Dr Karen Cundy – Speech and Language Therapist, Brain Injury Community Service

Nicola Shearan – Parent
The Children’s Trust:

Inpatient Rehabilitation

Brain Injury Community Service (BICS)

- Inpatient neuro-rehabilitation/Surrey teaching centre
- BICS multi-disciplinary team based at The Children’s Trust, Surrey
- BICS clinicians based in major trauma centres (Sheffield, Leeds, Nottingham, St. Georges)
- Provide support across the UK
Content

- Childhood Stroke
- Range of difficulties from an acquired brain injury (ABI)
- What are transition points and why are they important?
- Case Study – Ollie
- A parent’s perspective
Causes of Stroke

Varied:

- Arterial dissection (torn artery)
- Arteriovenous malformation (AVM)
- Aneurysms
- Secondary to infection
- Diseases of blood vessels
- Unknown (10%)
Areas of the brain that might be affected

Frontal lobe
- Executive functions, thinking, concentration, planning, organising and problem solving, emotions and behavioural control, personality

Motor cortex
- Movement

Sensory cortex
- Sensations

Parietal lobe
- Perception, making sense of the world, arithmetic, spelling

Temporal lobe
- Memory, understanding, hearing, facial recognition, language

Occipital lobe
- Vision

Cerebellum
- Coordination of muscular activity

*Image 4: Regions of the brain*
How can a brain injury affect a child after stroke?

Image taken from: Head Injury: A practical guide, Speechmark Editions, 2004
ABI is – developing condition

Transition points

Acute → rehab
Rehab → home
Home → school
Primary → secondary
School → college
Child → adult services
Best Practice for therapy

Intervention Recommendations

- MDT approach
- Assessment
- Intervention needs to be:
  - Individualised
  - Context-based
  - Holistic
  - Functional
  - Goal-based
- Focus on addressing activity and participation
- Raise awareness of effects of ABI and long term and hidden effects
- Systematic long term monitoring throughout development
- Work across environments

Effects at the time of the injury

Late effects

Persistent effects

Cumulative effects

Transition points will come at different times along this pathway
Why are transition points important?

- Needs change
- Family situations may change
- Demands change/increase
- Developmental demands
- Improvements and new difficulties
- Lack of awareness
- Planning
Childhood Stroke Guidelines 2017

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It is possible that your child will not follow this pathway in a simple step by step way. Some steps, scans and tests may need to be repeated a number of times, and some therapy programmes may not commence until after your child returns home.
Ollie’s journey/transition points

- Stroke February 2015
- Discharge from hospital April 2015
- Return to school
- Assessment by BICS June 2015
- Inpatient stay at The Children’s Trust
- Specialist community follow up for 1 year from BICS
- Input from other specialist services (Bobarth)
- Input from community therapy and private therapy
- Moving to a new school year
Ollie’s story – hospital

- Stroke February 2015
- Scans showed evidence of a previous stroke
- Limited speech and language therapy – challenges

Nicola:
Ollie’s story – discharge home

- Discharged home April 2015
- Community: Physio, limited SLT and OT
- Back to school (Nursery at school)

Nicola:

First time outside
Things that help transition home:

• Meeting before discharge for key staff and family/child to plan going home
• Talk to other parents and organisations
• Know who key therapists are who they are referring to in the community
• Who to contact once you have left hospital
• Hospital social worker
• Linking in with school/visits
• ? Financial resources you may be entitled to
• ? Education, Health and Care Plans (EHCP)
• Referral to specialist services (local rehab, BICS, CCPNR, Bobarth)

CCPNR (Cambridge Centre for Paediatric Neuropsychological Rehabilitation)
EHCPs – Education, Health and Care Plans
(In Wales this system is still the ‘Statement’ system)

• On return to school your child may need extra support
• Timing of EHCPs (primary, secondary, college)
• The process
• Who can support you with the process
• SENCOs (special educational needs co-ordinator)
• The local offer (of all SEND services)
• IPSEA
Ollie’s story - Assessment by specialist services

Wide range of cognitive, communication, emotional and social difficulties:

- right sided hemiplegia affecting mobility
- unilateral hand/arm use
- attention
- flexible thinking
- expressive language
- Speech (dysarthria)
- cognitive communication skills
- social skills
- self-care difficulties
- eating and drinking
- mouthing/chewing behaviour
- perceptual – visual/sensitivity to noise
- behaviour changes – eg impulsive, frustrated, over-familiar
- Emotionally labile
- maintaining personal safety

Note: Hidden difficulties
children can have subtle cognitive and communication difficulties which may not be picked up by commonly used standardised assessments.
Ollie’s story – Specialist inpatient neurorehab

- Speech and language therapy
- Occupational therapy
- Physiotherapy
- Neuropsychology/clinical psychology/educational psychology
- Play/music therapy
- Surrey teaching centre

Nicola:
Intervention:

- Brain injury education for family, school and local services
- Supporting school to implement strategies and move goals forward
- Supporting school to plan for transition to the next school year
- Observations at school
- Informal assessment with Ollie
- Attending meetings at school e.g. EHCP review meeting
- Liaising with local SLT services to set joint goals
- Support family

When to consider private therapy input in addition to local services #
- what experience they have with stroke?

Nicola:
Ollie now
The journey continues..

- **Primary school → secondary school**
  - Teenage development!
  - Brain development
  - GCSEs
  - Year 9 planning
  - Increasing independence
  - Social skills

- **Adolescence**

- **School → college**
  - Continue EHCP support
  - Planning for the future
  - Working
  - Increasing independence
  - Social skills

- **Children's services → Adult services**
  - Planning
  - Independence
  - What support is needed?
  - What organisations?
  - Accommodation
  - Finances

- Reduced awareness of ABI
- Higher educational demand
- Making new friends
- Increasing independence

The Children’s Trust
Your child’s rehabilitation needs in the following areas might be assessed: mobility, vision, hearing, pain, eating, drinking and swallowing, communication and speech, reasoning, memory and attention, interpersonal skills, learning, self-care and independence, mental health, equipment, home access, and orthotics.

Health and education professionals will work with your child and your family to set goals for their rehabilitation and review these goals at least once per year.

You and your family should be provided with information about accessing care for your child and sources of support and information. Your child’s school should also be contacted and the needs of your child explained.

There should be ongoing communication about the progress of your child between yourself, the school and your child’s healthcare professionals and key worker. Your child’s therapy during school should take into account their needs and be flexible and integrated. You may need an Education, Health and Care Plan which details your child’s therapy and education needs. You may need written documentation of your child’s medical and care support needs.

Moving from child to adult healthcare may be challenging because your child will be expected to take more control of their own care. You should have a meeting with your child’s health professionals to plan this transition where the roles of all the different professionals will be explained. You might need to have more than one of these meetings.

Planning for your child’s/young person’s transition into work or higher education should begin early and should actively involve them.
Useful resources

The Children’s Trust (parent handbook, Me and my brain – teenage handbook)

Brain Injury Hub [www.braininjuryhub.co.uk](http://www.braininjuryhub.co.uk)

Stroke Association – Childhood Stroke Guide/Childhood Stroke handbook

Childhood Stroke Guidelines 2017 [Royal College of Paediatrics and Child Health](http://www.rcpch.ac.uk)

United Kingdom Acquired Brain Injury Forum (UKABIF) [ukabif.org.uk](http://www.ukabif.org.uk)

Child Brain Injury Trust (CBIT) [www.cbituk.org](http://www.cbituk.org)

Different strokes