The Upper Limb Clinic and Three Week Intensive Upper Limb Programme at Queen Square

Pushing the boundaries

Will Chegwidden
Senior Occupational Therapist
The National Hospital for Neurology and Neurosurgery
Harry, Young person
The team

- Consultant Neurologist: Professor Nick Ward
- Consultant Physiotherapist: Fran Brander
- Consultant Occupational Therapist: Kate Kelly
- OTs: Will & Sarah, PTs: Dhiren & Christine
- Rehab Assistants: Chloe & Jordan
Who we see

- People with difficulty using their arm and hand because of a neurological injury or condition.
- Mostly stroke, but also brain tumours, traumatic brain injury, metabolic and infective causes of brain injury etc.
- 16 and over
- Typically at least six months since stroke, often much longer
The clinic

- One hour appointment with Professor Ward and the Consultant Therapists
- Assessment of upper limb function and discussion around goals
- Possible outcomes:
  - Advice & information for the individual, family or current therapy team
  - Referral on to other specialist services e.g. shoulder pain, spasticity management, splinting, NMES clinic for further treatment (and possible admission in the future)
  - Admission to the three week intensive programme
The three week intensive programme

- Patients come in from 9am-4.30pm Monday to Friday, for three weeks
- If they live locally we provide taxis
- If not local we provide a hotel from Tuesday night to Thursday night and taxi to and from the hotel
- **Full on programme!** Every day:
  - Two sessions of physio
  - Two sessions of occupational therapy
  - Rehabilitation Assistant 1:1 sessions
  - Self-directed tasks and exercises
  - Groups – OT, PT, RA & joint
- Review appointments at six weeks and six months
### Upper limb treatment – Queen Square Programme

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**100 hours over 3 weeks**
Eligibility criteria…

We recognise people are complex and consider each situation individually.

Things we take in to consideration:

- Some return of movement (hand opening, reaching)
- Is this the optimal time?
- Where you are at with local therapy services
- Other related issues e.g. spasticity, contractures
- Do you have goals to work on that we can help with?
- Ability to cope with 7hrs/day therapy
The first two days

- We complete a range of assessments including tests that look at quality of movement, strength, sensation, grip, grasp, reach and dexterity
- We set goals that are personal and individual
- We see the programme as a six month programme with the three weeks being the “kick-start”
- A key aim is to enable people to have the skills to continue their rehabilitation afterwards.
- We encourage people to have aspirational goals
### Example goals

<table>
<thead>
<tr>
<th>To write using the right hand and to be able to highlight text using the right hand</th>
<th>To hold purse my in left hand get cards and money with right hand</th>
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<td>To independently cut up food with a knife in the right hand and fork in the left hand</td>
<td>To independently put hair in a ponytail with a clip or a scrunchie using both hands</td>
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<td>To incorporate the left hand in to using the XBOX controller.</td>
<td>To carry my bag on my right shoulder and tie my shoe laces on my hiking boots</td>
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Improving movement through handling

Primary treatments
- Improving underlying movement through handling, strengthening, stretching
- Improving movement using everyday, meaningful activities
- Specific techniques: e.g. sensory work, constraint, neuromuscular electrical stimulation, taping
- Splinting – resting and functional splints

Adjuncts
- Robotics & gaming
- Finger extension orthoses
- “Priming” – cardiovascular exercise, mirrorbox
- Education – individual and groups
Key principles

- Evidence-based
- Repetition
- Personalisation
- Intensity
Examples of treatments

- We complete a range of assessments including tests that look at quality of movement, strength, sensation, grip, grasp, reach and dexterity
- We set goals that are **personal** and **individual**
- We see the programme as a six month programme with the three weeks being the “kick-start”
- A key aim is to enable people to have the skills to continue their rehabilitation afterwards.
- We encourage people to have **aspirational** goals
The last two days

- We repeat our outcome measures and feed back
- We put together a discharge pack with photos and videos
- We help people set up their own programme for home
- Review from Professor Ward and the consultant OT & PT on the last afternoon
- We provide whatever resources and kit we are able to do and signpost how to get hold of whatever else is needed
So – does it work?

- “meaningful clinical improvement” on Fugl-Meyer, ARAT and CAHAI (our “outcome measures”)
- People achieve their goals!
- Feedback – focus group
## Results

- We completed 1 staff focus group that included 4 occupational therapists, 4 physiotherapists, 2 rehabilitation assistants.
- We completed 3 patient focus groups that included 17 stroke survivors and 2 carers.

### Stroke survivor themes:

- Individualised goals
- Communication
- Pushing the limits
- Access enablers
- Motivation
- Skill set
- Structured timetable
- Facilities & equipment
- Values and beliefs
- Supports
- Opportunities to learn
- Confidence

### Psychosocial

- “This programme is individualised - tailored to you, your needs, your goals”
- “Team made you feel positive and made you feel things were achievable”
- “You get confidence; you get independence”

### Team

- “Highly professional staff, educated, highly motivated, devoted”
- “Actually being with other people who were in a similar situation, I found very advantageous”
- “Teamwork makes you work harder, its having a common bond between you all”

### Behavioural training

- “Grueling and goals get higher every day. Making you improve more...”
- “Structure forces you to extend yourself and you need to be forced”
- “If we couldn’t do something one way an alternative way was shown. I think it really came together because you could see how much you were learning”

### Resources & Environment

- “I didn’t think I would even try any equipment but after I finished here I went and joined the local gym”
- “Accommodation was very good. It made me feel that yes I can do it on my own and I can....take my case and I can zip it up”
- “A very resource intensive course, there is space and staff available to make us do things here...”
What people are getting in the first phase after stroke

Dose of arm activity training during acute and subacute rehabilitation post stroke: a systematic review of the literature

Kathryn S Hayward and Sandra G Brauer

Clinical messages

- Stroke survivors engage in a limited time of activity-related arm training during rehabilitation: less than four minutes during physiotherapy and 11 minutes during occupational therapy in acute rehabilitation; and less than six minutes during physiotherapy and 12 minutes during occupational therapy in subacute rehabilitation.
What we provide on our programme

What’s in the black box?

- Time
  - 86% active
  - 12% other-based time
  - 28% U.L.-based time
  - 15% passive
  - 33% sensory

- Repetitions
  - 94% active
  - 12% unassisted, non-functional
  - 36% unassisted, functional
  - 31% assisted, non-functional
  - 15% assisted, functional

- Other-based time
  - 50%

- U.L.-based time
  - 50%
Things to consider for younger patients

- The service is co-located with an inpatient neuro-rehab unit, using the same gym and sharing the dining room at lunch time. Some of the patients may have some obvious physical difficulties such as brain surgery scars and protective helmets, or may have some mild behavioural issues.

- We will work hard on any appropriate goal and that has in the past included sports, schoolwork/writing/computer use, hobbies, make-up and clothes, games console use etc. but we are by no means educational experts – but happy to work with teachers and parents around specific goals.
Referrals

Referrals should be sent to:
Professor Nick Ward
The National Hospital for Neurology and Neurosurgery (Box 146)
Queen Square, WC1N 3BG

Referrals need to be made via the GP

uclh.referrals.upper.limbadmin@nhs.net
The future

...for us

- We are getting busier and the wait time is going up. We hope to expand!
- We move to electronic notes in 2019 which will allow patients to access records like video instructions…
- We hope to set up a sister service for people who aren’t ready for, or can’t manage three weeks intensity
  More kit, better environment!
  Driving simulator, raised garden beds, virtual reality…

...for stroke rehab

- Other services use our model and replicate us up and down the country
- More research to know more about how much of, when and what therapies work
- Stroke services to put more emphasis on the upper limb from day one
- Don’t ignore arms with what appears to be limited potential
Harry and his reflections on the Upper Limb Queen Square programme

- Two strokes at the beginning of 2017
- Initially had no movement in my left side, could not stand or use my arm or hand at all
- 15 weeks inpatient rehabilitation at a children’s specialist centre
- Started the 3 week intensive programme at Queen’s Square in June – at 16 I was their youngest ever patient
- I had to have an assessment to check if was able to access the programme, and seek local funding via my clinical commissioning group
Harry and his reflections on the Upper Limb Queen Square programme

- I had to be motivated to take part in this programme
- I was taking part in therapy alongside stroke survivors who were older than me – but very friendly and up for the challenge!
- Queen Square provided accommodation which reduced the fatigue associated with travelling and meant I could focus on therapy
- A busy mix of group sessions and individual therapy
- Programme goal focused and measurable so you could track and see your progress
- Gave the confidence to get back to things I wanted to do like tennis, and this confidence continued after the programme
Harry and his reflections on the Upper Limb Queen Square programme

- Wide range of goals including eating independently, using a zip, going swimming, getting back to tennis
- I was treated more like an adult, and practiced skills that would get me ready to be more independent
- Lots of different ways of accessing rehabilitation through the programme – group gym sessions, technology sessions, cooking group, swimming and tennis, physio sessions, saebo glove, robot therapy room
Harry and his reflections on what motivated him during the Queen Square programme

- Trips out to do functional things
  - Playing tennis
  - Swimming at a pool
- Having a laugh
- Having clear goal/s, and seeing progress
- Clear planned sessions
- Being in a group with others
- The nearby ice cream van, Franca Manca and the blueberry pancakes in the café in the church hall in the square!
Harry and his reflections on the therapy team at the Queen Square programme

- “Didn’t MAKE me do stuff, but established authority and confidence from the start”
- “kind”
- “treat me like an adult as much as possible”
- “make me laugh and are funny”
- “tell me what is happening and why”
- “give me all the technical information and detail”
- “doesn’t talk too much and for too long ….Does things”
- “practical sessions …. Too much talking early on and I’ve switched off”
- Get the timing right e.g. rejected FES initially, but they gave me time to decide when and didn’t give up …
- Planned sessions so I was clear about what we were doing, and what I had to do ..
Harry and his reflections on rehabilitation after Queen Square

- Since Queen Square I have accessed the ARNI programme and Dr Tom Balchin – challenging and positive therapy programme led by stroke survivors – I continue to work on upper limb rehabilitation
- Encouraged by the ARNI programme I have taken up a new sport – taekwondo. First new thing since my stroke – been a positive experience
- Able to continue to access follow up at Queen Square including FES (Functional Electrical Stimulation) and NMES (Neuro Muscular Electrical Stimulation)