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St Helens and Knowsley Teaching Hospitals **NHS**
NHS Trust



Setting up inpatient rehabilitation for recovering critical care patients with very complex needs

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Intensive Care Research Group

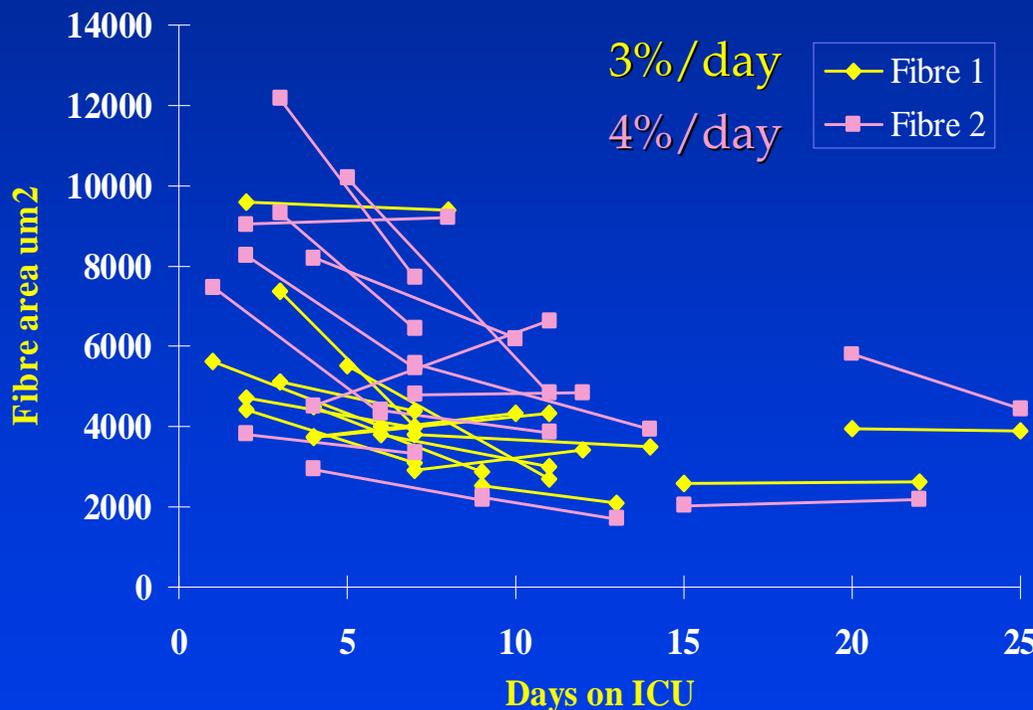
- Research programme over the last two decades
 - Follow-up study (1985 – 1988)
 - outpatient clinic (1990 -)
 - questionnaire follow-up (1990-1994)
 - ward visits (1990-)
 - support group (1992-1997)
 - Validation ICU Memory Tool (1997-1998)
 - Rehabilitation intervention study (1997-1999)
 - Validation of tool for post traumatic stress disorder (1999 – 2001)
 - RACHEL I Multi-centred study examining factors in ICU and psychological recovery (2003-2005)
 - Cognitive Function following critical illness (2004-2005)
 - Benchmarking Psychotherapy service (2006-2007)
 - RACHEL II ICU diaries (2006-2008)
 - REMAIC RCT outpatient physiotherapy 2010-2014

Follow-up in 1990 showed....

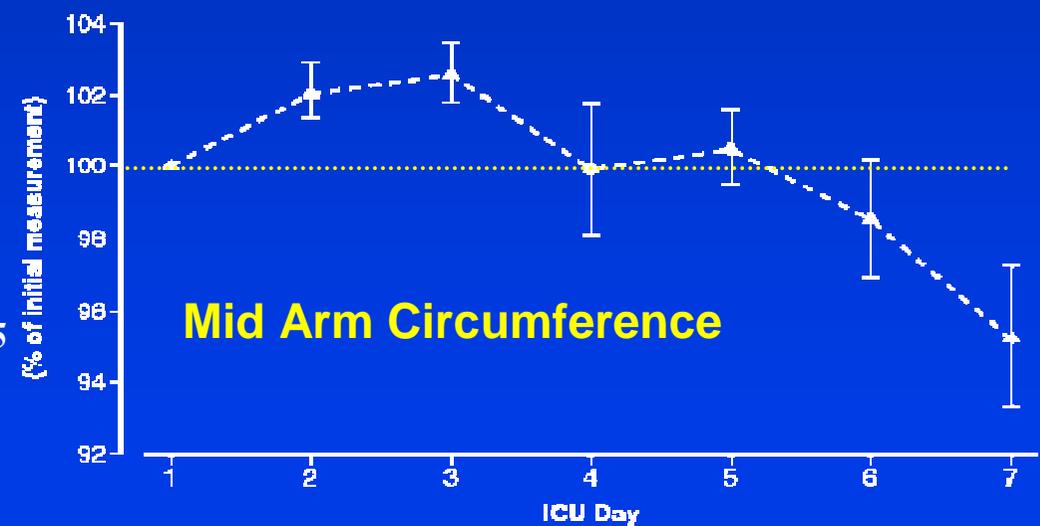
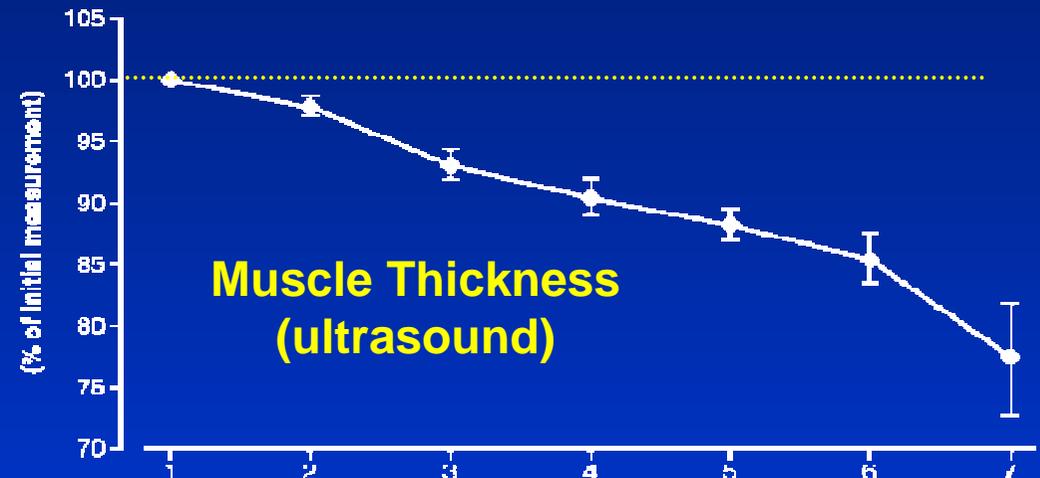
- Weakness & incapacity on the wards
 - Beyond patient expectations (no memory)
 - Ward nurse expectations (outside the norm)
- Unable to feed without assistance
 - Difficulty chewing & swallowing
 - Food being collected uneaten
- Unable to mobilise without resource input
 - Remaining in bed, joint contractures
 - Postural hypotension, Motor & sensory neuropathy
- Discharged home without services
 - Expectations too high (outside of experience)
 - Calamity at home & relatives unable to cope

Loss of skeletal muscle is early & extreme but hidden by oedema

Fibre area in Paired muscle biopsies
16 ICU patients



Helliwell, Wilkinson, Griffiths et al
Neuropath & Appl Neurobiology
1998; 24:507-517

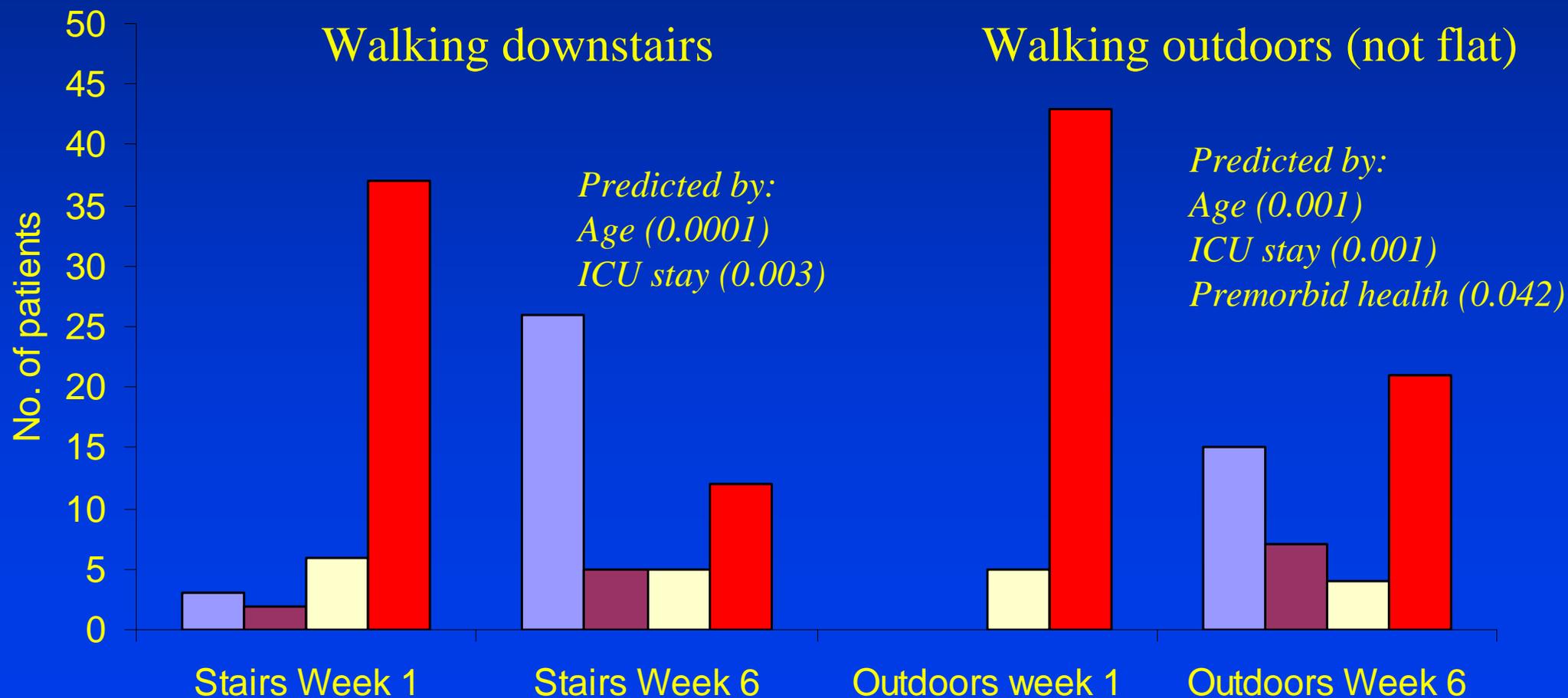


Reid CL. Clinical Nutrition 2004; 23: 273-280

Physical activity at 6 weeks post-ICU is determined by muscle wasting (age & duration of ICU illness)

Jones C, Griffiths RD *Clinical Intensive Care*. 2000; 11(1): 43-46

■ Light (6-11) ■ Moderate (12-15) ■ Heavy (16-19) ■ Impossible (20)



Critical illness poly neuropathy and myopathy

- Critical illness polyneuropathy (CIP)
 - frequent complication of critical illness
 - primarily affecting the motor and sensory axons
 - causes severe limb weakness and prolonged weaning from the ventilator
 - distal loss of sensitivity to pain, temperature, and vibration

Bolton et al Critically ill polyneuropathy. J Neurol Neurosurg Psych 1986, 49:563-573.

- Critical illness myopathy (CIM)
 - Where muscle is primarily involved, it is called myopathy
- Zochodne et al Myopathy in critical illness. Muscle Nerve 1986, 9:652

Recovery of CIP & CIM

- Important impact on the outcome of patients in the ICU
 - typically cause severe muscle weakness and paralysis and impair rehabilitation in up to 100% of patients with a prolonged stay in ICU
 - may prolong the need for ventilatory support where the phrenic nerve and diaphragmatic muscle are involved
 - Improvement occurs within weeks in mild cases and but months in severe cases
- Recovery characterised by progressive reinnervation of muscle
- In CIP restoration of sensory function is required
- Full recovery reported in over 50% of patients

Patient directed rehabilitation



- Six-weeks guided rehabilitation after ICU
- Physical and psychological advice
- Educational principles
 - self-directed
 - monitors & reviews
 - self discovery
- Involves the family

Jones C, Skirrow P, Griffiths RD et al Crit Care Med 2003; 31: 2456-2461

Available free to download as pdf <http://www.sthk.nhs.uk/pages/Guidelines.aspx?iPageId=4483>

Self-guided physiotherapy

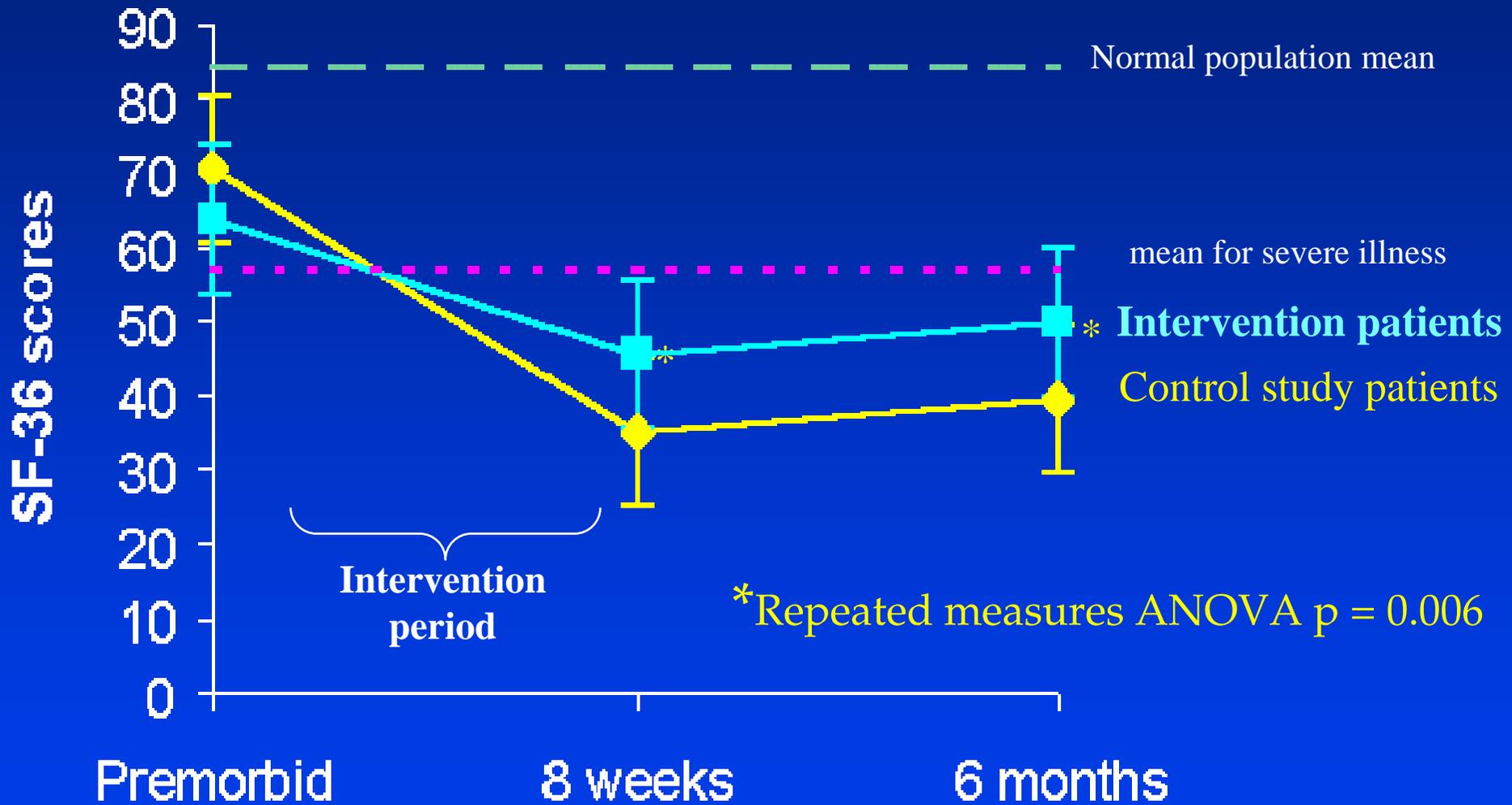
- Exercise diary - activity record
 - » From washing self to walking briskly
 - Record if able *and* how easy
- Borg effort scale
 - Patients learn to grade degree of effort daily
 - » choose activity
 - » to grade difficulty & show improvement
- Exercise diary links to guided weekly exercise program
 - Menu to suit all kinds of patients
 - » Warm up, back & joint movement
 - » Leg, arm, heart & lung exercise

Borg Effort Scale

6	
7	very, very light
8	
9	very light
10	
11	fairly light
12	
13	somewhat hard
14	
15	hard
16	
17	very hard
18	
19	very, very hard
20	



Improved Physical Recovery



Jones C, Skirrow P, Griffiths RD et al Crit Care Med 2003; 31: 2456-2461

Smoking cessation

Smokers	Intervention <i>n</i> = 31	Control <i>n</i> = 30
Pre-ICU admission	20	16
8 weeks	2 (10%)	5 (31%)
6 months	3 (15%)*	10 (62%)*

*Fishers Exact Test $\chi^2 = 7.53$, $df = 1$, 2-tailed $p = 0.006$.

Jones et al. Intensive Care Medicine. 2001;27:1547-1549.

Cognitive deficits

Cognitive deficits

- ARDS patients most extensively studied
 - Two year follow-up study
 - » Almost half (47%) still had impairment at 2 years
 - » With most recovery taking place over first year
 - » Affected memory, problem solving, making decisions and quick processing
 - » Principally the defects found involved executive function.
 - Hypoxaemia associated with worse cognitive defects at one year
 - » Relationship was less strong for the deficits remaining at 2 years suggesting a combination of aetiological factors.

Hopkins RO et al Neurophysiological sequelae and impaired health status in survivors of severe acute respiratory distress syndrome. Am J Respir Crit Care Med 1999, 160:50-56

General Intensive Care Patients

- 51 patients followed up to 9 months
 - At 3 months
 - » Slow response times, poor strategic thinking, poor memory
 - » 18% performed at or below the lowest 5% of the normal population on all tests
 - » 55% had abnormal results on at least one test
 - At nine months
 - » only 4% were abnormal on two or more tests and 27% on one test

Sukantaret KT et al Prolonged cognitive dysfunction in survivors of critical illness
Anaesthesia 2005;60:847-853

- 41 patients followed to 6 months
 - 32% cognitively impaired
 - Significant depression found on 27% of impaired patients ($p=0.02$)

Jackson JC et al. Six month neuropsychological outcome from medical intensive care unit patients. *Critical Care Medicine* 2003;31(4):1226-1234.

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Richard D. Griffiths
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Sally Wilson

Significant cognitive dysfunction in non-delirious patients identified during and persisting following critical illness

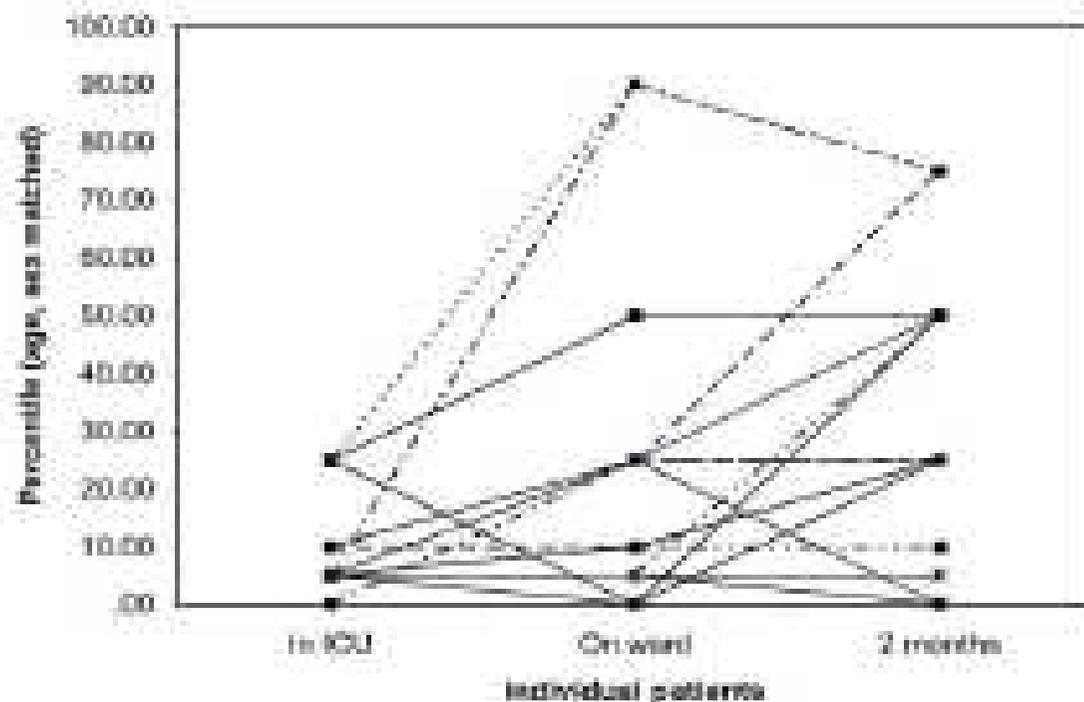
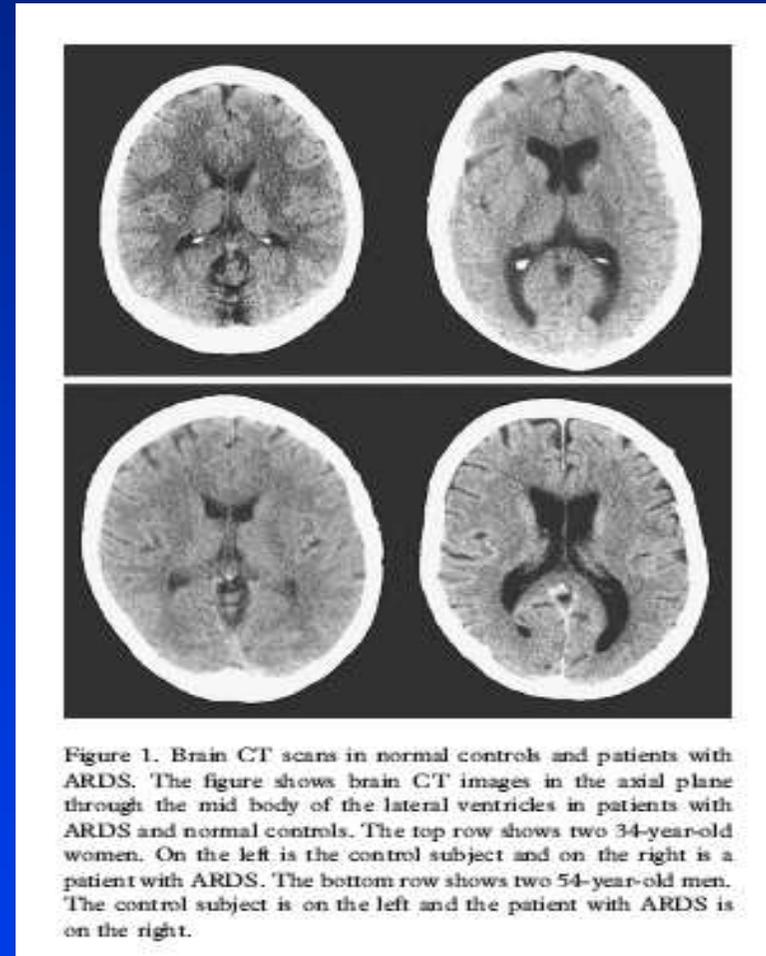


Fig. 1 Stocking of Cambridge (SOC) test of problem solving in patients with complete 2-month follow-up ($n = 16$)

Cognitive impairment in survivors of acute respiratory distress syndrome

ARDS patients vs normal controls

- Significant brain atrophy
- Larger ventricular volumes:-
 - Lateral ventricles ($p=0.02$)
 - III ventricle ($p=0.02$)
 - L temporal horn ($p=0.006$)
 - R temporal horn ($p=0.05$)
 - Total ventricular volume ($p=0.02$)
 - Ventricle to Brain Ratio (0.008)



Correlation between CT findings and cognitive impairment

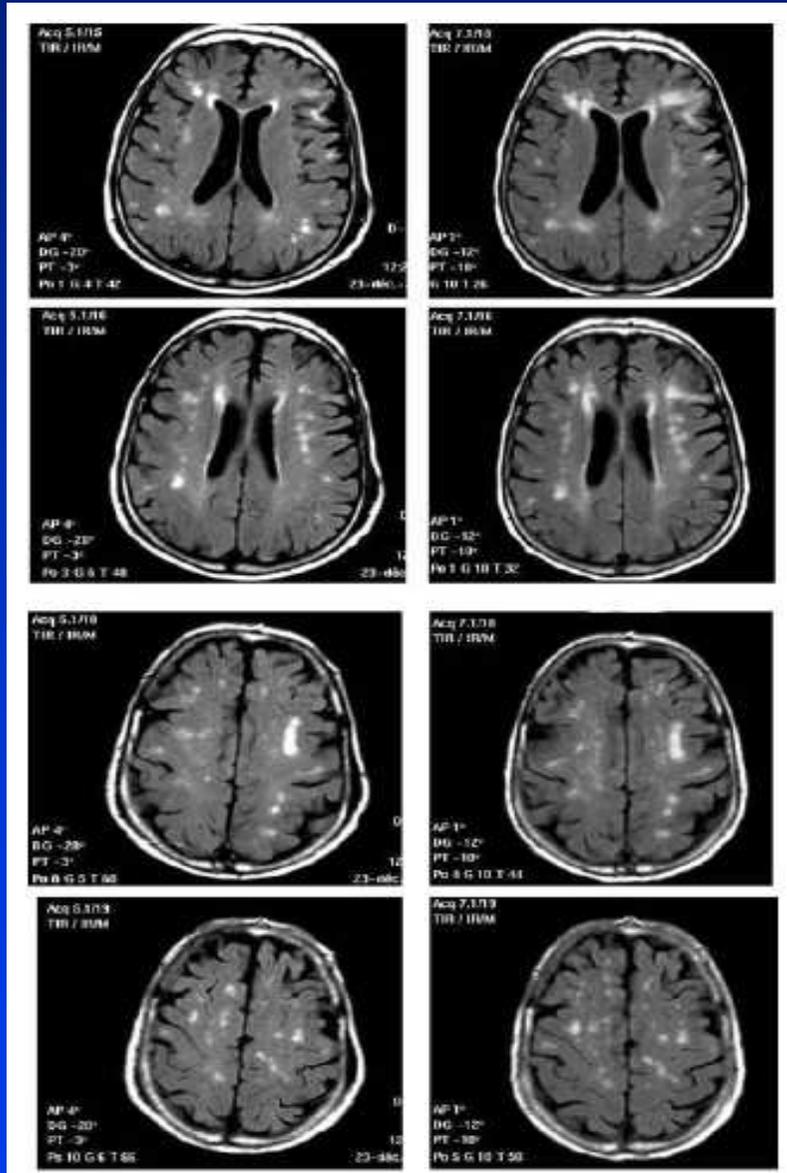
- All ARDS patients had significant cognitive deficits at hospital discharge
 - Impaired memory, attention/concentration and impaired processing speed
- At 1 year follow-up
 - Memory impairment still present, improvements processing speed and executive function
 - Third of patients still with significant impairment
- No significant correlation between ventricular volumes and:
 - Medical data
 - Duration or severity of hypoxia
 - Neurocognitive scores

Tarek Sharshar
Robert Carlier
Francis Bernard
Céline Guidoux
Jean-Philippe Brouland
Olivier Nardi
Geoffroy Lorin de la Grandmaison
Jérôme Aboab
Françoise Gray
David Menon
Djillali Annane

Brain lesions in septic shock: a magnetic resonance imaging study

- MRI scanning showed:-
 - Brain damage predominantly within white matter
 - These lesions worsened over time in 2 patients including one patient who survived
- Possible mechanism
 - Suggests predominant perivascular oedema
 - » blood-brain barrier breakdown allowing blood borne- inflammatory mediators to accumulate in the brain

Change in MRI scan in sepsis



- 79 yr old woman
 - ARDS due to Streptococcus pneumoniae
- Left day 3 Right day 30
- Multiple bright signal areas
- Extensions seen at day 30
- Grade 2 leucoencephalopathy
- Moderate disability

Confounding factors

- Post traumatic stress disorder (PTSD)

- PTSD Patients describe difficulties with concentration, attention and memory

- Some studies have shown poorer performance:-

- » Tests of attention and declarative memory

Bremner JD et al *Biological Psychiatry* 1997;41:23-32

- » Others have not

Neylan TC et al. *Attention, Learning and Memory in Posttraumatic stress disorder J Traumatic Stress* 2004;17(1):41-46

- Depression

- Associated with reduction in memory performance

Burt DB et al *Depression and memory impairment: a meta-analysis of the association, its pattern and specificity Psychology Bulletin* 1995;117(2):285-305

Psychological problems

Post Traumatic Stress Disorder

- **DSM IV-R American Psychiatric Association**
 - Exposure to a traumatic event/s in which the individual experienced/witnessed or was confronted with event/s involving actual or threatened death/serious injury or threat to the physical integrity of self/others AND responded with intense fear, helplessness or horror
 - 3 symptom groups
 - » Intrusion (nightmares, flashbacks)
 - » Avoidance (avoiding reminders)
 - » Hyperarousal (not sleeping)
 - Symptoms are experienced for more than one month
 - Clinically significant distress/impairment in social, occupational or other areas of functioning

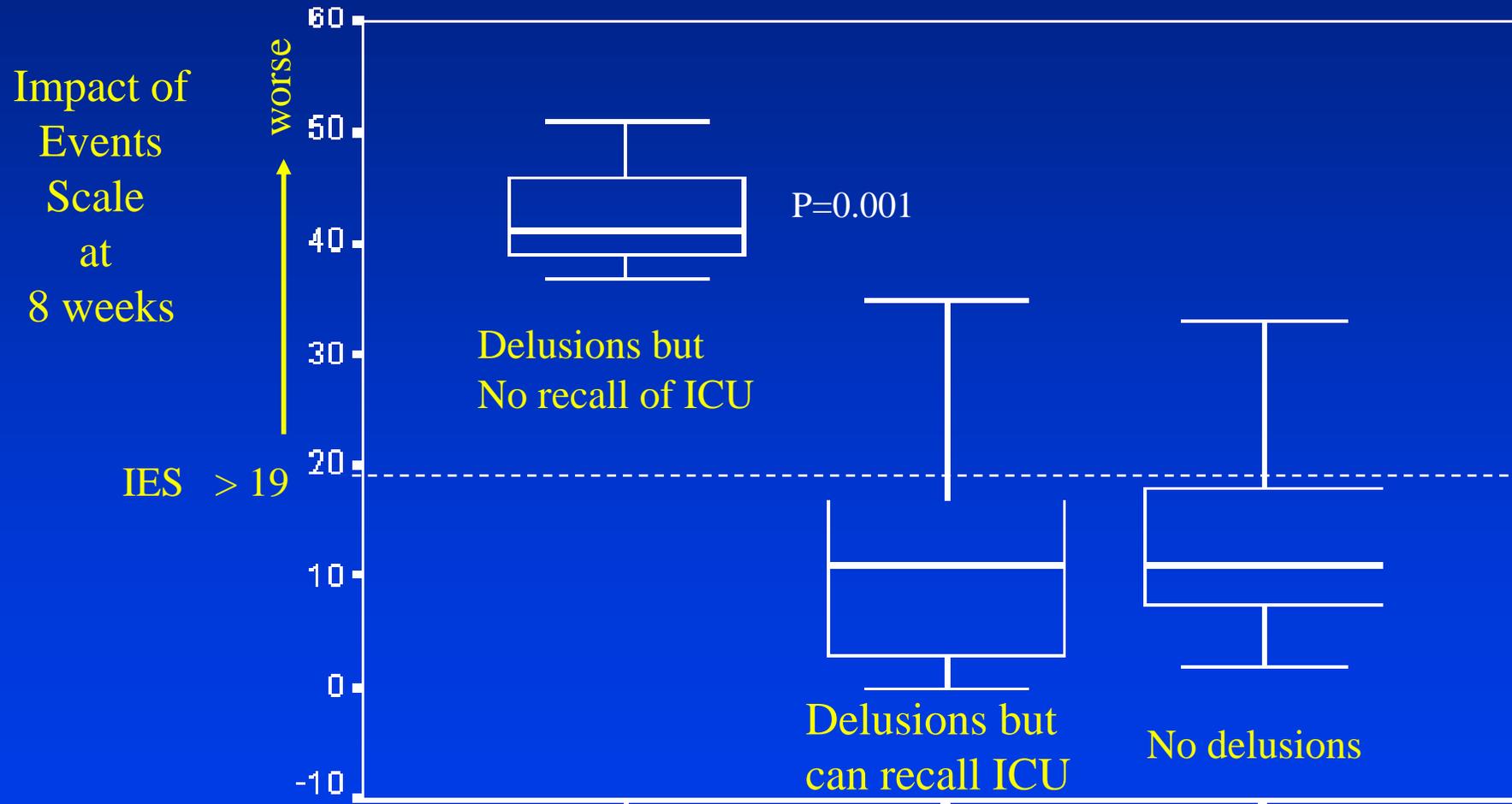
Possible clinical signs

- Recurrent nightmares replaying traumatic memories
- Finding it difficult to sleep even when no nightmares
- May be phobic about coming near ICU
 - May transfer to being phobic to coming to the hospital
- Hold themselves very tense (flight, fight, freeze)
 - Raised shoulders
 - On watch for potential threats
 - Look frightened
- May do not want to talk at all about their illness
 - Helps them control their symptoms
- Challenging for ward staff to care for

Importance of memory for ICU

PTSD related symptoms & ICU memories

30 ICU patients recall tested at 2 weeks & IES at 8 weeks post ICU



RACHEL 1 (2002-2005)

- 5 ICUs across Europe
 - Ratio of PTSD and relationship to:-
 - » patient previous psychological history
 - » In ICU periods of delirium or withdrawal symptoms
 - » patient care practice, e.g. sedation depth, opiate and sedation doses or physical restraint
 - » Memories for ICU using ICU Memory Tool

Factors associated with PTSD

In ICU

- Physical restraint (23% of restrained patients)
 - Combined with no sedation
- Deep sedation/large sedative doses
 - Found to be related to delirium
- Recall of delusional memories

Patient factors

- Recall of delusional memories for ICU
 - More common where history of previous psychological problems
 - » Depression, anxiety, panic attacks, phobias
 - Deep sedation/large sedative doses

Jones et al. Precipitants of post-traumatic stress disorder following intensive care: a hypothesis generating study of diversity in care. *Intens Care Med* 2007;33(6):978-985

PTSD rates

- Average rate of acute PTSD was 9.2%, range 3.2%-14.8%
 - 22 patients out of 238 followed up at 3 month
 - 7 patients already had undiagnosed PTSD at ICU admission
 - 96 patients had sub-clinical PTSD
 - » 90 (39%) had levels of distress that effected their every day functioning

Delusional memories and trauma

- 239 ICU patients admitted because of physical trauma
 - Assessed 6-18 months post ICU with ICU Memory Tool
 - » 15% had no ICU memories at all
 - » 26% delusional memories
 - » Majority no memory of admitting trauma
- Delusional memories
 - More common in younger patients
 - Longer ICU stay
 - Sedation
 - » Unexplained feelings of panic after ICU discharge
 - » Less likely to have gone back to work at 1 year

Ringdal et al Intens Crit Care Nurs 2006;22(6):346-354

ICU Diaries

- Idea originated in Sweden
 - Nursing intervention
 - Daily account of ICU stay in every day language
 - Photograph of patient taken at start
 - » Aim to fill in memory gaps and help patients understand their illness
 - Given to the patient after their discharge from ICU
 - » At a time of the patients choosing
 - » With staff support to go through the diary and photos
- Bäckman C, Walter SM. Intensive Care Medicine 2001;27:426-429

RACHEL II Diary study

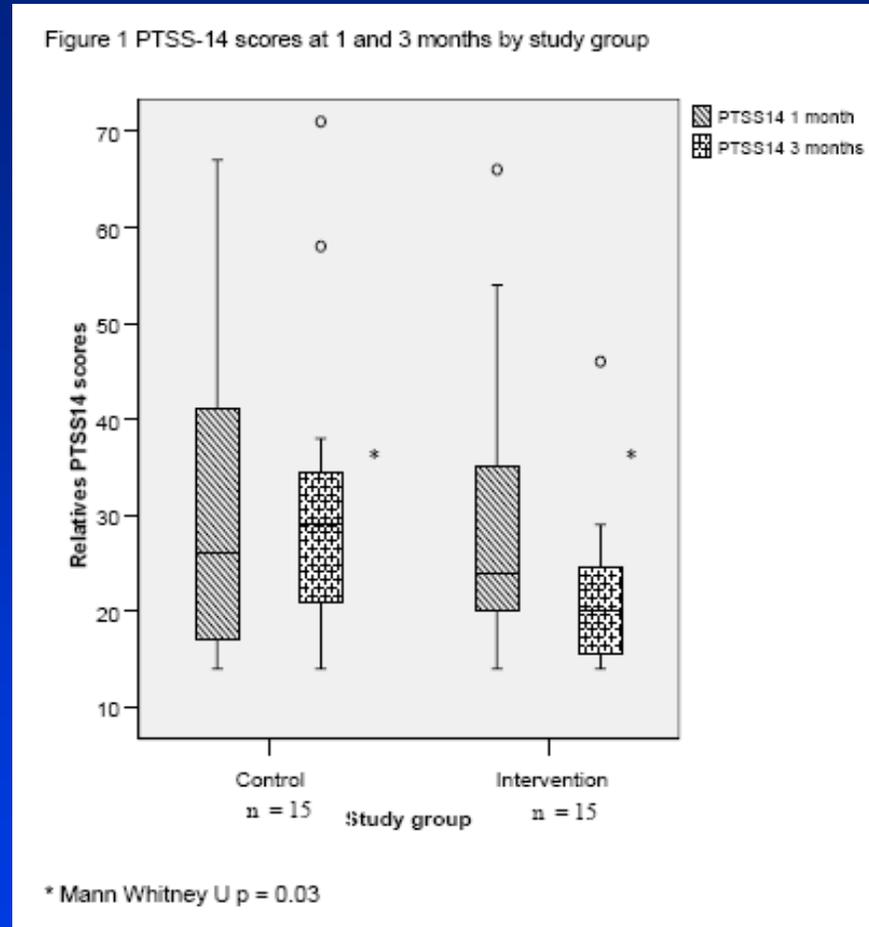
- To examine the impact of a diary on development of PTSD
- Randomised controlled trial
- Study units
 - Whiston Hospital, UK
 - Ferrara University Hospital, Italy
 - Haukeland University Hospital, Bergen, Norway
 - Ullevål Hospital, Oslo, Norway
 - Vrinnevishuset, Norrköping, Sweden
 - Gotenburg, Sweden
 - Malmo, Sweden
 - Hospital Pedro Hispano, Matosinhos, Porto, Portugal
 - Hospital Geral de Santo António, Porto, Portugal
 - Hillerød, Copenhagen, Denmark coordinating three ICUs
 - » Nordsjaelland, Odense, Skejby Hospitals

ICU Diaries

- RACHEL II study 352 patients were randomised
 - New cases of post traumatic stress disorder was reduced
 - 5% intervention vs 13% controls, $p = 0.02$

Jones C et al Intensive Care diaries reduce new onset PTSD following critical illness: a randomised, controlled trial *Critical Care* 2010,14:R168

Reduced PTSD-related symptoms in relatives



Jones et al Intensive Care diaries reduce PTSD-related symptom levels in relatives following critical illness Am J Crit Care 2012; 21(3):172-176

Setting up inpatient rehabilitation services

Very complex needs

Why Cheshire and Merseyside Rehabilitation Network was founded

- UK Standards for Rehabilitation Services
 - Recommendations in 2009
 - Need for local Rehabilitation Services
 - Range of different levels of services required to address individuals REHAB requirements
 - Providing services for people with profound and complex disabilities
 - whose needs are beyond the scope of local services
 - Planned and co-ordinated service delivery ensuring clear pathways that can be delivered across hospital and community settings

Population statistics

- Merseyside is a mixture of the metropolitan area of Liverpool, suburban surroundings and rural areas
- Population in 2012 - 1,385,666

Hub and generic spoke

- Hub (Walton Centre) 30 regional beds
- Spoke beds serving Merseyside (up to 16 weeks stay)
 - St Helens Hospital Elyn Lodge
 - » 10 beds (7th Jan 2013)
 - » 20 beds (1st April 2013)
 - Broadgreen Hospital
 - » 15 beds (1st April 2013)
 - Providing outpatient services including daily therapy, O.T. Physio and vocational REHAB for up to six weeks after inpatient stay

Slow stream rehabilitation

- Vancouver House 16 beds
- Mossley Hill 8 beds
 - Cognitive rehab and community re-integration
- Redford Court purchase on individual case need

Inclusion Criteria

Hub

- patient registered with a Cheshire or Merseyside General Practitioner

Spoke

- Patients registered with Merseyside GP

Criteria

- Adults 18 and over
 - Patients aged 16 to 17 considered on individual needs
- Significant deterioration due to injury or illness coupled with significant functional impairment
- Able and willing to participate
- Understand the benefits of rehabilitation
- Not diagnostic specific but based on patients needs

Exclusion Criteria

- Patients with little or no rehabilitation potential following comprehensive assessment by the team
- Patients with **severe** active mental health issues
- Patients with rehabilitation needs that can be met within well established pathways
 - Cardiac patients

Criteria for Rehabilitation within the Hub Category A

*These patients will have highly
complex needs, profound
disabilities or challenging
behaviours*

Criteria for Rehabilitation within the Spoke Category B

*These patients will have moderate
to severe disabilities, needs or mild
to moderate behavioural issues*

Key Worker

Main Responsibilities

- Promote, implement & deliver high quality, accessible and equitable rehabilitation services
- Act as the single point of contact for referrals for the Rehabilitation Network beds
- Work collaboratively to ensure a co-ordinated and timely transfer along the rehabilitation pathway
- Promote effective communication systems with patients, families and health and social professionals

Referral to network beds

- Rehabilitation Co-ordination team point of access for beds
- Referral can be made by any discipline
 - Having identified a patient as having a complex or ongoing rehabilitation need as a result of major illness, trauma or acute neurological event
 - Referral documents and criteria available via the internet
 - Patients in Critical Care or trauma units, the rehabilitation passport can act as referral document

Patients referred from ICU

- 8 long stay ICU patients accepted for St Helens Network Rehabilitation since January 2013
- Complex needs physical, cognitive & psychological
 1. 36 yr old woman severe Guillian Barre ICU 28 days
 2. 37 yr old woman with critical illness neuropathy following ARDS (ECMO) ICU 36 days
 3. 49 yr old woman vertebral artery dissection & CIN 65 days
 4. 20 yr old with encephalitis, L sided weakness
 5. 24 yr old man heat stroke with rhabdomyolysis ICU 37 days
 6. 56 yr old man sensori-motor axonal neuropathy following lithium toxicity ICU 25 days
 7. 71 yr old man cerebral bleed, hydrocephalus, Fourniers gangrene 35 days
 8. 72 yr old man acute on chronic renal failure due to dehydration, gross muscle wasting ICU 11 days

Further information

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