Follow-up clinics

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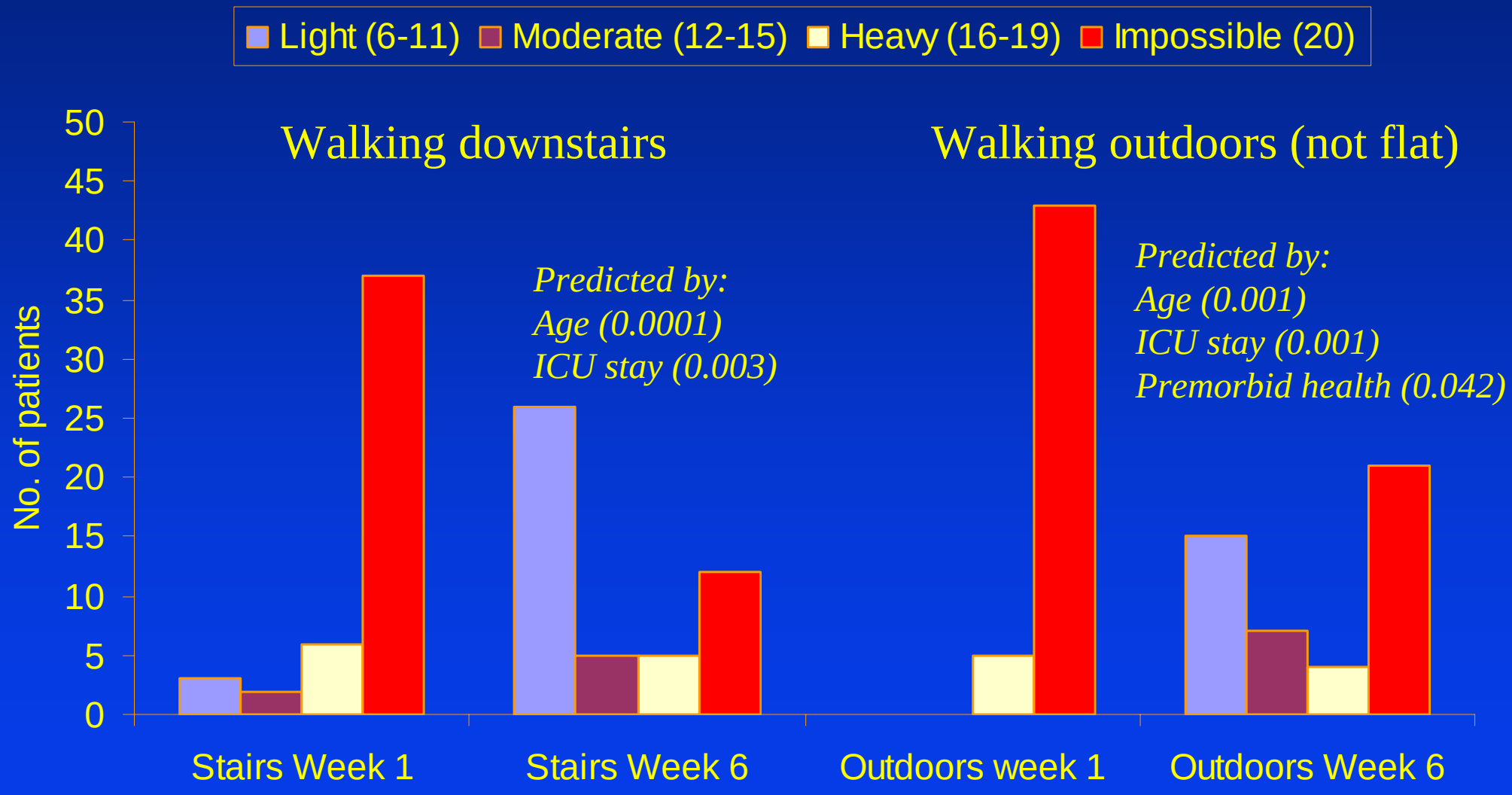
Follow-up clinic

- Founded 1990
- First in UK
- Resulted in first book on follow-up after critical illness
- Comprehensive Critical Care
- Over a third of ICUs now have clinics in UK
- Only part of the follow-up programme

Why do patients need following up?

- Physical recovery
  - Prolonged recovery 6 months – 1 year
  - Muscle mass loss and muscle weakness
  - Absence or poorly resourced physiotherapist services in UK
- Psychological recovery
  - Anxiety, depression, panic attacks, post traumatic stress disorder
  - Long waiting list for counselling/psychology
  - Amnesia for ICU experience

Physical activity at 7 weeks post-ICU



Perception of physical changes

- The following frequently cause distress:
  - Taste changes & altered appetite or eating pattern
  - Severe muscle wasting
    - weakness, difficulty with daily living
    - change in body image, poor fit of clothes
  - Paraesthesia
  - Joint stiffness
  - Sexual dysfunction
  - Hair loss, scars, skin changes, nail ridges
- Distress arises in the absence of a memory for the illness

Physical recovery

- **Mobility at 2 month OPD (n = 148)**

Unable or difficulty climbing stairs		65 (44%)
Mobility indoors	Stick	17 (12%)
	Zimmer frame	6 (4%)
	Wheelchair	7 (5%)
Mobility outdoors	Stick	15 (10%)
	Zimmer frame	1 (1%)
	Wheel chair	43 (29%)

(C. Jones, RD. Griffiths. Clinical Intensive Care. 2000;11(1):35-38)

Psychological problems

- Anxiety
- Depression
- Panic attacks
- Agoraphobia
- Post Traumatic Stress Disorder
  - Follows exposure to an extreme life-threatening stressor or traumatic event
  - Requires a loss of safety where response is with fear & helplessness

Post ICU PTSD

- 27% incidence of PTSD following ARDS
  - Retrospective (10yr) of patient experiences after ARDS
    Schelling et al Crit Care Med 1998; 26: 651-659
  - Patients recall of adverse experiences
    - » *Terrifying nightmares (64%),* Anxiety (42%), Pain (40%), Respiratory Distress (38%), None in 21%
  - Suggested less symptoms in steroid treated groups ?
    ICU: Schelling et al Crit Care Med 1999; 27:2678-2683
    Cardiac Surg: Schelling et al Biol Psychiatry 2004; 55:627-633
- 5 -14% incidence after general ICU
  - Relationship to duration of ventilation
    Cuthbertson BH et al Int Care Med 2004, 30: 450-455
- Drug usage in ICU
  - PTSD correlated with days of sedation and paralysis
    Nelson, Weinert, Bury, Marinelli Crit Care Med 2000;28(11):3626-3630

Long-term significance of psychological problems

- Alcohol or drug abuse for symptom numbing
- Not returning to work or socialising
  - Social isolation
  - Stressful for other family members
    - » May only leave the house if with someone
    - » Marriage breakdown
- Chronic physical problems
  - Chronic pain
  - Psychosomatic illnesses

Patient & Relative "conflicts" in care

- Patient
- Amnesia for ICU
  - No true experience, gap in autobiography
    - » Lack reality check and feelings of safety
  - Distorted perspective on illness & recovery
- Delusions
  - Strongly held & frightening
  - risk of PTSD
  - Only experience of ICU if amnesic

- Relatives
- Vivid experiences conflict with patients
  - Over protective and fearful
  - Unable to support and talk through with patient
- Highly stressed
  - risk of PTSD
  - exceeds personal & social coping

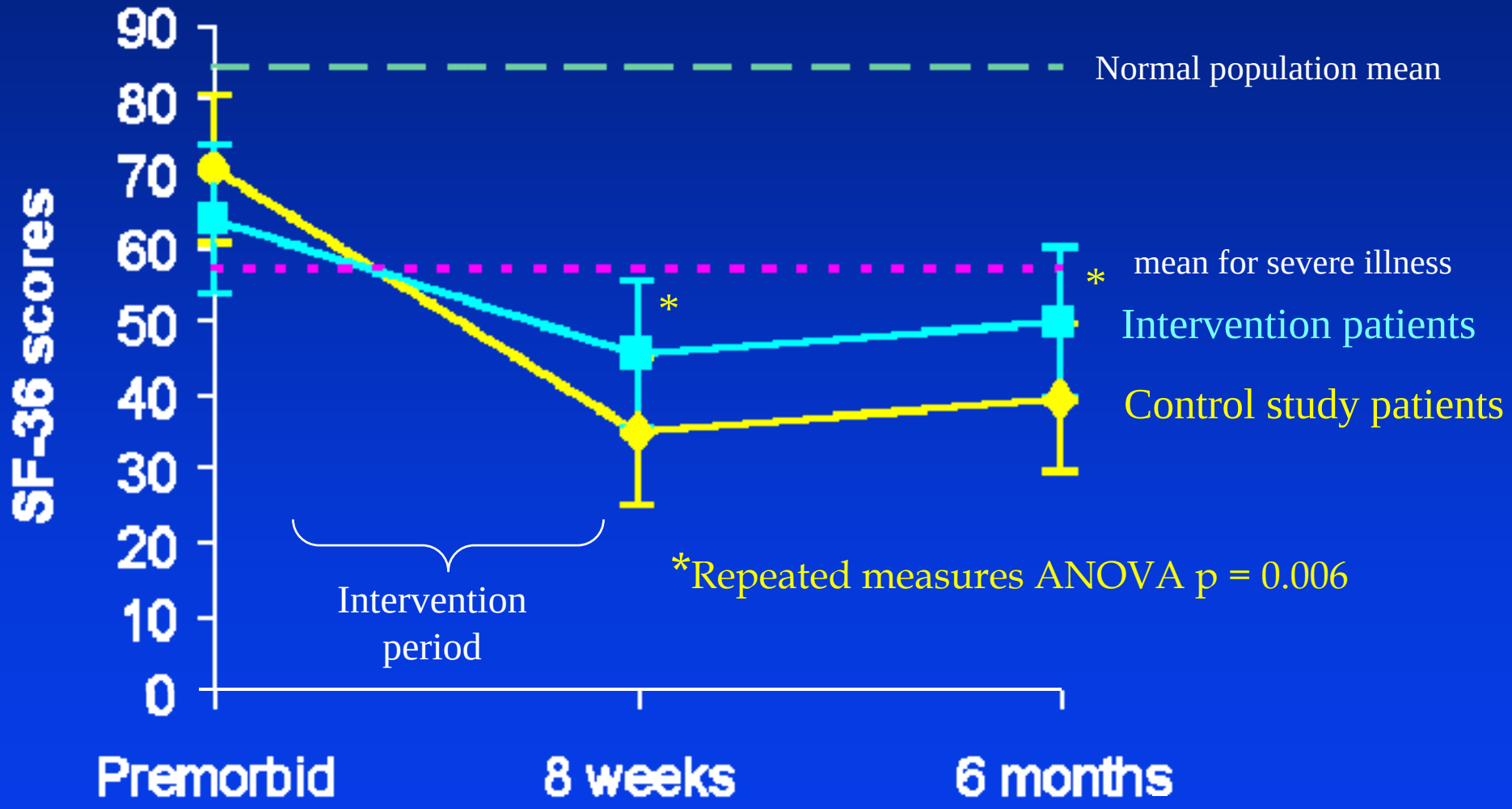
Information needs to be shared

Aiding recovery post ICU

Patient directed rehabilitation

- ICU Recovery Manual
  - psychological advice on coping with anxiety, depression, stress management etc
  - Grade exercise programme
- Educational principles
  - self-directed
  - monitors & reviews
  - self discovery
- Programme commenced at 1 week
- Close relative shares information

Physical Recovery



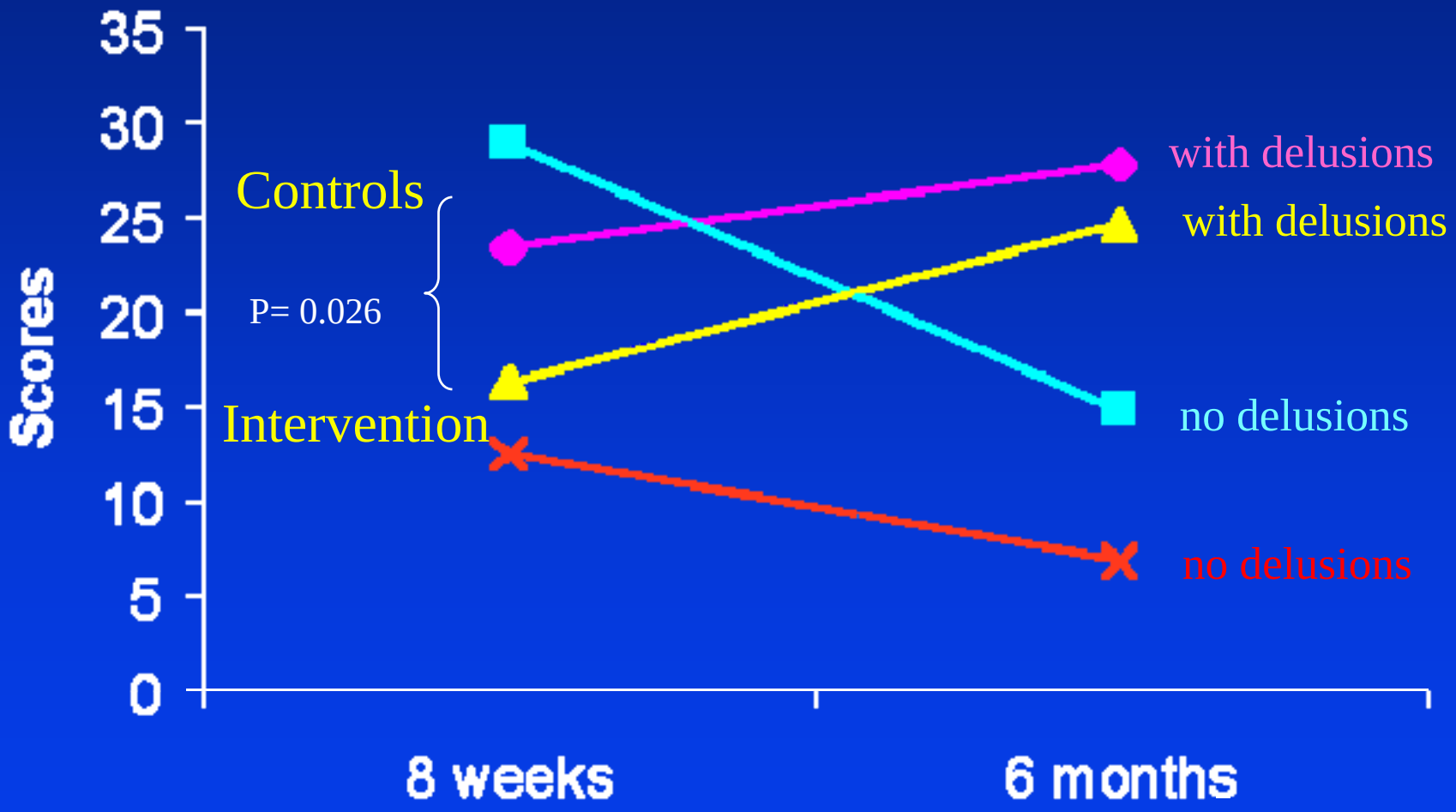
Psychological recovery

- At 8 weeks suggested reduction in depression
  - 12% rehab manual
  - 25% controls
  - HAD score>11 just not significant (p=0.06)
- No difference anxiety
- Reduced symptoms of acute PTSD at 8 weeks
  - IES, intrusion & avoidance (p=0.026)

- At 6/12 rate of depression the same
  - 10% rehab manual
  - 12% control
- No difference anxiety (30%)
- But ***No*** effect on symptoms of PTSD at 6/12
  - analysis of ICU memory explains results

Impact of Events Scale

Significantly lower intrusion/avoidance at 8 weeks in the intervention group that is lost at 6 months



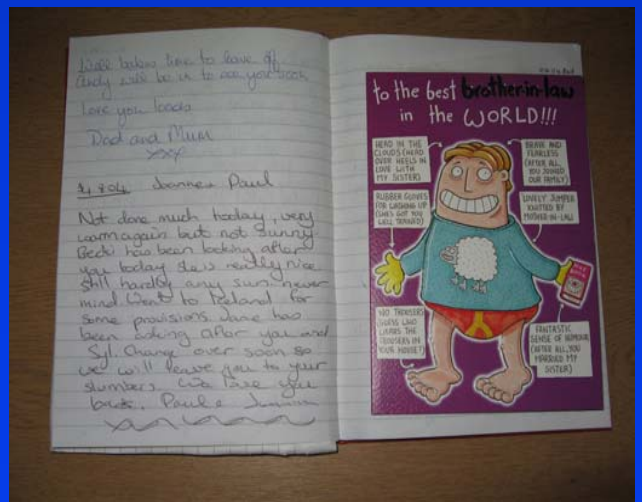
Coping with delusional memories

- Ward visits as soon as possible after ICU & repeated
  - Examine memories for ICU
  - "Normalisation" – telling it is normal
  - Helping to handle nightmares
  - Severe symptoms for referral
  - At one month if mild symptoms "watch & wait"
    - » Reassess after 1 month
- Outpatient appointment 2 months
  - Going through their ICU story (once they are ready)
  - Revisit symptoms if no recovery refer on
- Revisiting the ICU/HDU
  - Putting delusional memories into context
- Prospective ICU diaries with photographs
  - Given to patient either on the wards or in clinic
  - Acting as natural cognitive behavioural therapy?

Diaries within ICU

Pioneered by Nurse Carl Backmänn
Dept. of Anaesthesia & Intensive Care, Norrköping, Sweden

- Real time record of ICU/HDU stay
- Relatives can contribute as much as they want
- Anyone can write but must sign name, include what happens in ICU and at home.
- Photos during stay
  - Released on patient consent
- Read at home during recovery



ICU Diaries

- Prospective record of ICU
  - Everyday language
  - Photographs
- May be difficult to get staff to write in them
  - Litigation fears
- Patients want to receive them
- Used to challenge flashbacks
- Needs further studies as an intervention

Role of the outpatient clinic

ICU clinic

- Team of two nurses and one ICU consultant
  - One nurse qualified counsellor
- Funded out of critical care budget
- Held once a month
  - Maximum 8-10 patients
  - Relatives encouraged to attend
- Two rooms in the outpatient building
  - Some patients do not want to come back to ICU
- All patients staying on ICU > 4 days
- Patients seen at 2 and 6 months post ICU

What happens in clinic?

- Physical Recovery
  - Reassess physical recovery
    - » Pulmonary function tests
    - » Chest X-rays
    - » Bloods
    - » Weight
  - Checking medication stopped
    - » E.g. amiodarone commenced in ICU
  - Referral to other services
    - » ENT
    - » Physiotherapy
    - » Dieticians
    - » Counselling provided by team

What happens in clinic?

- Psychological recovery
  - Revisit memories for ICU
  - Further information about their ICU stay
  - Are they sleeping?
  - having nightmares or panic attacks?
- The rehabilitation message
  - Re-emphasising smoking cessation
  - Importance of exercise and eating well
  - ICU Diary revisited

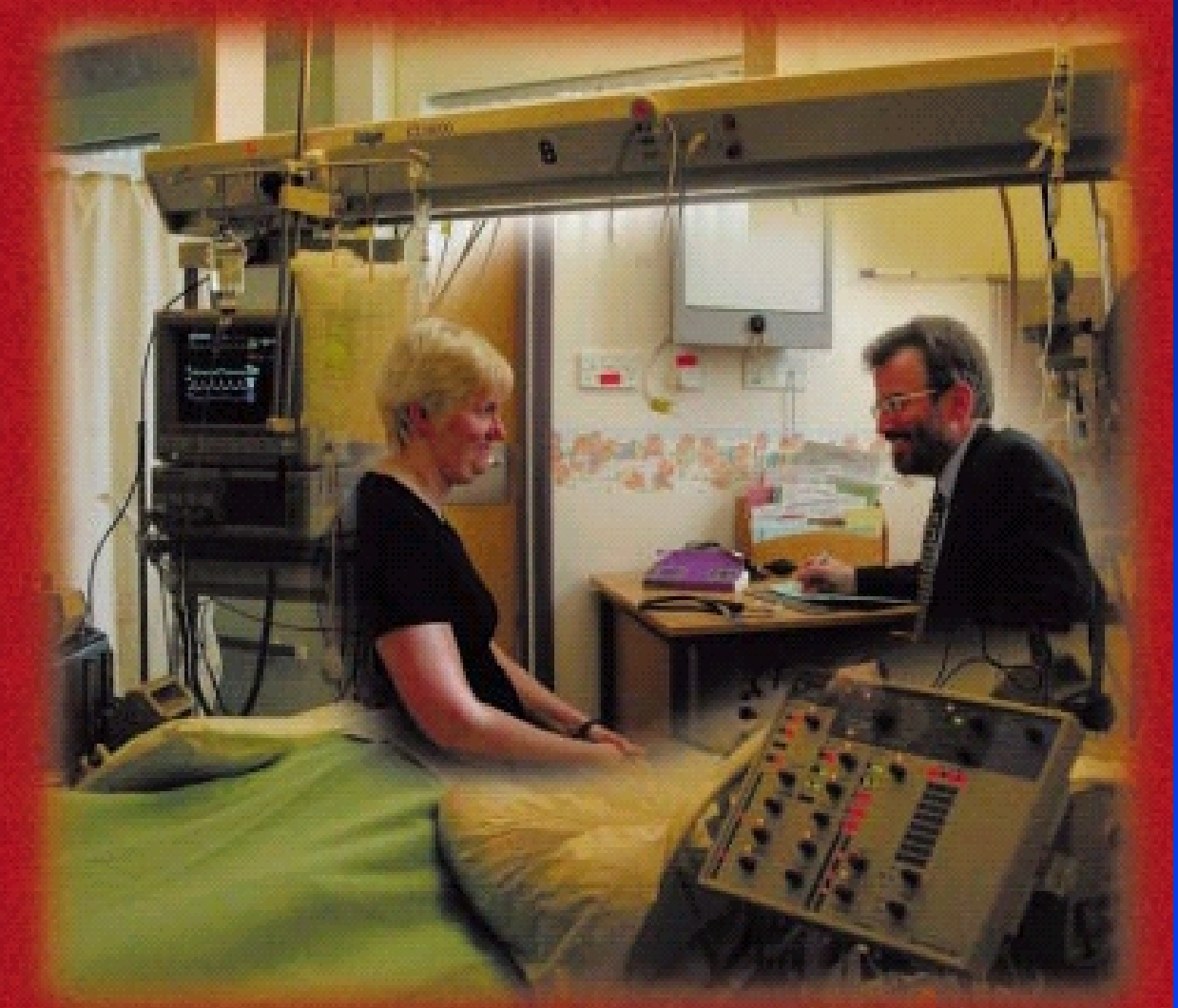
Non-attenders

- Contact GP to check if deceased
- Then contact patient
  - may have become agoraphobic
  - may get panic attacks attending hospital
- Home visit may be required

Intensive Care Aftercare

- Combination approach
  - Early exercise in ICU
  - Recognition of early psychological symptoms
    - » Watch and wait if not severe
  - Diary of ICU/HDU stay
  - Rehabilitation package post ICU
  - Assessment of psychological recovery
    - » Normalisation of symptoms first line
    - » Medication for nightmares
    - » Refer those with severe symptoms for help
  - Reassessment in outpatient clinic

Intensive Care Aftercare



Griffiths RD & Jones C,
Butterworth Heinemann Oxford,
Jan 2002 £20.99

- Immediate problems after ICU
  - physical & psychological issues
- After discharge from hospital
  - sex & nutrition
  - physical & psychological recovery
- After care programme
  - where, when, how and who
  - Active rehabilitation
  - Patient Diaries
- The greater role for aftercare
  - Bereavement, outcome and supporting staff

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