LEADING ARTICLES
Where now for therapeutic apheresis? TERRY HAMBLIN ........................................ 779
How to induce ovarian cancer: and how not to JAMES S SCOTT ........................................ 781
At least one centimetre for each millimetre F H J RAMPEN ........................................ 782
Do minor affective disorders need medication? H G MORGAN ........................................ 783
Bedside neurology EDWIN R BICKERSTAFF ........................................ 784
Correction: Ample scope for improving the health of prisoners SMITH ........................................ 784

CLINICAL RESEARCH • PAPERS AND SHORT REPORTS • PRACTICE OBSERVED
Safety of treatment for subclinical osteomalacia in the elderly D J HOSKING, G A CAMPBELL, J R KEMM, R E COTTON, R V BOYD ........................................ 785
Effect of an oral serotonin antagonist, ketanserin, on plasma ACTH concentrations in Nelson's syndrome R W G PRESCOTT, W A RATCLIFFE, P KENDALL TAYLOR ........................................ 787
Is there a link between cot death and child abuse? JACQUELINE ROBERTS, JEAN GOLDFING, JEAN KEEING, BETTINE SUTTON, MARGARET A LYNCH ........................................ 789
Lower cranial nerve motor function in unilateral vascular lesions of the cerebral hemisphere ERNEST W WILLOUGHBY, NEIL E ANDERSON ........................................ 791
Placebo controlled trial of nicotine chewing gum in general practice KONRAD JAMROZIK, GODFREY FOWLER, MARTIN VESSEY, NICHOLAS WALD ........................................ 794
Bone marrow necrosis after treatment with sulphasalazine J E W VAN DE PETTE, D T E CUNNAH, T M SHALLCROSS ........................................ 798
Diabetic thoracic polyradiculopathy presenting as abdominal swelling A J M BOULTON, E ANGUS, D R AYYAR, R WEISS ........................................ 798
Accumulation of midazolam after repeated dosage in patients receiving mechanical ventilation in an intensive care unit C M BYATT, I D LEWIS, S DAWLING, G M COCHRANE ........................................ 799
Alerting close relatives of patients with glaucoma J M MACKEAN, A R ELKINGTON ........................................ 800
Hypoxia, depression of testosterone and impotence in pickwickian syndrome reversed by weight reduction PETER D' A SEMPLE, ALASTAIR GRAHAM, YVONNE MALCOLM, GRAHAM H BEASTALL, WALTER S WATSON ........................................ 801
Fixed drug eruption masquerading as herpes simplex labialis J BOYLE, B MOUL ........................................ 802
Recording the consultation: model for assessment T JONES ........................................ 803
Rethinking Established Dogma: The team in general practice IAN TAIT ........................................ 805

MEDICAL PRACTICE
How to beautify your old hospital J H BARON ........................................ 807
Appropriate Technology: Ophthalmology in developing countries JOHN SANDFORD-SMITH ........................................ 811
Communicable Diseases:
Cryptosporidiosis in an urban community D A HUNT, R SHANNON, S R PALMER, A E JEPHcott ........................................ 814
Brucellosis in Britain COMPILED BY THE PUBLIC HEALTH LABORATORY SERVICE COMMUNICABLE DISEASE SURVEILLANCE CENTRE AND THE COMMUNICABLE DISEASES (SCOTLAND) UNIT ........................................ 817
Clinical Algorithms: Recent widespread scaly rashes ANDREW Y FINLAY ........................................ 817
ABC of Poisoning: Analgesic poisoning: I—Salicylates JOHN HENRY, GLYN VOLANS ........................................ 820
Lesson of the Week: Indigenous amoebiasis: an important differential diagnosis of chronic inflammatory bowel disease I R SANDERSON, J A WALKER-SMITH ........................................ 823
Any Questions? ........................................ 810, 813, 816
Medicine and Books IAN TAIT ........................................ 824
Personal View LESLEY REES, VIVIENNE VAN SOMEREN ........................................ 827

CORRESPONDENCE—List of Contents ........................................ 828

OBITUARY ........................................ 841

NEWS AND NOTES
Views ........................................ 838
Medical News ........................................ 839
BMA Notices ........................................ 839
One Man's Burden MICHAEL O'DONNELL ........................................ 840

SUPPLEMENT
The Week ........................................ 845
From the GMSC: Deputising services: guidance sent to LMCs ........................................ 846
Maternity medical services: a proposed new scheme ........................................ 847
From the CCCMCH: Civil defence planning in the NHS ........................................ 849
Cremation fees and the Inland Revenue: BMA statement ........................................ 850
Who does what, and how much in the preschool child health services in England J A MACFARLANE, UMSIE PILYAY ........................................ 851
CORRESPONDENCE

Motor neurone disease: can we do better? A study of 42 patients

D J Oliver, MRCP, N E Early, DRCOG; Barbara A Thornley, FFARCS; C W Roy, MRCP; Mary C P Groves, MB

Ablative radiiodine therapy for hyperthyroidism: a long term follow up study

R E Young, MRCP, and A J Hedley, FRCPED 829

Prospective comparison of three non-invasive tests for pancreatic disease

I Cobden, MB, and others 830

Disaster at the dining table

M C Kelly, MB 830

Health care in the United States

C C Penney, FRCS; Sir Reginald Murray, FRCS 830

Cervical cerclage

J T Wright, MRCOG 831

Home care for patients with suspected myocardial infarction: use made by general practitioners of a hospital team for initial management

T C O'Dowd, MRCP, and N C H Stott, FRCP 831

Failure of long term luteinising hormone releasing hormone treatment for prostate cancer to suppress serum luteinising hormone and testosterone

S R Ahmed, MRCP, and others 831

Medical problems with breath testing of drunk drivers

P Duflus, DRCOG, and J A Dunbar, MRCGP 831

Severe hypophosphataemia during recovery from acute respiratory acidosis

E L Brown, MB 832

Plasma lipids and insulin—gall stone disease: a case-control study

J R Thornton, MRCP 832

Spinal cord disease due to Schistosoma mansoni successfully treated with oxamniquine

N M Home, MB 832

Current practice of diagnostic lumbar puncture

F P Ellis, FRCP 833

Bronchoconstriction induced by intrapulmonary bromide in asthma: relation to hypotension

J K Dewhurst, MB; C K Connolly, FRCP 833

End of static decade for coronary disease?

G Cannon 833

Pituitary gland:

T M Macdonald, MB, and R A Clark, FRCPED 834

Conscience and nuclear war

J M Cundy, FFARCS; A M Cartwell, MRCGP 834

Should pharmacists be able to prescribe?

R C Redman, MRCGP; N E Ballantine, MPS, and P A Ball, MPS 834

Overwork and waste in orthopaedics

K Tucker, FRCS 835

Motor neurone disease: can we do better? A study of 42 patients

Sir,—In the survey on motor neurone disease by Drs P G Newrick and R Langton-Hewer pain was a problem for 64%, of the patients and was not well controlled (1 September, p 539).

In a large survey of 100 patients in the terminal stages of motor neurone disease 40%, complained of pain and three types of pain were identified. These were musculoskeletal pain from stiff joints which had restricted movements and altered muscle tone, muscle cramp, and pain from skin pressure, as the patient is less able to move spontaneously.1 2 The treatment will vary according to the cause—non-steroidal anti-inflammatory drugs for musculoskeletal pain, diazepam or quinine bisulphate for cramp, and analgesics, including opiates, for skin pressure pain. All these treatments should be combined with careful positioning of the patient and physiotherapy.

Opiate analgesics can be safely used for these patients but the symptoms of pain, dyspnoea, cough, restlessness, and, on occasion, feelings of hunger. In the large series 84% of the patients received morphine or diamorphine orally as a mixture in chloroform water or as a slow release morphine sulphate.1 The starting dose is usually 5 mg of an oral mixture or 10 mg slow release morphine sulphate, and for many patients a single night time dose may be sufficient. Occasionally, however, regular daytime administration may be necessary. The dose can be increased slowly and titrated to the patient's pain, and when opiates are used in carefully selected doses they effectively control these distressing symptoms. Patients should not be denied this relief. By controlling distress opiates do not necessarily shorten life but may lengthen it, and treatment has continued for over five years in one patient. All the symptoms experienced by the patient must be carefully assessed and then treated, and much can be done to reduce the distress of this disease.

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GMC annual report

Sir John Walton, TD 835

Points: Which patients are likely to die in an accident and emergency department? (M J Shelley; R M Wilcock); Observations on the mechanism of hypoxaemia in acute minor pulmonary embolism (G A Chadwick and J R Stradling); Labelling of lignocaine ampuoles (J Cox); Atypical falciparum malaria (D Fegan); A fair trial? (J S Phillips; M Fletcher and A G Wade); Oral rehydration without added bicarbonate for childhood gastroenteritis (J Grabianar); Low osmolar contrast media (D A R Burd and G Sanits); Why does time seem to pass more quickly as we grow older? (C S Good); 836 Management of obstructed balloon catheters (S E McCabe and J G Paterson); Locum cover for junior doctors' leave (J Weinberg); Augmentin (amoxycillin-clavulanic acid) compared with co-trimoxazole in urinary tract infection (S G Flavell Matts and K MacIntyre); Spinal cord disease due to Schistosoma mansoni successfully treated with oxamniquine (R T Mossop); Deaths from asthma (K W Wong and D P Davies); Car seats and scatica (R T D Fitzgerald); West Berkshire perinatal management trial (L S Lewis); Major epileptic seizures and topical gammabenzene hexachloride (V T Kelly); Generalised eczema caused by sodium cromoglycate (H A Eveleigh and A M Edwards).

Motor neurone disease: can we do better? A study of 42 patients

Sir,—I found the article by Dr P G Newrick and Dr R Langton-Hewer extremely interesting because I had to cope 10 years ago with a close family member with motor neurone disease. It is a particularly unpleasant disease, but the symptom that was the most distressing to this patient was loss of support and control of the head. Splints and collars were un-

Sir,—Dr P G Newrick and Dr R Langton-Hewer (1 September, p 539) have shown deficiencies in the care of patients with motor neurone disease. Viewed from general practice this indicates shortcomings in management for which the primary care team should be responsible. Their study did not consider whether this was so or how the “general practitioner's close interest and involvement” are to manifest themselves. It is premature therefore for them to conclude that, “The GP is unlikely to have the necessary skills to manage the disease effectively.”

They suggest that a key worker (possibly a nurse) be appointed, but her job description in many ways matches that of the primary care team. The tasks proposed do not seem so esoteric as to be impossible for us, and individual difficulties could be met by specialised nursing and medical advice for the primary team— as is happening in other forms of domiciliary terminal care.

N E EARLY

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