

LEAVESCENE

JOURNAL OF THE
**LEAVESDEN HOSPITAL FRIENDS
AND RELATIVES GROUP**

Number 11

JUNE 1987



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The Committee meets on the last Sunday in every month at 4.30 pm in the Board Room. A number of Open Meetings have been held, to consider Hospital policy and to meet members of the Regional and District Health Authorities.

We have had talks from Miss P. Hudson, Regional Director of Nursing Services, and from Mr D. Sherratt, Unit General Manager, Leavesden Hospital, who presented a series of diagrams showing how the 'run-down' of the hospital would proceed into the 1990s, with patient numbers reducing to between 180 and 400. The Annexe site would be disposed of to raise capital, with residents and facilities transferred to the main site, and new sheltered workshops, training and occupational therapy buildings etc., and the Patients' Clubhouse being built on the edge of the cricket field.

FUTURE ACTIVITIES

The Summer Fete 1987 will be held at the Hospital Grounds on Sunday 19th July, from 12.30 until 4.30. Refreshments will be available.

Gifts for the stalls will be welcomed - they can be left nearer the day at the Patients' Clubhouse. Chairman Mrs M. Sladen will attend Fete Committee meetings.

Discussions have taken place on the feasibility of setting up an *Advocacy Scheme* for residents. Mrs Sladen has attended meetings of the Advocacy Alliance which has established schemes in several hospitals.

The Management has committed itself and a Steering Committee has been set up which will be attended by Mrs Spector.

ANNUAL GENERAL MEETING

The ANNUAL GENERAL MEETING took place on Sunday April 26th in the Board Room at the Hospital. The Minutes of the previous AGM were approved and the Financial Statement by the Treasurer was adopted. Officers and Committee for the coming year were elected as follows:

Chairman: Mrs Marlene Sladen
Vice-Chairman: Mr Henry Sainer
Hon. Secretary: Mrs Elisabeth Spector
Hon. Treasurer: Mr D. Marshall
Hon. Editor: Mrs J. Fryd

Committee: Mr Clive Nicholls; Mrs Joan Brown; Mr Peter Matthews;
Mrs Gerda Sainer; Mr & Mrs Hay-Plumb; Mrs Pauline Bateman;
Mrs Mason; Mr & Mrs A. Bladon; Ms Linda Fryd

Co-Opted: Ms Kathy McLoughlin; Ms Anne Cooper; Miss Jane Reynolds

The Chairman welcomed Miss Jane Reynolds who is the new Hospital Unit Manager, replacing Mr Sharratt who has moved to the Mental Handicap Policy Unit (for the three Hospitals) at Harperbury. Miss Reynolds has worked for many years in residential care of mentally handicapped people and was formerly Matron of Westminster Mencap Society's Alison House.

The meeting was addressed by Mr Tom Freeman, Director of Mental Handicap Services, N.W. Herts, who gave a detailed account of the proposed management structure and the strategy for resettling patients in the community. The objectives were integrated patterns of care for each individual with consultation and monitoring of standards. There would be a review in 1990 of the future of the hospital, when and how to close, by which time the Annexe would have been vacated with £3½ million capital redevelopment on the main site. There would, he said, continue to be facilities for in-patient care for people who required specialised services. The School and other facilities would be used for the lifetime of the hospital even after evacuation of the annexe.

Mr Freeman was warmly thanked for his address and for answering a considerable number of questions and anxieties from members.

Heartfelt tributes were paid to the retiring Chairman Mr Henry Sainer, for his valuable work over many years on behalf of the hospital and its residents.

FROM THE EDITOR'S CHAIR

Since its formation in 1953, the Friends of Leavesden has had many achievements to its credit, having provided a play therapy room, purpose built motor-coaches, record players and other equipment for wards, and of course the Residents' Clubhouse, 'Friendly Leaves', including a major extension and improvements. The cost of all these amenities continues to be raised by activities - Fetes, Bazaars etc. - together with generous donations from charitable groups and individuals.

The formation of the Relatives' Group in 1984, following a meeting to discuss the strategy document of the Regional Health Authority proposing the closure of Leavesden Hospital within ten years, brought a new impetus to what has become a united Friends and Relatives Association. A memorandum was drawn up, setting out our doubts and fears for the future of our residents, and after endorsement by a members' meeting, was forwarded to the Regional Health Authority and others concerned.

Since then, the events outlined in this issue of Leavescene indicate the efforts we have been making to keep abreast of and, if possible, to influence the development of the authorities' plans. Their most recent pronouncements about the why and how of the project demonstrate some understanding of the importance of caring for each individual resident's needs; but parents and others (including some of those who will be charged with implementing the policy) continue to express doubts about the possibility (let alone the rightness) of trying to cater for the needs of all the aged, the profoundly retarded, the multi-handicapped and those with severely disturbed behaviour, out in the community, within the financial constraints and the short time scale envisaged.

It may not, as our Chairman fears, be possible to get the plans reversed or even postponed. But at least we can try to get 'the wind tempered to the shorn lamb' by insisting on the letter as well as the spirit of the promise that *no resident will be discharged unless and until the appropriate facilities are there and available in the community.*

Originally, the stated policy was to close hospitals and release all the money and land 'locked up', relying on local authorities and voluntary bodies to provide care for the discharged residents. It is now recognised that this was putting the cart before the horse. Initially it is going to cost, not save, money. The care must be provided *before* the hospitals can discharge people with mental handicap into the community. And individual assessments, on a multi-disciplinary basis, must be made before appropriate facilities can be set up.

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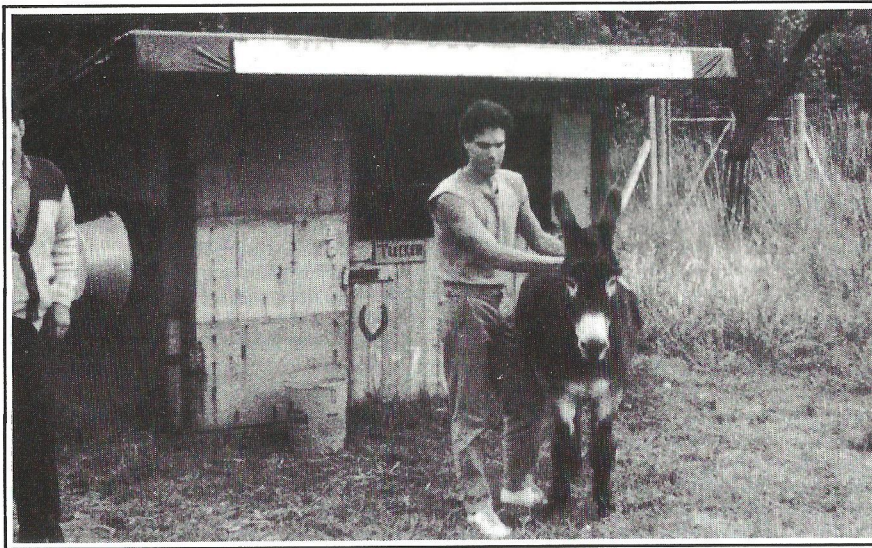
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PARTICIPATION IN PLANNING

The Friends of the three hospitals - Leavesden, Harperbury and Cell Barnes - have been represented on the Mental Handicap Group of the District Health Authority by Mr Finucane, of Cell Barnes Friends (along with Mr Richard Capewell, Divisional General Manager of MENCAP). Mr Finucane has been appointed to the Regional Health Authority, and the Friends' representative is now Mr Bertie Wheeler, of Harperbury Friends.

MENCAP CONFERENCE

In February, a number of our members attended a Conference called by Southern Division of MENCAP at St Bartholomew's Hospital. Speakers included Mr Richard Jackson of RESCARE who defended the concept of 'hospital homes', and called for a halt to closures and transfer to the community, pending a Government inquiry into the whole situation. Other speakers gave instances where admirable schemes of community care had been set up, eg. in bungalow type living accomodation adjacent to hospitals. (The authorities have consistently resisted such a development which the Friends have put forward as appropriate for Leavesden). Sir Brian Rix of MENCAP spoke in favour of Community Care, saying that it was not only about group homes and minimally staffed hostels, but about a range of services for all, including specialised facilities such as medium secure units and highly staffed units, and a contribution from hospital services as had been described at MENCAP's recent conference at Manchester on the Profoundly Retarded and Multi-Handicapped. We should not halt progress with community care, but make absolutely sure that it will work - the Tom Clarke Act would provide further safeguards, as would parents serving on Joint Planning Teams and monitoring services.

Other speakers expressed doubts whether the community would or could provide facilities appropriate to the needs of elderly, highly dependent or very disturbed hospital residents whose safety and continuity of care must be assured for their sake and for that of their families.

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JOINT PLANNING

Mr Sainer, Mrs Spector, Mrs Fryd and others recently attended a meeting in St Albans to discuss Joint Planning. Two representatives of voluntary organisations concerned with mental handicap were to be elected to the Joint Care Planning Team; these were Mr Will Wilson, of Friends of Cell Barnes and St Albans MENCAP, and Mrs Roma Mills, of the Coalition for Mental Handicap (comprising MENCAP and Friends' Groups and various other bodies concerned with mental handicap). Both these representatives are also parents. They will report back to quarterly meetings called by the Coalition, under the chairmanship of Mr Paul Lerwill of Hemel Hempstead. Progress towards Joint Planning so far was outlined by Mr Tom Freeman and Mr Michael Layzell, Area Director Social Services, who is Chairman of the Joint Planning Team.

Members of our committee endeavour to keep abreast of developments in other parts of the hospital's catchment area; for instance, in Ealing there is a Strategy group with representatives of Health and Social Services and MENCAP.

We should ask each of the 'sponsoring' authorities for a copy of their strategic plan for integrating hospital leavers into local community services. We are concerned not only with somewhere to live, but with all the essential back-up services - occupation and training, further education, social welfare, employment, recreational services etc. Friends and relatives who are not already members of their local MENCAP societies will find their addresses on page 10 and details of the Community Mental Handicap Teams are on page 11.

It is our firm belief that no resident should be discharged from hospital until the services appropriate to his needs are available in the community. In this connection, Section 7 of the Tom Clarke Act (Disabled Persons' [Representation, Consultation and Services] Act 1986) requires all residents before discharge to have a full multi-disciplinary assessment and an individual programme plan. A lobby of Parliament was tried, held on April 6th when hundreds of parents and others tried to persuade their MP's to support an Early Day Motion calling for implementation of this and other sections of the Act.

SEMINAR ON IMPLEMENTATION OF REGIONAL STRATEGY

A series of Seminars were held in March, to provide information on the proposed implementation of the strategy for services to people with mental handicap.

The one held at Abbots Langley Hospital on March 25th was attended by Mrs E. Spector, Mrs M. Sladen, Mrs Pia Duran and Mrs J. Fryd; most of the other participants were representatives of Social Services departments or Nursing officers from the various parts of the catchment area.

Discussion was led by Mr Tom Freeman, who presented slides with diagrams showing the patient numbers and projected run-down into 1990, due to deaths and removals and cessation of admissions. It was hoped to speed up the process by discharging about 150 residents each year from the three hospitals; catchment districts would be expected to take 10 or 12 people per year. Mr Freeman said there were big problems of management to be resolved. He emphasised points in the paper which was distributed - that residents would not be discharged until the facilities appropriate to individual need were available. This would require multi-agency provision, based on Joint Planning machinery, and should be small-scale, flexible and evenly spread throughout the Region. There would be a thorough assessment of patients' needs and full account would be taken of all levels of dependency. Arrangements would be made to prepare Staff to take opportunities in the new pattern of service and to contribute to inter-disciplinary discussions on the training and recruitment needs of the new services.

The Local District based plans and the Health Service (Mental Handicap Unit) plan would be brought together to provide a framework, supported by Regional Bridging funds and a 'Development Pool' from existing finance - additional funds being available from patients' own Social Security/Board and Lodging allowances.

Mr David Pashley (of the Directorate of Planning and Information, R.H.A.) outlined the proposed methods of financing the changeover. This would admittedly be high - including housing and day activity provision it would be up to about £7.4 million for a typical district, since probably some capital expenditure would be necessary for certain patients requiring Home placements. It was hoped to use the Regional Capital programme, ie. £1m per annum, plus proceeds from sale of lands, and use of other sources, eg., Housing Associations and Mortgages.

Those present had nothing to criticise in the statement of intentions but many questions revealed disquiet about the possibility of achieving the network of facilities required. The shortage and high cost of housing accommodation within London and the Home Counties; the difficulty of recruiting staff because of this; the problems of integrating multi-handicapped or disturbed patients into local residential communities; the uncertainty about being able to cover the cost of doing things in the way intended.

Some people expressed doubt about getting the right conditions for each discharged person. Others pointed out that if the individual programme plans were carried out as required in the 'Tom Clarke Act' Section 7, it would have to be right; but the speakers affirmed that it would not be possible to allocate resources, in money or personnel, to carry this out. It was suggested that these resources would be better spent beforehand than afterwards if it became necessary to retrieve mistaken situations.

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THOUGHTS OF THE CHAIRMAN

I am writing this on one of the rare Sunday afternoons when I've had some time to relax and I started thinking of a conversation with someone from a Community Health Council, and one remark in particular.

'You must feel very frustrated'.

Thinking it over, I realised how true that had been. I suppose that I'd become inured to it because for almost half a century I've been dealing, not to say battling, with the Inland Revenue, and other Government authorities.

Turning to Leavesden, the first time I saw the Hospital was when our son, Derek, who is now in Plover Ward, was sent there for a short stay holiday. We could only too easily understand why it was subsequently chosen for the Television programme 'Porridge' as representing the nearest image of a real prison.

At a later date he was transferred from Normansfield Hospital to Leavesden. We tried to argue about this but were frustrated by the fact that Normansfield could no longer cope with an hyperactive young man of considerable strength, and that there was nowhere else to send him.

Not for the first time, consolation came after frustration, when we realised that notwithstanding its outward appearance Leavesden did present, within its limitations, 'tender loving care'.

I attended the Annual General Meeting of the Friends following Derek's removal to Leavesden and was incautious enough to ask a question. As a result I was hijacked on to the Committee.

I had had considerable experience of work for the Mentally Handicapped; my wife and I were founder members of the Retarded Children's Aid Society which established several residential homes for higher grade patients in Barnet and Potters Bar. We were also founder members of the 'Society for Autistic Children', of which I was the first Treasurer. I had also had experience in taking the chair at meetings, so that when the Chairmanship of the Friends fell vacant I was asked to take over.

Up to then the Friends had contributed to Patients' Welfare, mainly in small but important ways, sending Birthday Cards and Christmas gifts and supplying wards with such extras as the Charge Nurse asked for, within reason. I had come to the conclusion that what the patients needed was somewhere where they could have some social life and that the Friends could raise the money if pushed hard enough.

Having sold the idea first to the Committee and then to the Hospital, I persuaded an Architect to plan something which was a complete contrast to the Hospital itself. A brilliant plan was produced - good enough to be published in the Architects' Journal. Alas, frustration crept in. Tenders for the erection of the building were in but before we could proceed to Contract we were informed that the proposed site could not be used. Plans were being considered to shift the emphasis of the Hospital to the Annexe site.

After long deliberation, the present site of the Patients' Clubhouse was settled. We went out to tender once more. Frustration set in once more - the tender prices had trebled and were now beyond any reasonable expectation.

Back to the drawing board. We had to settle for a prefabricated building and since there would be no overall Contractor, we were unable to get a firm price. Indeed, the finished building cost more than twice the original tenders for the much more elaborate edifice.

Once again, consolation after frustration. The Clubhouse was an immediate success and we felt that the lives of the patients had really been enriched. We had just managed to pay off the bank overdraft when the Recreation Department pointed out that despite a liberal margin over the maximum number of patients we had been told would be using the Clubhouse, it was being overcrowded to a considerable extent. Would we please extend the Clubhouse. Naturally prices had risen, and the annexe cost as much as the

original building. We had made good progress in paying the debt we had incurred for the annexe and we were ready to discuss a future project when we met the dread influence known as 'Revenue Consequences'. A patients' coach, to replace the one that had ended its useful life - one, moreover, which would have the capacity to take wheelchair patients. No.

A small electric engine to pull a 'road-train' round the Hospital, again capable of taking wheelchairs, with other patients seated or standing. No.

Converting the waste ground behind the Clubhouse into a garden or horticultural area. No.

Setting up a Village Community, where the Friends would pay for the first Building, at least. No.

Providing a hydrotherapy and paddling pool. No.

Apart from the inability to provide any major project because the Hospital did not have the money to take it over and run it, there was the rumour that the Annexe site was to be sold off. There was the plan to run the M25 Motorway through the Annexe site.

There was and still is the plan for 'Care in the Community'. A fine idea propounded at the Department of Health, but with a major flaw. The effect had not been worked out in detail. The resources to meet the decanting of patients into the community were not there and, given the financial position of Local Councils, were not likely to be provided. The Social Services too, who would be expected to play an important part in this were not geared for the responsibility.

Now there is the Regional Strategy which plans to close Leavesden in the next ten years and also either Cell Barnes in St Albans or Harperbury. The reason Leavesden is chosen for closure is the fact that the Buildings are mid-Victorian and the site is very valuable. Presumably, this is because Leavesden is in a developed residential area, whereas Cell Barnes is in the factory area to the South of St Albans and Harperbury is much more isolated.

I may be wrong but I get the feeling that the policy of the Department will be resistant to change, in spite of much evidence that the cost of Care in the Community is much more expensive in money and in scarce nursing personnel. I'm not much more hopeful of getting the Regional Strategy amended - is it any wonder that I feel frustrated?

My consolation is that I have met so many people, and in particular young people, who have joined in helping to ease the life of the patients in Leavesden.

Above all, I must not forget the wonderful support that I had from the members of the Committee who have given up much time and effort in supporting the aims of the Group, and thus in keeping it going.

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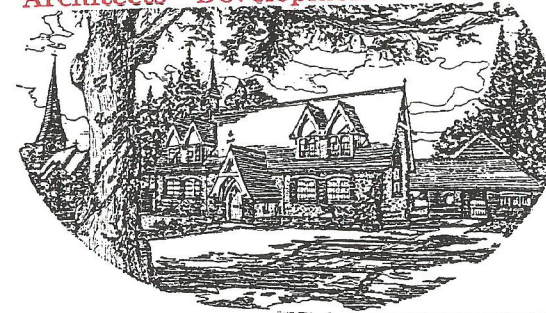
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