LIVING IN HOSPITAL

A quarter of a million people in Britain are in long-term hospital care. Once admitted to hospital, they seem to slide helplessly into apathy. Almost all suffer a marked loss of former independence and are cut off from old friends and old interests, and from the small, sweet pleasures of ordinary life. Does this have to be?

KING EDWARD'S HOSPITAL FUND FOR LONDON

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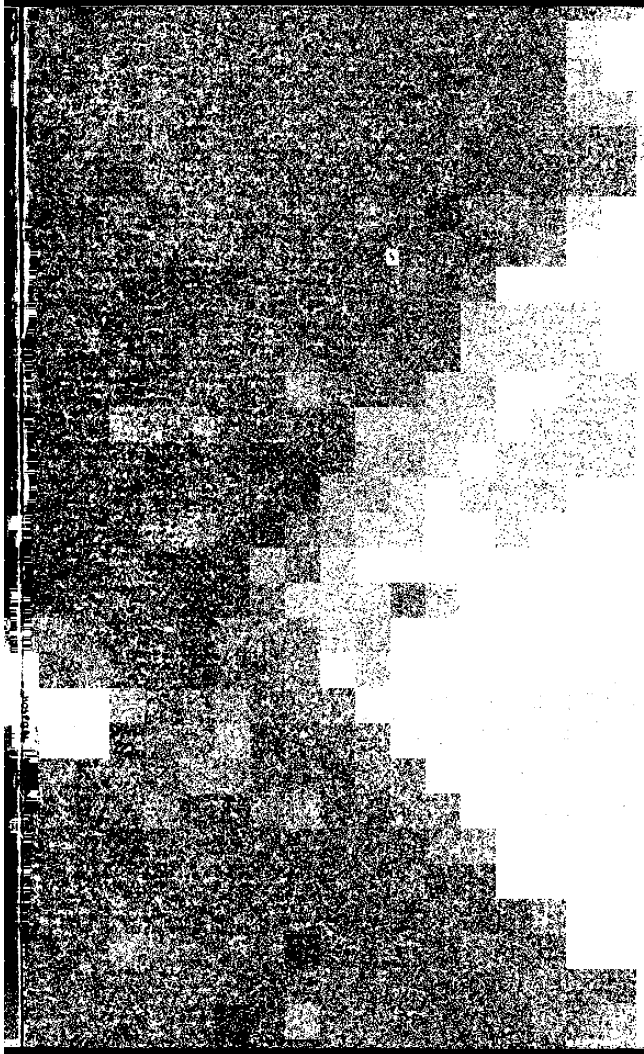

LIVING IN HOSPITAL

Many staff working in old or makeshift buildings, overcrowded and understaffed will realise only too well the need for smaller and more purposeful residential units, better domiciliary back-up, and better access to the ordinary social and housing services of Britain. They fear that none of these will happen until long-term care is recognised nationally and locally as a strong contender for financial priority. But in the gathering economic clouds of the present years there is a risk that enthusiastic staff may abandon all hope for a better deal for the people who are due to spend much of their lives in hospital care.

Yet the problems are not all insoluble. We can start improving matters today, if members and staff of health authorities will commit themselves to achieving change in the ordinary day-to-day life of the long-term resident. This book shows how, without the need for major expenditure, long-term residents can be enabled to achieve a much better quality of life which will not only add to pleasure but will nourish a healthy independence.

To achieve this great change, two things are needed: an understanding of the social objectives of long-term care; and a determination to undertake a whole range of small, often mundane, tasks, in order to meet those objectives, in the course of which, procedures and practices hallowed by time may well have to be abandoned.

We hope that this book will encourage the whole health care team in a united effort to improve long-term care today.

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LIVING IN HOSPITAL

The Social Needs of People in Long-term Care

Text by James R Elliott MBE FHA
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*Now part of the Alcohol, Drug Abuse, and Mental Health Administration of the US Department of Health, Education, and Welfare.

This book is a joint effort between staff of the King's Fund Centre and a group of advisers whose work includes the care of long-term hospital residents. During the course of preparation, King's Fund Centre staff talked with many residents in long-term hospital care.

We do not suggest that every recommendation we make can apply to every person in long-term care whatever his degree of disability; but we believe that every resident could benefit from at least some of our suggestions. Thus, we have not prescribed for this class or that, but have tried instead to suggest the general considerations which should influence long-term care of any kind. The needs of children do not form part of the argument of this book.

What we offer is not so much a set of procedures as a way of looking at the needs of people like ourselves, who may well at some future date need long-term care, whether in hospital or residential home.

It might be objected that our ideas have no applicability to long-stay residents who are already 'too far gone'–whatever that may mean. We would say that for many thousands who are not yet in that condition, a further downward slide may at least be postponed by measures such as we have outlined. Furthermore, a modest thoughtfulness, which regards a resident as an adult social being, rather than as a medical parcel, or an aged baby, may yet strike some chord in those who appear to be beyond recall, and will certainly preserve the remnants of human dignity.

We have to make a start on this huge social problem. And the only way is to start from just where we are. If, as the result of our renewed efforts, a better quality of life emerges for only some of those in our care, even this limited advance will have been worthwhile, and may encourage further effort.

CONTENTS

People who live in hospital

There are a quarter of a million long-term residents in Britain's hospitals today: few have come there from choice. Many once lived more independent lives in the community: their habitat was office and shop, kitchen and parlour, library and corner pub. It was an environment which each one could modify or control to suit his own needs and tastes.

At some point, everything changed. Independence was replaced by dependence. Perhaps the cause was accident or injury, or the inexorable tide of mental or physical infirmity, or a family pushed beyond endurance and no longer able to cope. Whatever the reason they came into hospital care. And there, for the most part, they stay: some old and decrepit, some mentally ill or mentally handicapped, some young people, severely disabled.

All these people came into hospital as a refuge, for the care they could not get elsewhere. But their needs are not only medical: they are social also. And that is the subject of this book: the social needs of people for whom home is a hospital bed.

Why bother?

Few hospitals would wish to be considered as mere storage for people thought to be no longer able to function in society: but many hospitals are in danger of becoming just that. They seem to take over staff and residents alike: staff become more protective and authoritarian than they would be in their own homes: residents rapidly lose whatever degree of independence they came in with. The problem is not confined to Britain. An American publication on mental health institutions summarises the position[6]

'It is in the nature of the institution that residents increase their dependency and tend to withdraw from meaningful involvement; but it is not inevitable that they do so. A strong awareness on the part of all staff is the minimum condition necessary to prevent the psychologically noxious aspects of life that occur in even the most luxuriously and physically adequate institution. It is for this reason that the observation and evaluation of institutional life must include concern with physical, social and emotional conditions. It is easy to accept as "normal" and therefore as right, practices that go unquestioned merely because time honours them. Many institutions show strong tendencies to organize residents and activities so that the system runs efficiently from the standpoint of organization and administration. For example: insisting that all patients go through the cafeteria at one time, to "get it over with"; insisting that all beds be made by 7 a.m. regardless of the resident's wish to sleep; insisting that all residents get into their night clothes immediately after supper. The tendency is always for organizational efficiency to become the dominant theme . . .

'The emphasis on institutional efficiency at the expense of individual dignity also contributes to one of the most distressing aspects of institutional living: the loss of the sense of "self." In exchange for having his physical needs met, the resident often must surrender his psychological sense of self. In exchange for the security of a closed communal life, the resident may lose touch with the "outside world" and his sense of belonging to it.'

In Britain, of recent years, hospitals for the mentally handicapped have been making sustained efforts to reduce the dependency of their residents, in the belief that the mentally handicapped person should come into hospital for something more than custody; that since his greatest difficulty is to learn the normal ways of the community, his greatest need is for normal social experiences; that life in a typical institution is so abnormal as to deny a person these normal experiences; and that therefore it is crucially

important to change the pattern of life inside the institution so that it becomes much more like the pattern outside.

In short, if care is not taken, hospitals can increase the handicaps of mentally handicapped people by preventing them from learning the ways of the workaday world. Hospitals can just as easily increase the handicap of other sorts of people in long-term care, simply by allowing them to lose the power of decision and to forget what ordinary life is like.

This short guide could be filled with weighty references, all establishing without doubt the nature and extent of the harm inflicted on the residents of institutions by staff who are genuinely trying their best to help. The road to this particular hell is certainly paved with good intentions. We now know how institutionalisation harms residents – what we have to find out is how hospitals can change themselves so as to harm less and help more. In an attempt to answer that portmanteau question, we have tried to identify the factors which cause the most difficulty; to suggest some remedies which might be tried; and to produce a checklist for use by all those, whether members and officials of health authorities or community councils, senior staff of hospitals, or ordinary visiting citizens, who have a moral or legal responsibility to ensure that long-term residents have a fair deal. We might, at any rate, try to ensure – to paraphrase Florence Nightingale – that the institution does no positive social harm to the long-term resident.

One proviso: we could have spent much time discussing how many of the people already in long-term care really need to be in hospital. We know that professional opinion is moving towards the idea of a service of smaller units, much more dispersed, with a parallel reduction in the size and number of large institutions. Indeed, many would go much further: for them, social justice lies in ensuring that large numbers of handicapped or frail people be enabled to live in scattered, sheltered housing, or in their own homes, with good community back-up.

We feel sure that a more dispersed service will eventually come, and we hope that our suggestions will help those smaller homes to avoid the very real risk of becoming institutionalised enclaves in the community.

Most of all, we hope that our proposals will help the two hundred and fifty thousand people who, though they are living in hospital, are entitled today to a fuller life.

Look and listen

The lay member visiting or supervising a hospital finds himself in a particular difficulty. Faced with the sight of hundreds of people shut off from the community in their wards and departments, the visitor soon realises that he cannot easily comment on the professional quality of medical or nursing care, or of the work of paramedical departments. He tends to fall back on examining and reporting on the physical facilities, the standard of decoration, and so on. Very quickly he finds that the hospital authority and its officials know only too well the physical imperfections of the facilities, and have for years been struggling to attract enough money to long-term care to enable something to be done. Baffled, the visitor decides to talk to the staff, or to the residents, but not being too sure of the fundamental purpose of his visit, and fearful of overstepping the limits of his authority, he relapses into small-talk in the hope of satisfying himself that all is well.

We hope this book will encourage the hospital visitor not to look at his hospital through traditional professional spectacles, but instead to look with his own unaided eyes, and to believe what he sees. He will perceive whole aspects of residential life where he can make a real contribution which, if his efforts be diligently pursued, could result in a totally different quality of life for people who are living in hospital.

Later sections in the book will consider the varied social, cultural and emotional components of the resident's life in some detail. We have not produced a checklist of physical facilities which can be ticked off on a yes-or-no basis; instead we have tried to remind readers of those other, less tangible, factors which embody what might be called the 'social dimension'. These factors are not easily defined or measured; but they suggest a different way of looking at long-term care. Collectively, they offer a frame of reference for anyone concerned with the quality of life in long-term residential settings.

When considering long-term care, it is useful to keep certain main principles firmly in mind.

A primary objective of any long-term institution must be to make the utmost of the potential of the resident.

The social and emotional aspects of life really matter to long-term residents, and they influence physical and mental well-being. Given the right milieu, residents will deteriorate less quickly, monotony and boredom will be reduced, and the onset of costly full dependency will be delayed.

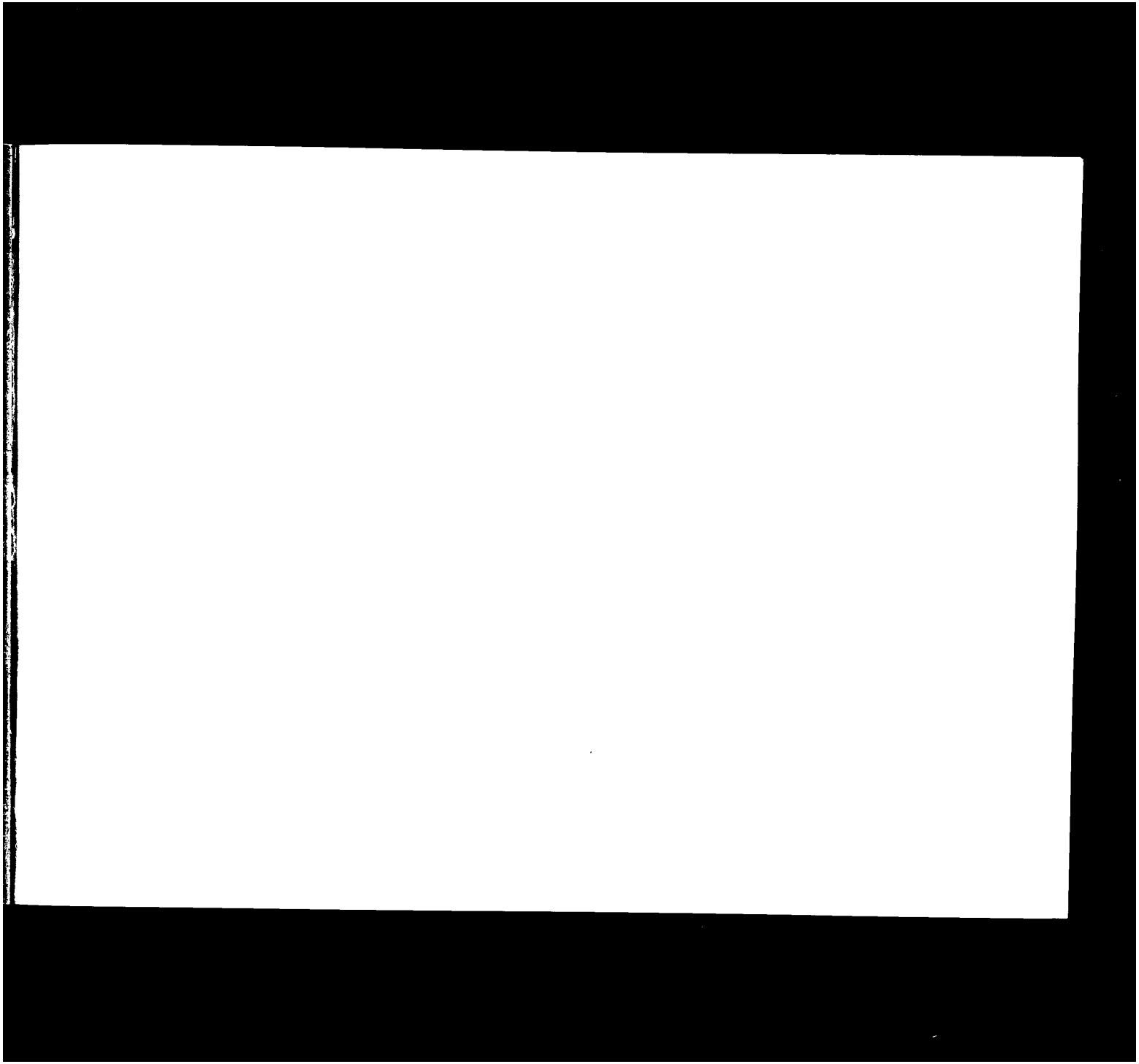
An important indicator of the quality of residential care is the extent to which residents do all they can for themselves–sometimes with special help–to meet their own needs.

Most of the daily life of an institution centres on relationships among the residents themselves: these include the way residents get along with one another, and help one another in the tasks of daily life.

The attitude and manner in which staff approach their everyday tasks are as important as the technical skill with which the tasks are carried out. Activities which appear to an outsider to be of a routine nature can assume a profound significance for the resident.

The way long-term hospitals are managed directly affects the quality of life of each person living there. Inevitably there are constraints on the degree to which normal social needs can be met: in an institutional setting the task of organisers of long-term care is to minimise those constraints as far as is possible.

The system must never be allowed to emphasise the smallness and futility of the social aspirations of the individual human being caught up in the organisational machine.



1 Coming into hospital

Are new residents made to feel welcome?

Is there reasonable privacy for admission procedures?

Is the new resident introduced to other residents?

Coming into hospital is often a frightening experience for the sick person and his family. As they cross the threshold of the hospital, what anxieties, fears and worries are held within them?

As they stand or sit there in the reception area, the way in which they are received can have a profound effect upon them and upon their future feelings about the hospital and the staff. Are they warmly welcomed with a smile and a handshake, or are they left to feel they are an intrusion upon the busy routine of a large organisation?

As they are taken to the ward, are they accompanied by a reassuring staff member or volunteer, or are they given impersonal directions, possibly confusing and unhelpful, and left to find their own way? This can be a time when the new resident and his family can ask informal questions about the hospital and get their bearings in a new and somewhat puzzling organisation. It is helpful if the staff member addresses him by name and introduces him personally to the ward staff on arrival. To be called 'the new patient' or not to be addressed personally at all, can make one feel like a parcel in transit.

And when he finally arrives on the ward, is there a warm personal welcome, a feeling of being expected? If the newcomer feels he is a nuisance, or an unwanted extra burden, anxiety will increase, perhaps

making him and his family aggressive, hostile or withdrawn. It is helpful if non-urgent admission can be arranged at a time when the staff will have time to devote to this important event in the new resident's life.

If he and his family have to wait, comfortable chairs in a day-room, cups of tea and an introduction to other residents, will help them over this difficult time. It is always reassuring if they can talk in an informal way with other residents and relatives. This sharing of worries can provide much mutual support.

Later, nurses, doctors, the new resident and his family will want to talk together about problems, symptoms, and special needs. There should be privacy and time for him and his family to discuss anxieties, to receive advice and reassurance, and to ask questions, no matter how trivial these may seem to the staff.

Although the staff will need to know the answers to certain questions, it is better if these can be drawn out in the normal course of conversation, rather than by the posing of formal questions about next of kin, age, or religion, by a nurse with pen poised over an official form.

If the part that the family has so far played in caring for their sick member is recognised, they will be encouraged to continue their support and perhaps arrange for occasional visits home. Instead of the family feeling guilty about sending him to hospital, family bonds will be strengthened.

If the new resident comes alone, he will need extra support in the strange environment. But whether he comes alone or with his family there should be no hurry to strip him of his clothes and put him to bed, take his temperature or start other routine clinical procedures. If he and his relatives are given time to adjust to the new situation, confusion or apparent hostility may well be lessened.

In a busy hospital, admission of a new resident may be just part of the day's work for the staff; but for him and his family it is an event they may never forget. If they are received in an offhand manner, abruptly, or with lack of concern, anxieties will grow. This does not help him, his family, or his future relationships within the hospital. If they are helpfully and warmly received, the new resident will face the prospect before him with less fear, and his family will be able to support him.[9]

The ground can be prepared if the new resident is given in advance an explanatory booklet, written in non-official language. Visitors, too, appreciate a leaflet which lets them know where they stand.

2 Daily timetable

From the day we are born a pattern develops in our daily life. A baby's day necessarily revolves around feeding, sleeping and nappy changing. As the child grows, he becomes more independent and even at nursery school is encouraged to make choices about toys, friendships and food. This process of discrimination and decision-making is part of the learning process which goes on throughout childhood and adolescence; and by the time a person reaches adulthood he has evolved a way of living based on his personal experience and those of his close family.

When this same person enters a long-stay hospital there is often a tendency to treat him as a baby, and once again the day revolves around feeding, sleeping and toileting. This time the mother-figure is the nurse, making decisions which the resident passively accepts. Although the resident may be totally incapacitated, for example by a severe stroke, is this mother/baby model the right one? Does it allow the resident to develop what potential he has for living within the limits of his capacity and the constraints of the organisation? Obviously not.

How far can the resident decide on the daily pattern of his own life? In many hospitals the routine of the day is seen pinned up in the sister's office, and sentences like 'All beds must be made by 8 o'clock' appear throughout. Mealtimes are always the same for everyone, followed by toilet rounds. Such a time-

table is designed to reinforce rigid routine. Visitors are seen as intruders, to be let in at a certain specified time and firmly ushered out when the bell rings.

Do all residents have to be awakened, washed and dressed at the same time? After all, some of us are at our best at the beginning of the day, whilst others are late risers who are brightest in the evening. Could not some residents have a lie-in, especially at the weekend, whilst others, the natural early risers, get up and potter about quietly, or go into the garden.

The early risers might like to give breakfast to those who like to lie in, while at night the roles might be reversed, with the more lively preparing an evening drink for those who like to retire early.

During the day, can a resident have a cup of tea when he fancies one, rather than waiting for the 'drinks round'? Some hospitals have facilities for residents to make their own drinks: this is especially enjoyed by elderly people.

After lunch, can those who wish retire to bed for a nap? In some hospitals it is literally impossible for a resident to go back to bed, or even the dormitory area, once he is up and dressed. In many instances dormitories are upstairs, and are kept locked during the day. This may be for administrative convenience or it may be felt that the resident would regress and not get up again. Yet a nap after lunch is a daily pattern for most elderly people at home, and for many younger people in other countries.

In effect, how early does the day end for the residents? In many hospitals they are put to bed at three, four or five o'clock, perhaps because most staff are on duty then. Sometimes the time of the evening 'drug round' sets the pattern for going to bed. In hospitals where residents may stay up, are there any activities or entertainments other than television? How often is television turned off at a pre-ordained time regardless of what the residents want to see? Volunteers are sometimes discouraged from visiting or arranging activities in the evening as this is said to 'excite the patients'. Yet many residents in long-stay units could do with some excitement! As one resident commented, *'I just drift through the day'*.

In some hospitals residents can get up when they wish, decide whether to forego breakfast for a lie-in, make themselves or a fellow resident a cup of tea, and go to bed when they wish. The result is a homely, comfortable atmosphere, yet the staff seem to feel they need to apologise for their apparent lack of organisation. It is as if a liberal regime has developed despite the organisation and not because of it.

We recognise the need for as many rules as are

necessary to allow residents to live together comfortably in close quarters, with as little loss of liberty as possible. For example, rules about transistor radios, or smoking in certain areas, are for everyone's good, particularly if they are imposed by mutual consent of residents and staff.

Incidentally some of the young people and adolescents we spoke with rather favoured a day which has a fairly firm framework and which spurs them on, instead of one which leaves them to drift through the day.

May residents go to bed at a time of their choice?

May residents rise when they like?

Subject to treatment considerations, may residents wash and dress when they choose?

May residents who are able make drinks when they like?

May residents go to bed when they fancy a nap?

3 Personal clothing

Everyone develops his own personal ideas about dress from quite an early age. Stand in Oxford Street, even in this day of mass-produced clothes for a mass market, and you'll hardly see two people dressed the same. The clothes you choose not only make you that bit different; the very act of choosing means that you have some control over your situation. You are deciding what you want to look like.

When Russell Barton first identified what he called 'institutional neurosis' in 1959 he was looking at a hospital population in which women still wore cross-over pinafores and pudding-basin haircuts, and men wore suits peculiarly colourless and shapeless, with hairstyles produced more by clipper than by scissors.[3] That was only sixteen years ago.

Things have changed a lot since then. Most long-term hospitals have vastly different ideas about clothes, and the general picture is much more attractive. Yet there are two big problems: one has to do with choice, and the other relates to the personalisation of clothes – are they used by only one person? Both these problems, big as they are, are dominated by one even bigger – the laundry service.

Under the old routine, stocks of standard, old-fashioned clothes were often distributed from stores on a ward-issue basis. It's not really much of an advance if all we've done is to issue more fashionable clothes on the same basis. The element of personal choice is almost entirely absent. Some hospitals have done better: they have introduced choice by encouraging patients to visit the clothing store individually or in small groups; others have arranged for a multiple or departmental store to hold a display of clothing three or four times a year in the recreation hall of the hospital. So some choice is possible: but it's still only choice from a limited range. What any woman (and most men) knows is that there is nothing to beat going to the shop yourself. But if the hospital authority is paying the bill – as it sometimes does – the problems emerge of public accountability for money. Here again, the problem has been surmounted by enterprising hospitals which have negotiated a discount and maximum-price arrangement with two or three large shops in town. This gives choice, and the excitement of a shopping jaunt. And the prospect of a jaunt is just as attractive to the increasing number of residents who like to buy their own clothes, and who should be encouraged to do so. Here the problem of logistics appears: *how* to find time and staff to take dependent people to the shops in groups small enough not to attract attention? Isn't this a job for the volunteer, as well as for staff?

Now, by such methods as these, clothing may be, as hospital jargon puts it, *personalised*. An ugly word, but it indicates that without these efforts the resident is decidedly *de*personalised. And what about

underclothes? Would any visiting member, manager, supervisor, or laundry manager for that matter, like to wear someone else's underclothes? Even the armed services in wartime avoided that ultimate degradation. Yet that is what many long-stay hospitals still ask their residents to do. Or they acquiesce in the fact, shrugging it off as unavoidable. Excuses commonly advanced include lack of money, lack of individual storage space, problems of incontinence, and the bulk laundry system. They ignore the fact that other hospitals, no better-off, succeed in arranging for all clothes to be distributed on a purely personal basis, and encourage residents to bring in, and regularly renew, their own clothes. Some hospitals use their 'clothing money' more ingeniously than others; some contrive functionally effective individual clothes storage by using special hangers, or by converting old linen cupboards and boot-rooms. These things *can* be done if they are seen as a priority action which will help to arrest the slide into further dependence.

Of course, some residents are incontinent, or otherwise afflicted, to the degree that good nursing demands a stock of underclothes and night clothes. Perhaps this is where personalised underclothes, but never outer clothes, become impracticable. Even so, the advances made by the work of the Disabled Living Foundation[14] and the King's Fund[12] show what can be done to retain personal attractiveness and dignity in spite of decrepitude.

Having done all that can be done, the enthusiastic improver of the clothing system now confronts what ought to be a saviour but is too often an ogre–the laundry service.

There cannot be many long-stay hospitals where the mere mention of the word 'laundry' does not produce a groan of despair amongst nurses. But are we being fair? Are we asking the impossible, when we expect a large power-laundry not only to cope with the thousands of sheets, towels and other 'flat-work', but also to give individual attention to personal clothes of every conceivable variety and material, most of them designed for washing by hand at home, or for careful dry-cleaning? Faced with this daunting task, the laundry will often seek to impose standards for the purchase of clothes, so that what is bought will 'stand up to the laundry'. This has the inevitable effect of reducing choice and standardising appearance. In ordinary life, commercial laundries for personal clothes are fast yielding place to the High Street launderette or the automatic washer at home, whilst the laundries offer a service mainly of 'flat-work'. Isn't this the way forward in long-term hospitals?

Many a ward, fitted with a good domestic automatic washer, or even with small sinks and a spin-dryer,

could not only give its residents a more satisfactory service, with their own clothes remaining in ward control, but could involve the residents in some part of the process: a small but useful step towards reducing dependency. Many residents would like to wash their own underclothes each day. A long-term hospital might consider establishing its own 'High Street launderette' coupled with individual washing machines on selected wards. There is no doubt that it is not so much lack of money for initial purchases of clothes, as the performance and turnover of a sometimes distant laundry, which have proved the giant obstacle to many a well-intentioned personal clothes scheme.

Does each resident have his own outer clothes?

Does each resident have his own underclothes?

Do residents choose their own clothes freely, from a good range?

Does each resident have his own wardrobe?

May residents, if able, launder their own clothes?

Is there an adequate laundry and dry cleaning service for residents' clothes?

4 Hairdressing and pocket money

Almost as important as individuality in dress is individuality in hairdressing and make-up. Many long-term hospitals have long realised this and have tried to do something about it. Often they have had to contrive a salon out of a washroom or locker room; sometimes they have been reduced to 'borrowing' a room for the occasional visit of the hairdresser. Some have succeeded in establishing a salon which bears some relationship to the High Street hairdresser, but have usually been forced to have recourse to funds raised by Friends of the Hospital, Rotary, Women's Royal Voluntary Service, or similar organisation. This is because hairdressing is looked upon as an amenity, an 'optional extra', rather than as a prescribed and necessary service which can have a marked therapeutic effect on the morale of a long-stay resident.

It could well be that some residents would be able to appreciate a trip outside hospital to a 'real' hairdresser. This seems to be another likely job for the volunteer. Many High Street hairdressers might be glad to offer appointments in off-peak periods. And many residents would enjoy the sheer act of paying, in money, for whatever service they choose to have. For those who cannot readily go outside in this way, an attractive and normal salon in the hospital, one in which service is paid for in the normal way, can prove an enjoyable centre for meeting and gossip.

Is there a hairdressing salon in the hospital?

Are residents encouraged to go to an outside hairdresser?

Does the visiting hairdresser attend to difficult or antisocial residents?

But there remain those who are perhaps unable to be moved, or are too disturbed or disoriented even for a visit to a hospital salon. Even so, they still need a personal hairdressing service which offers some choice and privacy. The hairdresser who visits the ward may tend to concentrate on the more acceptable or pleasing personalities: yet perhaps it is the markedly anti-social person who would be most helped. It is a real job of nursing to enter into this transaction in a prescriptive manner, to ensure that, as a social and therapeutic necessity, such a resident gets as non-institutional a hairdressing service as possible.

In summary: going out is best; then a visit to the hospital salon; then ward hairdressing in reasonable privacy.

Most of what we have said applies equally to men and women: even older people sometimes choose trendier hairstyles. And everyone likes choice.

This question of choice, not only in hairdressing, but in other matters too, is affected by the availability of cash. Some residents, particularly those who have recently been living in the community, may easily provide their own. Others, perhaps because they have been out of circulation for a long time, need to look to the State for pocket money. There are regulations which provide for payment of pocket money up to a permissible limit which is increased from time to time to take account of inflation. By no means all hospitals pay the full permissible amount to their residents. Some hospitals supply their residents with soap, face flannels, brushes, combs, toothpaste and so on. They then use the argument that since the residents do not require anything for themselves, they do not need any pocket money. This circular argument is then completed by the claim that patients do not need money and that if they were issued with it, they would only squander it.

A good system should ensure that each resident with the capacity for handling money is obliged to buy his own toilet requisites, pay for his own hairdressing and so on, and should have enough pocket money to manage these affairs. The system ought to provide banking facilities, so that residents may pay in or draw out small sums, and be provided with a bank statement.

Pocket money issued in this way is neither a dole nor a charity: it is a deliberate act designed to preserve the ability to make choices, and to combat dull acquiescence of a settled order.

5 Food and dining arrangements

Food is an important topic of recurring interest. When we move into a new environment–hotel, holiday camp, works canteen, or a new army unit–one of the first questions we ask is about food. Meals certainly are an event, a focus of interest, in the somewhat flat and otherwise eventless life of the long-term resident.

We are not here concerned with what might be the subjects covered by a catering or dietetic manual: our purpose is to consider food only as it affects the social well-being of the long-stay resident.*

It is in this context that we consider, for example, the routinised menu. Is it always fish on Fridays, or hot-pot on Mondays? How many residents are given mince every day? Or boiled egg at every breakfast? This sort of predictability is hardly a problem for the patient in the acute hospital, whose average stay is ten days and who hardly has time to notice the routine appearance of a particular dish on the menu. But it is a problem which could dominate the life of the long-term resident. Resident staff can escape by eating outside, or by cooking a meal for themselves. Patients in acute hospitals can have food brought in by relatives and friends. But in the long-term

*Many of the points we suggest here are included in a series of booklets being published by the King's Fund for Wessex Regional Health Authority, entitled *Better Food for Patients*.[17]

hospital these options rarely present themselves to the resident. Closely allied to predictability is the question of choice. A choice of meal is pleasant for all of us, but lack of choice means that the long-term resident has lost yet another chance for decision-making: from now on he takes what is dished up to him, like it or not. We know that as a matter of good practice, any good hospital catering department will offer people choice and variety: we mention it here to underline the fact that for the long-stay resident, variety and choice are fundamental social necessities.

The large hospital faces a problem when it tries to serve bulk-cooked food in an individual way. The logistic problems–from kitchen to ward block, from ward block to ward kitchen, from ward kitchen to resident–are formidable. So a compromise has to be sought which preserves some individuality at the receiving end. An individual plated meal service often scores over service from a heated trolley, but portions tend to be standardised as a result. Once again, choice–this time choice of quantity–is taken away. Given a normally-equipped dining room, it should be possible to serve vegetables, sauces and gravies in dishes placed on the table, so that people can help themselves according to individual taste and choice. Such ordinary things as a water-jug and glasses, clean cruet set, table napkins, and flowers on the table, make the meal table homely and inviting.

The residents will form their own congenial groupings, and could arrange the tables for themselves. What is more pathetic than the sight of an elderly person crouched over a tray stuck at the end of his bed, or balanced on another chair perhaps out of reach?

And do residents always have to dine as a race apart, with a gulf between themselves and the staff? Even occasionally, it would surely lessen social distance if staff and residents were to sit down together. This could be very valuable in helping disoriented people to retain, by following staff example, their grasp of ordinary eating habits and manners.

Any ward or living unit needs the kind of kitchen where drinks and snacks can be prepared at odd times, and there seems no reason why residents should not help in making drinks for themselves or for their relatives when they come in at odd times.

Special events such as birthdays and other anniversaries call for picnics or celebration teas. Any ward staff with the will can encourage this kind of activity, and many staff already take great pleasure in organising such events. It's all the better if the event can be planned and carried through by residents themselves, even if they need a little help. It all goes to increase the sense of having some control over one's own life.

To the resident it matters greatly whether he feeds himself totally, with some assistance or with maximum assistance, whether he is fed by staff with minimum assistance, or just 'fed'. And even if he is just 'fed'–this can be done nicely, neatly and with dignity or it can be a process of stuffing food through an aperture.

Is the menu for residents variable and unpredictable?

Do residents have a genuine opportunity to choose from a menu?

May residents indicate how much food they want?

Are residents permitted to provide food to suit their own taste?

Is there a dining room, or recognised dining area, in the ward?

Are the table settings homelike?

May residents help themselves?

Do staff ever sit down with residents for a meal?

Are residents ever permitted to organise for themselves a festive meal to mark some special occasion?

6 Noise

In 1960 the King's Fund began a project aimed at identifying the causes of, and ways of reducing, noise in hospitals. Thirteen years later another survey was undertaken: far from improving, noise had got worse. The 1974 report, *The Most Cruel Absence of Care*, lists the noises which trouble patients the most and offers suggestions for reducing noise.[10] Also available free from the King's Fund Centre are copies of cartoons by Fougasse aimed at supporting an anti-noise campaign. Much of the material which follows is derived from the report.*

At the outset, it must be said that noises which worry the acutely ill may not be nearly as troublesome to the relatively stable long-term resident. Some noises might be positively welcome. To see workmen coming and going when building a new ward block, with cranes working and hammers banging, might be really interesting to some–the noise would be only incidental. The same might be said of cars on a nearby road junction. One of our advisers recalls a dispirited old man confined to a wheelchair in the upper ward of a north country hospital. One day someone wheeled him out in the open, within sight of a major railway viaduct. Suddenly a new interest opened up. It turned out he had been a railway signalman for 40 years. Every fine day he would take up position, armed with an official timetable, and check the trains as they rattled back and forth overhead. But this was by chance: why didn't someone try to find out his former way of life, and then effect the link as a prescriptive act?

So the noises of street, hospital grounds and buildings may not be the ones which bother the long-stay resident. What about noises inside the ward or living area? Here we have a useful guide by Florence Nightingale.[15]

> *'Unnecessary (although slight) noise injures a sick person much more than necessary noise (of a much greater amount).'*

Readers may recall Danny Kaye's true-to-life comic song 'Bleep Bleep' which conveys the tension of a man who can't get to sleep because, somewhere in the house, a tap is occasionally dripping.

It's quite likely that the whine of a vacuum cleaner or the buzz of a floor polisher may constitute a positive event in the dull life of a long-stay resident. Even the telephone bell ringing in sister's office, or the clatter of crockery in the kitchen, may provide a form of interest. At any rate they mean something.

*Copies of this and the cartoons are available from the King's Fund Centre, 24 Nutford Place, London W1H 6AN.

As one resident told us,

'Complete or very nearly complete silence would be very depressing.'

But what about utterly purposeless and preventable noise? Like a kind of decibel-wallpaper, it's always there, the background to all that happens. The large television set, mounted high on the end wall of a long ward, sound full on, choice of channel controlled by staff, is often competing with disc jockeys on transistor radios. TV sound, and radio sound, should be available through earphones for each resident, unless there is a collective wish for general sound throughout the ward.

The noise of visitors, often complained of by patients in acute wards, may be quite welcome to long-stay residents: but it is as well to remember that their little bit of a large ward is all that they can call home, that is in the sense of private territory. Would we like visitors or staff to walk noisily through our own living room or bedroom, without permission, talking loudly as they go?

Are residents with transistor radios asked to use an earpiece?

Is the volume of the ward radio or television kept down to a level acceptable to the residents?

Are staff mindful, when they are talking in the ward, that they are in a place which is, in effect, the residents' only home?

7 Washing, bathing and toileting

Washing, bathing, going to the lavatory are everyday events which we all take for granted. Most of us have access to baths, hot water, and lavatories, whether at home or at work, which we can use how and when we wish. We choose how often we wash, how hot the water, and what time of day.

How different this becomes when we have to depend on other people to help us, or to provide these ordinary facilities for us in an institution which has a set of routine procedures by which everyone has to abide. Instead of the usual early morning clatter of bowls, with the lukewarm flannel around the face, could not the residents choose when they wash? Is it necessary for everyone to have a wash and bed made by a pre-ordained time which may have been decided upon many years ago? Must there always be a set day for taking a bath?

When a person is incapacitated and can't wash himself, how can he best be helped? Could relatives help? Many an old gentleman would rather be washed by his wife than a young nurse – whatever her professional expertise. Some residents may be able to help each other and would be glad to do so. How does a shy old lady feel when bathed by a male nurse?

A sense of privacy can be sustained if wash-basins have curtains which can be pulled around. Shelves and hooks, handrails and a bathroom chair, help

those who are trying hard to help themselves. Pride and dignity are fortified by a sufficiency of mirrors, including some at wheelchair height.

Privacy is something most of us value, particularly when we are concerned with personal bodily functions. How does it feel to be perched on a bedpan, with hastily drawn curtains, in the sight of other residents and visitors? How often are curtains not drawn when there are no visitors, as if it doesn't matter that residents see each other exposed? How does it feel to be sitting on a commode chair in the corridor, or an open toilet area, where visitors, messengers, and porters are constantly passing through? It doesn't happen everywhere; but it happens.

In units where ambulant residents of both sexes share facilities, are individual inhibitions and difficulties, particularly of the elderly, taken into account? Are staff sensitive enough to these feelings?

Do we give residents the chance to *talk* in private about their anxieties and worries about personal functions? Who wants his bowel function discussed in front of the whole ward? If a resident is worried about his incontinence, or feels that he may become incontinent, can he voice these worries to a sympathetic member of staff, out of earshot of other residents or staff? If he soils his clothes, can they be changed and washed with the minimum of fuss, in private, without the whole ward knowing of the 'accident'?

May residents decide for themselves when and whether to wash?

Are relatives encouraged to help with washing and toileting?

Are residents afforded due privacy for bodily functions, even when the ward is closed to visitors?

8 A place of one's own

We all need a place we can call our own – a place, however small, which is our own exclusive territory. In normal life, we have a house, a flat or a rented room. It has a door; we ourselves decide whether it shall be tidy or untidy, whether the lighting is brilliant or subdued, whether the radio is loud or soft; we decide when and what we eat and drink; we decide who is allowed in, and on what terms. It is, indeed, a place we can call our own. Not for nothing have we cherished the saying that an Englishman's home is his castle.

If, one day, we are enjoying this privacy and this control over our own environment, and the next day find ourselves confined by illness in a long-term institution, everything changes, instantly. If we are reasonable, we know that to get specialised care we shall have to surrender some of our long-cherished independence and privacy. But do we have to surrender it all?

If every long-stay resident could live in a single room it would be easier to define the area of independence. The room would be his own place: not just a room to sleep in, but something else besides; a place where he can relax, do nothing, invite friends into, or have an afternoon doze. It would be less tidy and more cluttered probably than a bedspace in an acute hospital, where he could keep some personal possessions.

It isn't enough just to provide a single room which is locked during the day, only to be used at bedtime, or with special permission. The resident should be allowed to use it, within reason, how and when he wishes. This territorial need will not be satisfied unless he himself is in control of the place. When he is there, he shouldn't have to mix with anyone else unless he wishes. It is only very rarely that a resident's physical or mental condition justifies his being permanently on view through an observation window, or his light being controlled by someone else, from the corridor.

A resident has a chance to keep his clothes in good order if he has a real wardrobe, or built-in cupboard: certainly he doesn't need a special 'hospital' wardrobe, or a steel locker, or a drawer under the bed. He'd like something by his bed to put things on and to keep things in, with at least one part which locks. It might be a typical domestic bedside locker, or a chest of drawers, or a dressing table: but not a 'hospital' locker with its special design. It is *normality* which is being sought. And the resident should be the only one to keep the key: he shouldn't have to find his locker cleared out without his consent. Clutter can be therapeutic: what is clutter to some people, is something different to others– memories, feelings and associations.

In a long-stay situation, the opportunity for the resident to furnish his own room with one or two pieces from his old home should be afforded whenever possible. The occasional table which had always gleamed in the hallway, the pottery figure which was a wedding present, could provide a strong link with normality. Even the opportunity to buy a different lampshade, or bed cover, would bring a feeling of individuality. Do such things really have to be sterile, or standard issue?

A single room can be transformed from a sterile box, controlled by staff, to a little home, controlled by the resident. This is all very fine if you have single rooms, but thousands of Britain's long-stay residents still live in overcrowded open dormitories, and are likely to do so for another decade or two yet. How can a sense of one's own home be brought into the open hospital ward?

It certainly isn't easy: all the cards seem to be stacked against privacy and independence. But there are some things which can be done to mitigate the harmful effects of regimentation.

Often, in the past, upgrading open wards has succeeded only in titivating the old accommodation. The same old system has prevailed. The staff still seem to be forced into custodial and over-protective ways, though the ward may be prettier and cleaner. Yet with the same amount of money, but the right

ideas, hospital wards can be converted to give not only better living conditions, but more interest, more privacy, and more independence. The principles we have suggested for single rooms are equally valid in the big dormitory, but their application demands more ingenuity.

Simple, straightforward homeliness should still be the aim, with an attempt to enable residents to live in small, somewhat self-contained groups. Nothing can be more demoralising than being forced to live in a large herd. Areas which were formerly large dormitories or day spaces could be broken up into smaller groupings.

The view of the Centre on Environment for the Handicapped is that each resident should have at least his own identifiable cupboard, with his own personal storage place for his own clothes and possessions. The effect should be more like that of a bed-sitting room, accessible at any time, even if, physically, all that can be provided is a curtained or partitioned area.[19] The CEH suggests

'Except where high dependency nursing requires adjustable beds, divans are generally preferable . . . Chests of drawers may often be more suitable than hospital lockers. Personal pin-up space should be provided.

'Low screens have been used successfully by several regional hospital boards but in future there may be some restrictions to their use as partitions. This is why, in the section on fire regulations, it is advocated that money is spent on dividing wards into smaller rooms, giving far greater freedom in the selection and use of ordinary furniture, which need not then be subject to such stringent regulations.

'Wardrobes or cupboard units, either built-in or freestanding, are essential. Curtains, mirrors, and towel rails should be provided. Furniture should be varied and individuality encouraged. Lighting should be domestic with an individual light for every bed, although a central light with dimmer switch might be needed for nursing purposes . . . Standard regional equipment lists should be examined critically, as they are often drawn up with clinical requirements in mind and applied unquestioningly (e.g. clinical thermometer holder over every bed!).

'To summarise, a variety of accommodation should be provided to suit different needs, but in order to obviate fire risks at the same time as providing smaller units, no bedroom space should be for more than six people. If this is not possible, permanent structural subdivision may not be worthwhile and it may be preferable to concentrate on improving other amenities.'

But, in the end, there's no doubt that it's the way the ward is run which really makes the difference. No-one working in or visiting a long-stay ward should ever forget that he is in a place which the residents have to regard as home. With this fact permanently in mind, many insensitive intrusions upon privacy can be avoided, and many opportunities to foster and bolster initiative can be taken. Rules should be limited to just as many as are necessary to enable the community to exist harmoniously, and to enable vital medical and nursing procedures to be properly undertaken. A rule or system which aims at fostering independence and self-reliance, and at combating unnecessary dependence and apathy, is a good rule or system, however administratively inconvenient it may turn out to be.

If a resident has a single room—

Are there any limitations on when he is allowed to use it?

May he bring in any furniture or furnishings of his own?

Is a reasonable domestic untidiness and clutter permissible?

If a resident is in an open ward—

Is the ward arranged in such a way that each resident has a small piece of territory which is his to control, as though it were a single room?

Do staff respect the human need of all residents for a place of their own?

9 Boredom

Boredom haunts every institution and does not discriminate between residents and staff. It makes the day dreary, it causes the victim to wish away his life, and it takes all interest, initiative and joy out of living. Not only does it affect the mind: it can ravage the body. It can push the sufferer into a state of semi-inert apathy, so that he sits in a chair all day, gazing at nothing. Unused muscles atrophy, and become weak: immobility is made more acceptable than mobility, and further atrophy occurs. And there is some evidence, though not so clearly proven, that failure to use the brain can also result in atrophy, with a deterioration in its function at various levels.

Thus boredom in the extreme can destroy both the brain and the body.

Institutional neurosis is an illness now generally accepted as one which really exists, and is produced by institutions where the staff have rigid attitudes and where regimentation destroys the residents' initiative. One of the factors which create institutional neurosis is boredom.

Individuals vary in their susceptibility to boredom, and many people living unfettered in a so-called 'free' society suffer from it. If you can become bored when there are few restrictions on your activity, how much easier it is to become a victim of this

malaise if you are confined in an institution and severely restricted in what you can do. Boredom is not prevented by simply providing the person with something to do, regardless of his or her interests, desires and wishes. To some, weaving a basket can be unbelievably boring, while to another, listening to music of any kind can have a similar effect.

Boredom can be only countered if each individual is considered as unique, with his own likes and dislikes. This means that activities must be varied, with possibilities for further change, and further choice. Painting a picture, making a model or listening to a symphony can all be delightful, provided the activity does not go on for too long. Few people can tolerate listening to music every morning and afternoon and having no other activity or interest available, yet it is not uncommon to find residents exposed to the same activity day after day, and staff believing that they are countering boredom and institutional neurosis by providing this dismal repetitive activity.

Workers on production lines suffer unbelievable boredom: to mimic the production line when providing activity and interest for residents must be doomed to failure. Admittedly, people being prepared for life outside hospital must be reminded what life is really like, and if they are to become production line workers, preparation for this is useful.

But life is more than work. Any programme of activity, be it for preparation for life outside, or a method of making life within an institution more acceptable, must consist of much more than dreary, repetitive tasks. The opportunity for activity and involvement must be wide enough to provide some satisfaction and interest for everyone.

Everyone cannot be free of boredom all the time, but most should be free for most of the time.

10 Worthwhile work

It is more worthwhile for the visitor to observe *how* a resident is occupied than to note *whether* he is occupied. Is he working usefully, or just filling in time? Is he working for himself or his fellows, or is he just completing a packaging contract?

Here are three real-life incidents.

An elderly lady remembered the days when her institution was maintained by inmate-labour: she herself used to clean and polish the villa where she lived, and sometimes she worked in the kitchen or laundry – always for little or no pay. Though the work was sometimes hard, she felt she belonged. Now all that work is taken from her and is done by paid staff. So she goes each day to the industrial workshop, packing hair grips and plasticine to meet the demands of an outside contractor.

A man had been some years in an ortho-paedic hospital when the occupational therapist discovered that before falling ill he had been a master-baker. So every now and then in the little occupational therapy kitchen, he bakes a small tray of fancy cakes, which are consumed with alacrity in the department.

In one area, mentally handicapped people help other people by knitting blanket squares for refugees, packing clothing for the Save the Children Fund, preparing used postage stamps for a local dealer in aid of charity, raising money by making and selling marmalade, collecting milk bottle tops, collecting magazines for the elderly, and laundering the cathedral choristers' surplices.[5]

People in residential care need to contribute to their own care in some way: if not, they become excessively dependent and apathetic. No-one likes to be a passive receiver of care all his life. Working for yourself gives you independence. Working for others earns esteem and gives satisfaction. 'Patient-labour' is not shameful, provided it is not exploited. A lady who has looked after her own kitchen for 40 years can take a pride in washing the ward dishes in the company of a few friends, and enjoy the gossip at the same time. It's more fun than watching a dishwasher. She gets the chance to imprint her standards on the ward. Though only in a small way, she has some control over her environment. Good pastry cooks are hard to come by. Why shouldn't the baker make a few trays of cakes once a week, for payment, in the main kitchen; or do some regular baking in his own ward kitchen?

Residents help one another, and talk as they do it. They benefit socially, financially and physically from their work. They feel they are producing and contributing. But these production skills may have to be re-learned. Why not use existing skills?

One of our interviewers visited a ward in which the most profoundly handicapped residents had to be fed. By one bedside a young mentally handicapped woman was feeding one helpless girl with infinite patience and compassion. Was this to be seen as the exploitation of patient-labour, or as an insightful act which enabled someone who is usually at the receiving end, to be, for once, a giver? We believe that this young woman's skills were being rightly used, and that her personality and dignity were thereby strengthened.

Too much of the so-called 'work' which long-term hospitals allow their residents to do is mere busyness, or contract performance, with little or no relationship to the activities of daily living. What has happened to all the trades and occupations which residents used to follow before coming into care? Can none of them be salvaged? Is there no place for the skills of confectioner, dressmaker, clerk, bookbinder, carpenter, accountant, gardener or linguist?

No doubt objectors will anticipate opposition from

trades unions. We feel that few if any unions would object to incidental work of this kind by residents, provided the reasons are explained in advance and it can be shown that there will be no exploitation.

Are residents who are able, given the opportunity to undertake work of any kind?

Does the work help the resident community?

Are residents encouraged to offer their old skills, or to learn new ones?

Is there a fair system of payment for work done?

11 Recreation: holidays and outings

Many people find their greatest relaxation in watching television, filling up football coupons, betting on horses, or playing Bingo. They wouldn't thank the person who tried to direct them to other, more 'cultural', pursuits. But these latter activities are there: they are available. People have choice to play Bingo or bridge, to use bottles for putting ships into or drinking out of, or both! They have a free option.

Such options are rarely available to the long-term resident. Hospitals often organise mass entertainment very well but don't respond as readily to minority interests. In some places, residents are expected, if not pressurised, to join in mass recreation, even though their personal inclinations may lie in other directions. There is a lot of room for much more creative recreation: some is suggested in the next section on further education. Hospitals sometimes seem to measure their success in providing recreation by the numbers attending, rather than by thinking about the individual who came, and what he gained. Residents need a wide variety of activities to choose from. Not everyone always wants to join in a group to have fun. Quiet areas are needed where residents, alone or in pairs, can relax and engage in activities of their own choice–draughts, chess, dominoes, crosswords, or reading.

Usually recreation is planned and provided *by* the staff *for* the residents. But some residents could be

more closely involved if the hospital were to encourage them. They could form a residents' committee for recreation. A lot could be provided by residents themselves. They don't always have to be passive recipients of other people's ideas. They should be encouraged to contribute their talents through teaching of skills, entertaining others and so on.

Somebody needs to have clear responsibility for stimulating a personalised recreation and holiday programme, and he needs to have transport, like a mini-bus, for small group expeditions or visits.* Some large mental hospitals have a member of staff, a nurse or social worker, carrying out this task. In others it is done by the voluntary help organiser.

Whoever has the responsibility, the cooperation of a residents' committee is needed to give more choice to the residents, and to involve them in making decisions about their own lives. The important point is that organising leisure and educational activities should be seen as a central function of the long-stay hospital, not an optional frill. Somebody has to be designated to coordinate the effort, or it won't happen.

*The Central Council for the Disabled publishes a very useful annual booklet, *Holidays for the Physically Handicapped.*[4] The address is 34 Eccleston Square, London SW1.

Is there somebody responsible for a full programme of widely varied recreational activities?

Is encouragement given to those who wish to pursue minority interests?

Are residents enabled to take a part in planning the recreational programme?

Does the programme include special items for those confined to bed?

Is use made of volunteers in developing the recreational programme?

12 Further education

Most people go on learning throughout life: not in a formal way, maybe, but learning about books and music and art, about particular hobbies and interests, about politics and current affairs, sports and pastimes. A few older people cast in a sterling mould take university degrees at the age of 65 and more; but for most of us mental ability may fall well short of formal courses of higher study. It must not be forgotten that some long-term residents are young people who would hope to continue and develop their formal studies. And there are many young mentally handicapped adults who could benefit greatly from a carefully thought-out programme of adult education.[1]

Long residence in an institution can cut people off from such activities, or may force them to canalise interests into rather irrelevant diversional channels.

A 'library service' can mean a hopeful weekly pick from a trolley, or it can mean a key to the local public library service, and through that a key to the whole range of libraries, specialised and general, in Great Britain. Local authorities have a legal duty to bring a real library service to the long-stay resident. The Library Association has a special section which deals with services to hospitals and the handicapped. If the visiting librarian is on the staff of the public library, he or she can carry out a really creative and liberating job of librarianship, backed

by immense resources. Whether the desired reading is diversional, or broadly educational, or strictly vocational, the librarian can open doors to a new world. Large-type books and taped books are also available.

The service involves expenditure on a room and fittings by the hospital, a payment towards the librarian's salary by the hospital, and the willingness of the local authority to provide and turnover a stock of books. Other more diversified activities which could be included in a library service are described in Mental Handicap Paper No 3 available from the King's Fund Centre.[2] The main point to remember is that long-term residents are citizens who are entitled to as good a library service as any other citizens.

Some hospitals have thriving art departments which succeed in teaching painting, drawing or collage to people who have never handled a brush before in their lives. Much more could be done. For example, a geriatric department has an art room and runs a yearly show of art by people who include nonagenarians. The King's Fund has sponsored special training courses for qualified art teachers wishing to work with long-stay residents.[7]

But many more people appreciate art than those who practise it. Why not art appreciation classes, run by the local college of art or of further education? Why not an occasional visit to an art gallery. Would college students like to participate in bringing art to long-stay residents? The possibilities are great, even though they might only apply to a few of the residents.

Music is particularly good to introduce, but it needs as careful planning as do other cultural activities. The further education service can also help here, and so can organisations like the Council for Music in Hospitals.* Why not talks on music linked with music cassettes on loan? Why not performances by local music students, opera by a travelling professional group, musical comedy by the local amateur society? Why not a show by a good folk group? And there is still room for the local amateur instrumentalist who is prepared to offer a performance suited to the audience. A lady of 94 commented with gratitude on the pianist who comes to her ward each week to play.

An adult education centre can often provide back-up for hobbies and interests; for example, puppetry, model-making, photography, dressmaking or radio. But help could come from the man in the street who shares that interest – if only someone in the hospital

*Secretary: Miss D F M Lindsay, 340 Lower Road, Little Bookham, Surrey.

makes the effort to link the man-in-the-bed with the man-in-the-street. Someone who used to go watching geese and waders may no longer be able to face the estuaries and lakes in cold winter, but with the aid of someone from the local natural history society, he can still observe the birds about him, and enjoy other people's slides of ospreys in the Cairngorms, or flamingos in the Camargue. More fun than watching television. Perhaps all the residents in a ward would not want such a programme in preference to Coronation Street! But it would be worth doing just for a few. A one-time ham-radio fan could be visited by a local radio enthusiast, or a group from the technical college. And if other residents don't object to the bits and pieces, the interested ones could even do a bit of transmitting and receiving themselves.

We are not suggesting that the wards should be full of people busily undertaking all these activities: but we make a plea for a more conscious effort to recognise individual interests of the individual, and to provide a far more purposeful range of intra-mural activities. We all want to 'do our own thing'.

A man doesn't cease to be a political animal because he takes up long-term residence, against his will, in a hospital. He ought to be encouraged and helped to record his vote at election-time. To maintain a political interest he needs access to radio and television. Here again, the further education service can make a significant contribution with courses on current affairs.

He also needs that special luxury: the newspaper or weekly journal which *he* likes to read. The sheer mechanics of regularly receiving, and paying for, the newspaper or journal of choice can be difficult, particularly in the large dispersed mental hospital. Could a resident perhaps undertake a paper round for the hospital shop–and be paid for it? The loan of 'ward' newspapers is not quite the same thing as the prompt and regular receipt of your own paper. It's even a satisfaction to tackle a crossword that someone else hasn't already started!

Particular care needs to be taken about formal courses of education for younger adults, but also for more elderly enthusiasts. The Open University provides a very wide range of opportunity. But residents need access to BBC 2, Radio 3, and a quiet room. Is this too much to ask for those who may have to spend a large proportion of their life in care?

We have given just a few examples of the possible use of the adult education service, both formal and informal. There could be dozens more. Success in matching service to need depends primarily on the recognition by the hospital that this is a real therapeutic necessity, not an optional extra or frill; and secondly on the hospital's willingness to see that, as

a full-time job, somebody–perhaps employed jointly by health service and the education service–has responsibility for ascertaining individual needs and then making the right contacts.[1] It is important to ascertain needs *before* classes are arranged.

Does the hospital have a formal link with the local further education service so that the educationai needs of residents are brought to the notice of the service?

Does the further education service interest residents in what it can do for them?

Have residents easy access to the public library service?

Has the hospital exploited fully the basic right of handicapped and bed-bound people to the whole range of public library services?

Is there a real encouragement to residents to retain or develop an interest in—

art?

music?

literature?

hobbies?

current affairs?

Are younger adult residents encouraged to pursue formal studies, and are they given adequate facilities and privacy for this?

Is it possible for a resident to obtain regularly the newspapers or journals of his choice?

13 Gardens, flowers and animals

Have residents easy access to a garden or similar area?

Are well-behaved pets allowed to visit residents?

Are residents encouraged to grow their own plants, or to tend the ward plants?

Do residents have any opportunity to care for birds or pet animals?

Do residents ever have the chance to look at wild life, to walk in woodlands and meadows, to sit by the river?

A garden with seats and flowers opens up a new life for many residents. The freedom to leave the ward and to be in an entirely different and natural environment is greatly appreciated. A hospital ward can never be as normal as a house, but a hospital garden, with seats, can be as normal as a cottage garden, particularly if geometric arrays of bedding-out plants can be avoided. And there might be some residents who could grow a few vegetables.

One resident told us about the garden, *'We get away from the hospital atmosphere'*. Another, in a gardenless psychiatric unit, reflected sadly, *'I crave for green trees, grass and a bit of nature'*.

A goldfish pond, clock golf or croquet provide added interest. A bird table of the type recommended by the Royal Society for the Protection of Birds, and a regular supply of bird seed and food scraps, can provide interest even in the harshest winter. Old interests in birdwatching can be revived, or a new interest can be developed, backed by a bird-watcher's guide and a pair of lightweight binoculars.

Even in places without a real garden, a few seats and tubs of flowers on a terrace or by the front door, or even on a flat, well-protected roof, can contribute to that longed-for feeling of being out and about.

And what about self-help? Some residents, who once

had gardens or window-boxes of their own, may be glad to help in the garden, or to bring on cuttings in pots on ward window-sills. A lady was shown on television who succeeded in growing a whole range of vegetables in large pots and boxes on the tiny balcony of her council flat. The Disabled Living Foundation, in association with Reader's Digest, has published a very useful guide to gardening for the disabled.[20]

Some hospitals have successfully and inexpensively planned garden areas with raised beds, for the benefit of those who cannot stoop or kneel, and a variety of paved surfaces to give walking practice areas.[8]

One often sees vases of cut flowers in serried ranks down a ward; sometimes exotic plants requiring somewhat specialised handling are brought in by the gardener. As well as these, why not some plants of a more common and hardy nature, like geraniums? A bulb in a glass, or seeds in a tray, or a bean in a glass jar, can retain a lot of interest in the living world.

Interest and love for animals are deep-rooted feelings in many people. The ward cat (neutered to avoid the distress caused by the disposal of kittens) brings happiness to many old ladies. One of them could be given responsibility for feeding it and cleaning its sanitary tray. What about a hutch of rabbits on a balcony or terrace, a pair of budgerigars or an aquarium? People who are themselves immobile like to see other creatures moving. If there is real difficulty about pets on a ward, what about establishing a pets' corner nearby, with animals which can not only be looked at, but handled?

Pets can be visitors, too. For many people the pain of leaving the family pet adds to the pain of leaving the family home. Pets are normally as well-behaved as people when they come as visitors, if not more so: yet many hospitals and homes refuse to admit them.

Some hospitals, particularly mental hospitals, have large grounds. Given a chance to visit the wooded or uncultivated fringes, the resident might see the occasional fox or squirrel, hear woodpigeon and cuckoo, watch rooks whirling and nesting. It seems a pity to confine residents to a circuit of the laid-out grounds, when glimpses of nature and normality are often so close at hand.

14 Religious beliefs

Respect for other people's religious beliefs – or non-beliefs – has been part of hospital life for so long that it seems unnecessary to elaborate.

Hospital chaplains work in quite different ways, but they share a concern to integrate their work with the healing and caring work of the hospital, be it long-term or short-term. This is not always easy to achieve with the rapid turnover and incessant pressures of the acute hospital; but in the long-term setting the chaplain has more chance to develop a stable relationship with the resident, just as he has with any other member of his parish, and with members of the staff team.

Experience shows two things. Firstly, the potential of the chaplaincy service is enhanced if the chaplains themselves meet as a group, exchange information, avoid overlap, and offer a unified policy on chaplaincy matters. Secondly, great benefits can flow if a representative of the chaplains' group is accepted as a full member of the hospital or clinical team.

Religion is an important part of the 'social dimension' of life for the residents.

Every chaplain practises his calling according to his own vision and conscience; but within the social dimension of long-term care certain points may be made.

We would hope that, in spite of difficulties, all residents who are able, and who have a religious allegiance, should be encouraged, invited, and helped, to attend the neighbourhood church or chapel and take part in women's groups, choir membership, flower rota, cleaning brasses, guild meetings, social outings, parish suppers, and so on. With the goodwill and help of members of the congregation, many physically handicapped residents could be brought to the local church. And those who are retarded or affected by some mental decrepitude can equally well be assimilated. This may not be possible for all, but it could be for many.

For those who must, for some reason, remain within hospital walls, religious services broadcast over the hospital radio need not be the only answer. Small gatherings are possible if the hospital authority see this as an essential part of social strengthening, and not as a troublesome extra which occasions the use of rooms after 'normal' hours, or the movement of chairs from one place to another.

Considerations such as this are not necessarily met by a purpose-built chapel. Much more useful, in the long-stay hospital, might be a simply constructed chaplaincy centre, with two or three offices, telephones, secretarial help, and one or two larger rooms for various groupings of residents for services, study groups or social meetings. Such a centre could also provide a good base for work amongst staff. One of the tasks of the secretary could be to effect and organise links with the churches and chapels outside.

Are residents who wish and are able, encouraged to go out to the local church?

If residents cannot go out, is there an attempt to bring church members in to them?

15 Choosing your neighbour

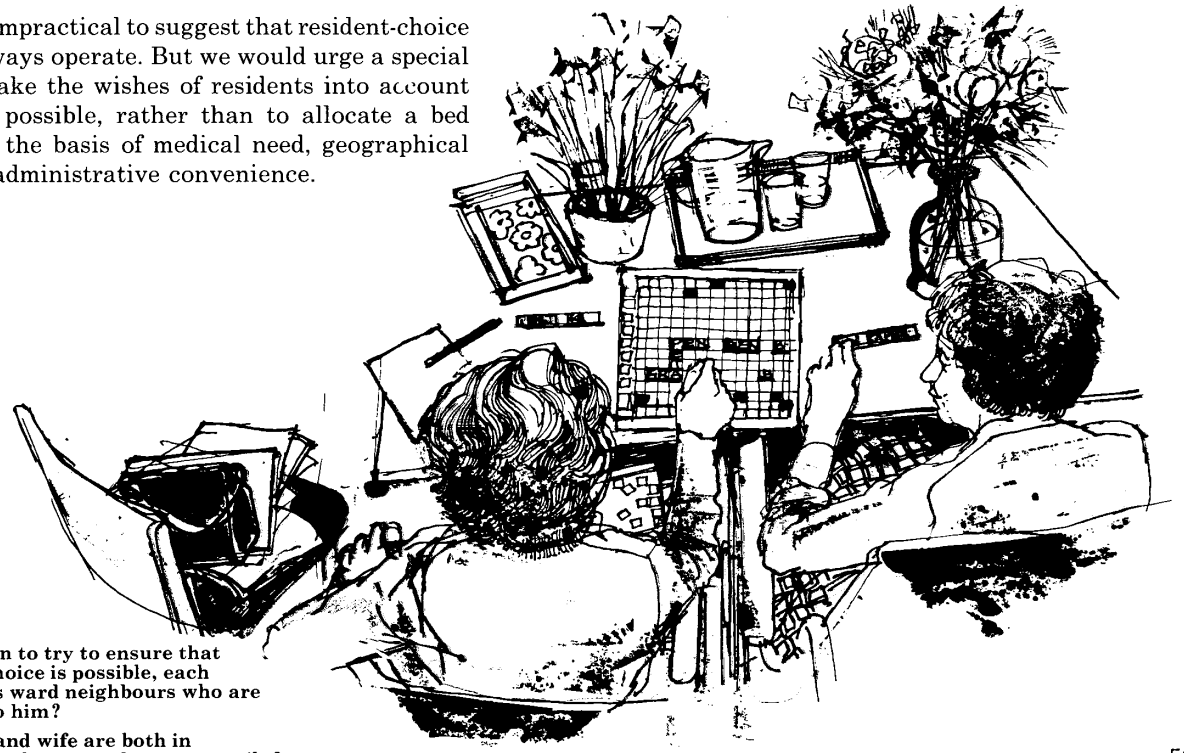
The resident who is one of 30 in an open 'Nightingale' ward, can be much affected, for better or worse, by the personalities of his immediate neighbours, particularly if he is a 'captive' resident confined to bed, or the bed area. And when you come into hospital for the first time, you can be helped very much by a feeling of kinship or identity with the people who perhaps will be your neighbours for years to come.

If the ward provides for bays of four or six people, having the wrong neighbours can be even more wearing. And the wrong neighbour in a two-bed ward would be intolerable. If you read *The Sun* and your neighbour prefers *The Guardian* it's a bit difficult to share in the fun of the crossword. If you are 80, and your neighbour is 20, conversation may not flow very freely.

Good ward sisters and charge nurses have known these things for generations, and they try to organise a congenial mix – though inevitably they may be inhibited by medical considerations such as ease of observation, access to piped oxygen, availability of a specially-designed bed, and so on. There are other constraints on achieving the right mix: overcrowding; allocation of wards to different consultants; grouping of wards to relate to defined sectors of the community or to achieve some defined functional purpose. All these factors may make it difficult to ensure that the lady in Ward A has as her hospital

neighbour her friend of 40 years standing, at present living in Ward B; or that the long-married couple may still remain together.

It may be impractical to suggest that resident-choice should always operate. But we would urge a special effort to take the wishes of residents into account whenever possible, rather than to allocate a bed purely on the basis of medical need, geographical origin or administrative convenience.



Is care taken to try to ensure that wherever choice is possible, each resident has ward neighbours who are congenial to him?

If husband and wife are both in hospital, are they parted unnecessarily?

16 Mixing the age groups

Older people enjoy the company of younger–maybe just for a time. As grandparents sometimes say about their energetic grandchildren, 'We love to see them come and we're glad to see them go!'

There may be a few residents who are positively troubled by the presence of the young, but most would be cheered by visits from children, whether of their own family or of other people's. Acute hospitals often limit or even prohibit visiting by the young, but this need not apply to the long-term hospital, where crowds of visitors are seldom seen. Staff may not like the upheaval, but at least the monotony is broken. And the sight of a loved grandchild, with talk about school and play and holidays, can strengthen family links which might otherwise weaken through separation.

But not every resident has family connections, and this is where organisers of voluntary services can help–not so much by organising so-called 'adoptions', but rather by ensuring the regular attendance of people who are encouraged to develop a relationship with the individual resident.

For younger long-stay residents, visits from their own or other age groups should not be so much of a problem: most will have good family links, or circles of friends. It is doubtful whether the younger disabled person struggling to achieve relative indepen-

dence, would appreciate visitors being 'fixed-up' on his behalf: he might well resent it as an interference with personal choice. Yet the relative scarcity and isolation of units for the young disabled may discourage their exhuberant friends from visiting. In fact, this is one of the strong arguments against specialised hospital units for the younger disabled.

Within the world of one hospital are several little worlds: a world of very old men, of old men, of old ladies, confused men, of confused women, of young disabled people, and so on. Here is a field for some social engineering. The task is to give people in these different worlds the chance to mingle, instead of living their entire life not only in the constraints of one hospital, but of one bit of that hospital. The large hospital for the mentally ill or mentally handicapped often has an advantage here. It has communal facilities – recreation hall, gymnasium, workshops, occupational therapy department, library, and art department. All these places provide opportunity for people of different ward backgrounds to mix with one another. Long-term hospitals without these communal facilities have a special problem if they are to avoid narrowing the world of the resident to the area circumscribed by the ward walls. It is a problem whose solution will call for ingenious effort, on an individual basis.

One specialised solution, probably applicable only to the mentally handicapped, is to develop family units deliberately structured to duplicate a typical extended family in different ages, from grandparent to grandchild.

Are older residents, when they wish it, given the opportunity of the company of young visitors?

Does someone see that those without family or friends receive occasional visitors?

Are younger residents allowed plenty of social interchange with visitors of their own age group, even though their boisterousness may disturb the calm of the ward?

Is there a real opportunity for the residents of one ward to mingle with residents of different age groups, or different medical conditions, or of the opposite sex, from other parts of the hospital?

Do inpatients and day patients mix freely?

17 The opposite sex

It hardly needs stating, except to establish a common starting point, that people of all ages need the company of the opposite sex. In old or young, behaviour is modified by the presence of the opposite sex. Nobody who has seen the effect on elderly men and women of mixed dining or day-room arrangements could doubt this proposition. Men shave more regularly, and curb their language: women dress more attractively. They talk on subjects of heterosexual interest.

The organisational pattern of the long-stay hospital usually works against the integration of the sexes, except in such areas as workshop or canteen. Even there, our interviewers saw segregation, explained by residents with the deadly phrase, 'That's how it always has been'. Certainly integration is still rare in living accommodation. It is worth looking hard at hospital buildings to see whether, for some residents at any rate, integrated wards would be possible. After all, why should man and wife live in two separate hospital blocks after a lifetime together? If one partner is in hospital for a long time, and the other partner visits, should they not sometimes, somehow have the opportunity for real privacy?

But there are younger people to consider also: the physically disabled, mentally disturbed or mentally handicapped. Because they are in institutional care, does this restrict them to life without love? The

disadvantages of a single-sex society do not need embellishment.

Society's attitude to the sexual relationships of people who happen, incidentally, to be disabled or handicapped in some way is now being questioned.[11, 13]

Given that a tolerant institution may uneasily turn a blind eye to sexual relationships amongst residents, is this good enough? Should there be a clear effort to counsel the young, not only on the plain facts of conception and contraception, but also on deeper aspects of the emotions and human relationships? Must it always be by connivance or stealth that sexual intercourse takes place? What about relationships between mature men and women residents or when one partner is a resident and the other is not. What is the institution's attitude to homosexual relationships?

It is easy for liberal-minded people to answer most of these questions, provided they themselves are not responsible for running the institution. But for those who have this responsibility – members or officials – there is little guidance from higher authority. To some extent there is a conspiracy of silence, or at best a nod of acquiescence. Whilst public attitudes towards sexual relations in general have changed greatly over recent years, there seem to be few signs that equal tolerance and understanding are extended to those men and women who happen to be in institutional care. This being so, staff without guidance take a non-permissive line, officially at any rate. But the situation is an uneasy one for resident and staff alike.

We can only commend hospitals to be prepared to adapt their rules so as to parallel the mores of responsible men and women in an open society. Normality in sex is as desirable as normality in dress or environment.

Does the hospital afford the maximum opportunity for men and women to meet?

Are there any wards for men and women?

Has the hospital authority given clear guidance to hospital staff about the degree to which sexual relationships between long-stay residents are permissible?

Is there an opportunity for men and women residents to meet in privacy, and without subterfuge?

18 Persistence of imagined rules

A long-stay hospital has to develop some routines, and establish some rules, otherwise chaos would prevail and residents would be at a disadvantage. Rules which are regularly reviewed and consciously retained are usually accepted by the resident community, particularly if they can be given a chance to take part in the review. But there seems to be a way in which rules long abandoned, or perhaps which never were, somehow persist within the institutional culture, transmitted down the decades from resident to resident. We found many examples.

One of our interviewers talked with a man who had lived in a mental hospital for a number of years. Each evening he visited a neighbouring pub to get, as he put it, some intelligent conversation with his friends. But he had to be back in by 8 pm, he said. That was the rule. In the same hospital, the organiser of voluntary help described a special concert put on for the residents. Everything went well, and the show was due to end at 8 30 pm. But just before 8 pm, everyone walked out. They liked the show, but had to be back in by 8 pm, they said. That was the rule. Diligent enquiry revealed the simple fact that there was no such rule, and there had not been one for at least 20 years. Perhaps it was convenient for the night staff, but it was an imagined rule, and it had persisted.

There are also rules, prefaced by the words 'Matron

says' or 'Doctor says', which still apply, even though that matron or doctor may have departed these many years.

A group of mental handicap nurses was discussing the need for handicapped people to learn how to bath themselves, and, once the lesson had been learned, for them to enjoy ordinary privacy for bathing. All agreed that this was the right approach, but, said several, there was a serious obstacle: the bathing rules. These turned out to be some rules from the pre-war era, never since confirmed or repealed, which hung on a curled yellow card in every bathroom and affirmed that no patient must ever be left alone in a bathroom, nor be allowed to turn on the taps.

A sister in charge of 40 children of low intellectual capacity decided to see that each child had its own mug, each of a distinctive colour or pattern. Eventually she succeeded in her aim and both she and the children were delighted. Each child now had a possession which was his own, visible and usable every mealtime. But on the next visit by a nursing administrator there were objections: the mugs were not of standard issue and had to be withdrawn. As she understood it, there was a rule about standard issues. In fact, there was no such rule.

We are not saying that there are hundreds of such rules. But probably each hospital has one or two and they are worth searching out. They can cause a lot of frustration and misery, to staff as well as residents.

Are the staff or residents working to any hospital rules which no longer need apply?

Are residents conditioned or inhibited by rules which do not officially exist at all?

Are the confirmed rules of the hospital aimed at developing each resident to his full potential?

19 Links with former life

Are residents, including the disabled or bed-bound, easily able to keep in touch with home by telephone?

Is there a planned effort to help residents to keep contact with the world they used to live in?

Is transport available for trips home?

Looking at the rows of people in a dormitory or day-room it is hard to believe that they each once lived separate and independent lives, taking an interest in local affairs and neighbourhood gossip. If we are not careful, the sum of their experience will be the artificial life of their closed community: not always the life of a large hospital–sometimes just the routine of one ward. The biggest event is that dinner's late, the floor polisher's broken, or a new resident has arrived. How can a man or woman in this situation keep a lifeline to the places and people known so well outside? It's easy enough when a resident has regular and thoughtful visitors, but suppose he hasn't? Does anyone make sure that he regularly receives his local paper, or church magazine or trades union journal? Does anyone try to introduce him to some other resident, perhaps on a different ward, who comes from the same area? By chance, one of our interviewers brought together two people who had been coming to the same hospital canteen for years without realising that they were brought up in the same district. The air became thick with gossip and memories. But it was all by chance: whereas one could almost say that this valuable social contact ought to have been prescribed, so important is it.

Plenty of hospital-bound people, given the chance, would enjoy an occasional visit to their old haunts and old friends quite as much as a visit to a theatre, or safari park. Well, a home visit like that might happen by chance, but is it ever prescribed? Is it ever someone's professional duty to see that such visits take place as part of a prescribed social programme?

With the best will in the world, some residents can't go visiting, or can do so only rarely. What about the rest of the time? No visitors–no visits. But there could be a telephone. Yet imagine you're disabled. A telephone is not much use if it's hundreds of yards away down a corridor, or if it's in a call box where you have to stand up but can't, or if you can't see the dial too well, or if everything's changed to STD since you last used a phone, or if there's a queue and you don't find it easy to stand. Maybe there is one of these excellent ward telephone trolleys, which have often been donated by Post Office staff themselves, but how often is it the turn of your ward, let alone your own turn? And if your old friend is out when you ring, when does your next turn come around? Perhaps the hospital could use a minibus, not just for 'fun' visits, good as they are, but also as an instrument of a planned policy to take a resident to his home area, to club or pub, to church or relative every now and then.

Without contacts of this kind, anyone would sink into apathy and lethargy. It ought to be someone's job to see that residents have a chance to keep in touch.

20 Relationships with other residents

Are residents encouraged to help other residents, in however small a way?

Are residents encouraged to help in small domestic chores, like dusting, washing-up, or making tea?

Are residents, particularly the mentally ill or mentally handicapped, given the chance to do voluntary jobs in the outside community?

Is there a residents' committee?

Are residents encouraged to organise social events amongst themselves?

Most people get far more satisfaction from giving help than from receiving it. Yet residents are often forced into being at the receiving end. It's so bad for their self-esteem. They should be actively encouraged to plan what they can do to help not only themselves but also other people, whether in their hospital or outside it.

Inside hospital, some domestic tasks can be shared: at present this seems to be hampered by the idea that patients will in some way be exploited if they are invited to do the very things they might have done at home–making tea, laying the table, washing up, minor laundering, and so on. This is not just an act of self-support; it is an act which gives to others.

Many people, women especially, would get satisfaction by 'adopting' another person–perhaps a child or helpless adult–and being partially responsible for him, possibly making his bed, helping him dress, feeding him or reading to him. If each person who is willing has responsibility for a specific task–delivering the letters or watering the plants–he will have something of that sense of being useful which is a fundamental need for us all.

Physically-able residents in hospitals for mental illness or mental handicap may well give help to the outside community, if someone will only organise this. For example, small parties might help old

people to garden, or redecorate, or they might serve meals at old people's clubs. One such patient said, 'It's grand to be doing something for others'.

If at first this seems an impracticable idea, remember that many long-stay residents in such hospitals are physically fit. The supervisor of a day centre succeeded in organising a number of regular voluntary jobs for the mentally handicapped people who attended her centre each day; she has them knitting blanket squares for refugees, making and selling marmalade for a good cause, collecting magazines for the elderly, laundering choristers' surplices, providing firewood for the housebound, helping at WRVS luncheon clubs, cleaning the cathedral brasses, growing pot plants for the local almshouses, lawn-mowing, hedge-cutting. All these jobs are regularly undertaken by mentally handicapped people.

There is another aspect: to what degree are residents given some kind of say in the affairs of the hospital community in which they spend their life? Why not a committee of residents to offer ideas on such things as the menu, service of meals, the ward timetable, recreation, control of radio and TV? Couldn't residents offer ideas about the procedure for posting and receiving mail, buying newspapers, or telephoning. The sense of participation might not only improve conditions, but could combat the loss of power and identity so often evident in long-term residents.

Another way to bring about participation is to encourage patients' opinion surveys. Experience shows that a good proportion of psychiatric or elderly residents are willing to complete questionnaires for surveys, provided there is some hope of a response from the management.[16]

At one mental handicap hospital, the residents have formed their own social club. They have adapted a surplus building, and to a considerable extent they run it themselves. If this is possible for mentally-handicapped people, how much more so is it possible for other people. It is hard to believe that in a collection of several hundred long-stay residents there cannot be found a dozen who could take an initiative of this kind. It may result in activities which don't quite fit in with the ideas of the management, but administrative tidiness should be subsidiary to the quality of life.

21 Relationships with staff and family; counselling

When we need care and support we turn to our family or a close friend. It is important that we can depend on them for close support and help without losing our feeling of being in control of ourselves and our bodies.

How can this sort of relationship be transferred to a long-stay hospital situation? The sick or disabled person needs the help of a warm sympathetic person who has certain professional skills and expertise, and who can use these skills without losing the ability to identify with the patient and his needs.

In some hospitals a nurse is attached to six or seven residents, so that they work together in one group day after day, setting their own goals and working out a programme of activity for themselves. This can only work successfully if the nurse doesn't dress up in uniform and becomes an equal member of the group.

Is there an opportunity in the day's routine for the resident and staff member, doctor or nurse, to talk together as *people*, where the resident can voice anxieties and share problems? Wouldn't it help if the professional did not use his official title, or wear uniform, but sat by the resident's bed talking as a caring, concerned person. Why do so many long-term residents address the charge nurse as 'Sir'?

The relationships between a resident and his family can be a strength which may need to be supported and encouraged by staff. Do official visiting times and restrictions on numbers of visitors help maintain family links? If an anxious son travels many miles to see his elderly confused mother, does it help him to be told that the doctors and senior staff are off duty, and that only they can answer his questions? Family and friends can be excluded in many ways, just when their support is needed. Yet they have so much to give, and can often give clues to reasons behind confused or difficult behaviour. Families and friends understand how the resident feels and, if helped to feel secure and welcome, have much to contribute to his well-being.

Skilled staff can often arrange mutual support groups for families who are visiting. This can be done informally over a cup of tea, and often it can be a great relief for relatives to share feelings and experiences which are common to them all. There may be expressions of anger and self-reproach, but if the staff can help support them through a stressful period, there is less likelihood that families will cut themselves off from their sick member.

In many less sophisticated societies, families still accompany their relative to hospital. They care for him, feed him, sleep near him and only relinquish him to professionals for expert skills they do not possess. Perhaps we need to get back to this sort of feeling in which the family is respected and recognised as being important; in which they can get advice and support from professional staff when needed but can still maintain a high degree of responsibility for their sick member, and in which the whole family, including the resident, can maintain secure and emotionally satisfying relationships.

This firm base of mutual understanding encourages the growth of such mutual support schemes as five-day admissions, month-in/month-out stays, home-for-the-holidays, or even home-for-the-day.

Is there a serious attempt to reduce social distance between professional staff and residents?

Are family relationships developed by staff as a possible therapeutic strength?

Are members of the family encouraged to take a hand in caring for their own resident member?

22 Problems which require medical and nursing intervention

Everyone in long-term care must of necessity be suffering from some degree of mental or physical handicap. This may range from slight confusion, or degree of deafness, or stiff joints, right through to complete paralysis of the body.

How can people be helped with problems which require medical and nursing intervention in such a way that they maintain their self-esteem, and to some degree their self-reliance?

When the resident is first admitted there will be a full assessment of his capacities, both mental and physical. There at the start, is an opportunity for the doctor and nurse to help the resident with his problems in such a way that he is fully involved and understands the choices involved. If he is prescribed a course of treatment, has he the option to decline or raise doubts? Is there time for him to discuss fully his anxieties about treatment? Are these discussions couched in everyday language, or is the resident excluded by the professional jargon of staff?

Many sick people, particularly those who have been in hospital for some time, passively concede that 'Doctor knows best', and suffer uncomplainingly such things as aches and pains, increasing deafness, failing sight, or even lack of false teeth. They need active intervention to help them to become more independent and assertive of their needs.

When specialist medical or nursing procedures become necessary, are these explained in advance to the resident, in understandable terms?

When the resident becomes more frail, or incontinent, is he helped to discuss with understanding staff his anxiety, insecurity, and feeling of demoralisation?

Even when a resident is quite helpless, do staff still respect his dignity and his personality, and avoid treating him as a baby?

Where a person is to a great degree dependent on staff for physical help, sensitive handling helps him feel less anxious and more secure. Incontinence is a fear and dread for many: for some it can be the beginning of the end, the loss of control which will mean increasing dependence on others. With medical and nursing help this problem can be much relieved, and there should never be the tendency to think of the incontinent adult as a baby. He must be helped to control his functions as far as possible, and this is not possible unless he is treated with concern as an adult. He knows from experience what is comfortable for him, at which time of the day he needs toileting, and what diet is helpful or otherwise.

When the resident is helpless and unable to feed himself there can also be a tendency to treat him as a dependent child. How often do we see food mashed up, or slops served unnecessarily? Even though the resident may be immobile, he still likes the feel and texture of food in his mouth, something crisp to bite on, and tastes which were enjoyed in former days. There may need to be some protection of the clothes, but how much more dignified is a napkin even if made of paper, than a bib tied around the neck like a baby. How much better if the nurse talks with the resident and is sensitive to his likes and dislikes, rather than standing up, talking over his head to another nurse.

When he needs to be moved about in bed, or from bed to a chair, can this be done at a pace to suit him? Is he asked which position or chair he finds most comfortable–where he likes the cushion? Can he put his feet outside the bedclothes, or does this make the ward look untidy?

All people respond to illness in different ways. Many meet it with strength and a determination to cope with difficulties. Some are frightened, and easily lose heart. Anyone will deteriorate if not given the opportunity to maintain a feeling of self-direction and self-reliance. This means strengthening him in every way possible, involving him in all decisions about care and treatment, and always taking account of what he says. It means treating him as an adult with many useful ideas, rather than as a child dependent upon others.

23 Staff morale

Does the health authority, through its members, its officials, its rules, and its decisions, consistently and constructively try to uphold the morale of staff in their difficult task?

Are there good and continuous arrangements for study days, inter-hospital visits and other forms of relevant inservice training?

Does the health authority listen to the views of staff and take account of them?

Is there genuine machinery through which staff of all grades and professions can arrive at a collective view?

Are junior staff encouraged to discuss their problems frankly with seniors?

Most of the staff caring for long-term residents are overworked. They feel that staff in acute hospitals undervalue them, that their work is lacking in technical or dramatic interest. As they see it, whilst other, more fortunate, people theorise or campaign, they, underpaid and unrecognised, are bearing the service on steadily-weakening shoulders.

At very least they carry out the routine procedures for physical care, even though they may treat the resident as a helpless or dependent child. Most go far beyond this: they have a very good idea of what interpersonal relationships ought to be like and try hard to respond to the social and individual needs of each resident. Yet they find themselves baffled and frustrated by shortage of staff, by their own diversion to duties like counting linen or buttering bread, by overcrowded and unsuitable buildings, and by an allocation of financial resources which tacitly assumes, regardless of official statements, that the main task of the institution is to provide safe and hygienic storage for ill men and women. Is it to be wondered that they shrug their shoulders at proposals for change, or regard inservice training as an amiable irrelevance which interferes with the main task of safe custody? Yet if the morale of staff can be raised, the morale of residents will almost certainly rise with it.

Good inservice training is one way to raise morale,

but only if it is relevant to the real-life situation. A week's course based on a well-staffed, well-sited, modern hospital unit can be almost a slap in the face to the nurse who has to return to an understaffed, isolated, century-old asylum. Staff need to see and hear about that which is good; but those who set themselves up as teachers or trainers must be prepared to indicate what can be done, in practical terms, to improve the bad situation. At the Institute of Mental Subnormality* the process is two-fold: in the first stage a team from a hospital visits the Institute for a week's course in behaviour modification; in the second stage, some time later, the Institute team visits the hospital and faces the problems put up by the local team. This process ensures that staff are exposed to new ideas, and that Institute staff are exposed to the reality of the situation.

Other hospitals have organised the exchange of teams. Each team stays and works at the opposite hospital for a week or two: they then meet for an exchange of views on what they have experienced. Even a one-day visit can be valuable, if it is to a well-chosen place whose situation bears some resemblance to that of the sending hospital. So it is worthwhile questioning how recently staff have had the opportunity of refresher courses or visits.

*Wolverhampton Road, Kidderminster DY10 3PP.

Another key feature in the maintenance of morale is the opportunity for staff to be heard. If they gain ideas from visits or training, if they have suggestions to make for a better service, if they are dissatisfied about their own conditions–do the hospital authorities listen? Views can be formulated in a variety of ways: ward meetings, contributions to a staff journal, a trades union branch, a joint staff consultative committee, or general interdisciplinary teach-ins or forums. The existence of machinery for expressing views is important, but much more so is evidence that the hospital authorities are prepared to listen to what is said and to respond. Staff are greatly heartened when members and top officials come into the middle of the hospital, to see, smell and hear what life is like on a bad day. It's much more effective than exhortation or emollient praise delivered from afar. As a former matron of Guy's used to say, 'It's footwork that counts!'.

Barriers between professions, or even worse, social distance between seniors and juniors, can insidiously destroy morale. Staff under stress, perhaps through overwork, heavy responsibility on night duty, or sheer concern, often need quiet counselling. It is worthwhile observing these relationships which exist between staff: if they are bad then relations with residents will be equally bad.[18]

24 Influence of the management system

The broad aim of the long-stay hospital is to make the utmost of the human potential of every resident. To do this, the hospital needs to

provide an environment which will not only preserve life, but will recognise the dignity of the individual

give the resident as much control over his own activities and environment as is consistent with the corporate purpose of the institution

enable each resident to form part of a small group

reduce social distance between staff and resident

avoid regimentation

avoid depersonalisation

avoid 'block' treatment

encourage worthwhile work and leisure activities

maintain close links with the community.

Does the hospital's management system encourage—

participation by staff of all grades?

development of the multidisciplinary approach?

When decisions which affect residents have to be made by the health authority or its staff, are these decisions designed to help make the utmost of the potential of residents?

The main reason for having a management system is to see these tasks are carried through. If the system does not do this, then however impressive it may look on a chart, it is of no value. So the funda-

mental question to be asked about the organisation of any long-stay hospital is this: Does it help or hinder the efforts of the staff to strengthen the independence of the individual resident?

What might be the characteristics of a management system which meets this test? For a start, good service is impossible in a hospital wracked by disputes about professional demarcation lines. So the senior professionals in each of the various disciplines need to work together in directing the strategy of the hospital: doctor, nurse, therapist and administrator, should be amongst those involved. This executive group must be committed to the broad aim of preserving individuality, and must define in practical and locally-relevant terms, precisely what results have to be achieved, and by which member or group of staff. Delegation would then begin, the aim being to place as much responsibility as possible at ward or departmental level; and here residents should be encouraged to form a representative resident-group, with at least an advisory function. There should be an easy and recognised routine procedure for people in the ward to exchange ideas quickly with the senior executive group.

In short, the desirable management system would provide for

collective professional acceptance of organisational objectives

definition of tasks to meet those objectives

maximum delegation to staff at ward level

real participation by residents

We list below a few simple issues as they have, in fact, been dealt with, and we invite you to ask yourself in every case: did this decision help or hinder the efforts of the staff to strengthen the independence of the individual resident?

Pony-riding for the mentally handicapped
STOPPED in case of accident

Variegated patterns of mugs for children
STOPPED because they weren't official issue

Privacy in bathing for residents
STOPPED because of pre-war bath regulations

Staff wearing ordinary clothes
STOPPED because a national uniform is now the rule

Staff dining with residents
STOPPED because of official insistence that staff should pay

Attendance of residents at a club
STOPPED because it clashed with set mealtime

Issue of personalised clothes
STOPPED because official laundry couldn't cope

Mentally handicapped residents trained in domestic work on ward
STOPPED because of introduction of incentive bonus scheme

Use of real money, instead of tokens, by residents
STOPPED because of fear of abuse

Behaviour modification trial
STOPPED because psychologist and nurses disagreed

Cookery instruction on ward for disabled residents
STOPPED because of fire regulations

Pin-ups on wall of bedspace
STOPPED because of risk of damage to wall surfaces

It comes to this: when you visit a place where long-stay residents live, ask yourself at every step:

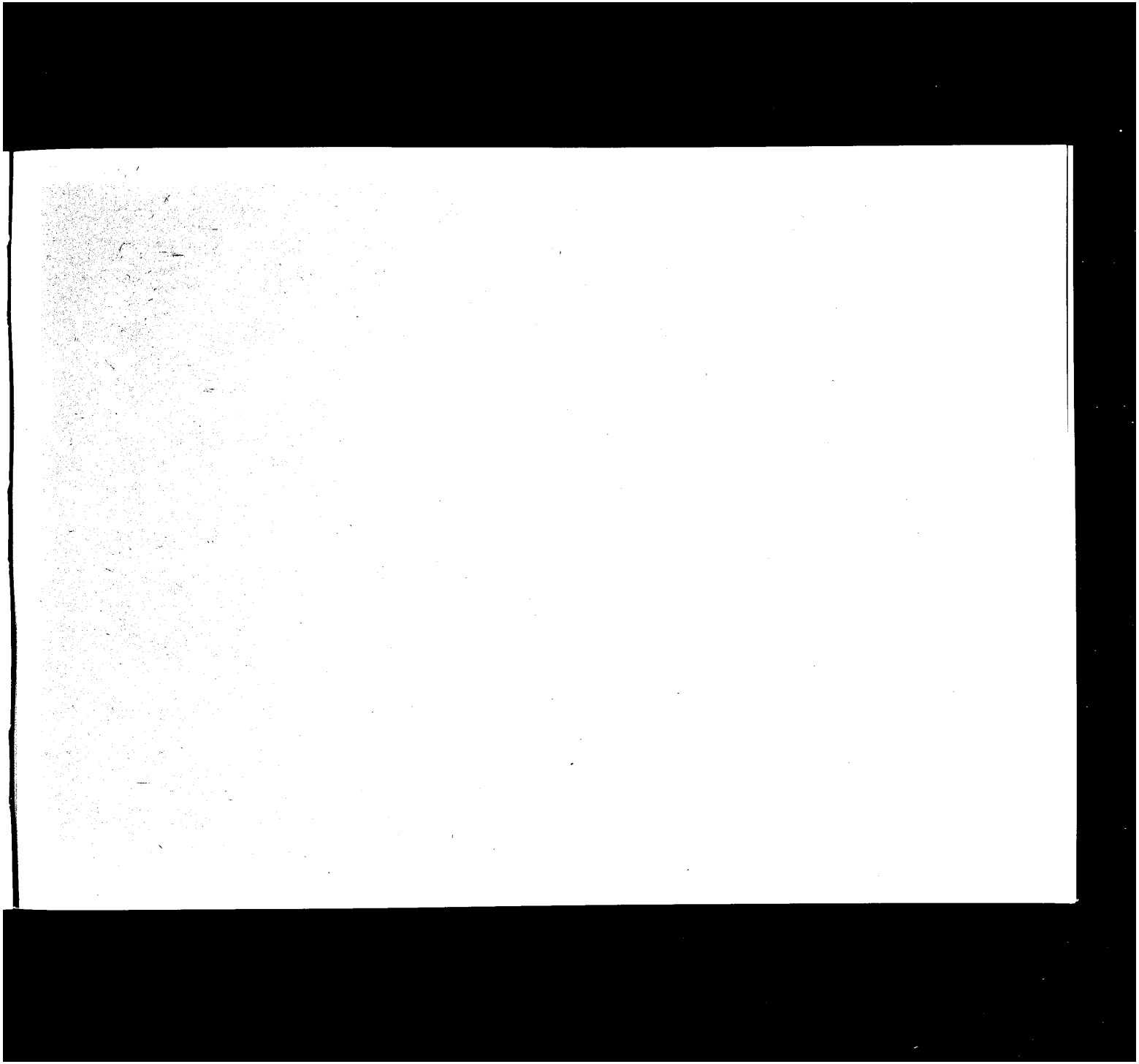
In whose interest does this hospital exist?

What is its effect on the people who come to live there?

Does it condone apathy or encourage independence?

Does the system fit the residents, or do the residents have to fit the system?

And finally, how would I like to be living in this hospital?



What can *we* do about it?

The answer is: we can do what we choose to do. Every suggestion and recommendation we make lies within the capacity of any health authority and its staff. A few recommendations may require a small amount of additional funds, but many require no money at all–just a different way of going about things.

Much more could be done if long-term hospital care were to be recognised as an area for priority attention. Better financial allocations would ensure the dismantling of bad old hospital buildings, a strengthening of community care, and the development of purposeful and well-staffed residential units, within the National Health Service.

Even so, today, many staff, with only the resources they can lay their hands on, are already succeeding in finding that different way of going about things. A way which recognises human values and human individuality. Most of the ideas in this book have come from them.

If we stop looking for alibis, we really can transform the scene today.

Coming into hospital

1 Are new residents made to feel welcome?

2 Is there reasonable privacy for admission procedures?

3 Is the new resident introduced to other residents?

Daily timetable

4 May residents go to bed at a time of their choice?

5 May residents rise when they like?

6 Subject to treatment considerations, may residents wash and dress when they choose?

7 May residents who are able make drinks when they like?

8 May residents go to bed when they fancy a nap?

Personal clothing

9 Does each resident have his own outer clothes?

10 Does each resident have his own underclothes?

11 Do residents choose their own clothes freely, from a good range?

12 Does each resident have his own wardrobe?

13 May residents, if able, launder their own clothes?

14 Is there an adequate laundry and dry cleaning service for residents' clothes?

Hairdressing and pocket money

15 Is there a hairdressing salon in the hospital?

16 Are residents encouraged to go to an outside hairdresser?

17 Does the visiting hairdresser attend to difficult or antisocial residents?

Food and dining arrangements

18 Is the menu for residents variable and unpredictable?

19 Do residents have a genuine opportunity to choose from a menu?

20 May residents indicate how much food they want?

21 Are residents permitted to provide food to suit their own taste?

22 Is there a dining room, or recognised dining area, in the ward?

23 Are the table settings homelike?

24 May residents help themselves?

25 Do staff ever sit down with residents for a meal?

26 Are residents ever permitted to organise for themselves a festive meal to mark some special occasion?

Noise

27 Are residents with transistor radios asked to use an earpiece?

28 Is the volume of the ward radio or television kept down to a level acceptable to the residents?

29 Are staff mindful, when they are talking in the ward, that they are in a place which is, in effect, the residents' only home?

Washing, bathing and toileting

30 May residents decide for themselves when and whether to wash?

31 Are relatives encouraged to help with washing and toileting?

32 Are residents afforded due privacy for bodily functions, even when the ward is closed to visitors?

A place of one's own

If a resident has a single room—

33 Are there any limitations on when he is allowed to use it?

34 May he bring in any furniture or furnishings of his own?

35 Is a reasonable domestic untidiness and clutter permissible?

If a resident is in an open ward—

36 Is the ward arranged in such a way that each resident has a small piece of territory which is his to control, as though it were a single room?

37 Do staff respect the human need of all residents for a place of their own?

Worthwhile work

38 Are residents who are able, given the opportunity to undertake work of any kind?

39 Does the work help the resident community?

40 Are residents encouraged to offer their old skills, or to learn new ones?

41 Is there a fair system of payment for work done?

Recreation: holidays and outings

42 Is there somebody responsible for a full programme of widely varied recreational activities?

43 Is encouragement given to those who wish to pursue minority interests?

44 Are residents enabled to take a part in planning the recreational programme?

45 Does the programme include special items for those confined to bed?

46 Is use made of volunteers in developing the recreational programme?

Further education

47 Does the hospital have a formal link with the local further education service so that the educational needs of residents are brought to the notice of the service?

48 Does the further education service interest residents in what it can do for them?

49 Have residents easy access to the public library service?

50 Has the hospital exploited fully the basic right of handicapped and bed-bound people to the whole range of public library services?

Is there a real encouragement to residents to retain or develop an interest in—

51 art?

52 music?

53 literature?

54 hobbies?

55 current affairs?

56 Are younger adult residents encouraged to pursue formal studies, and are they given adequate facilities and privacy for this?

57 Is it possible for a resident to obtain regularly the newspaper or journals of his choice?

Gardens, flowers and animals

58 Have residents easy access to a garden or similar area?

59 Are well-behaved pets allowed to visit residents?

60 Are residents encouraged to grow their own plants, or to tend the ward plants?

61 Do residents have any opportunity to care for birds or pet animals?

62 Do residents ever have the chance to look at wild life, to walk in woodlands and meadows, to sit by the river?

Religious beliefs

63 Are residents who wish and are able, encouraged to go out to the local church?

64 If residents cannot go out, is there an attempt to bring church members in to them?

Choosing your neighbour

65 Is care taken to try to ensure that wherever choice is possible, each resident has ward neighbours who are congenial to him?

66 If husband and wife are both in hospital, are they parted unnecessarily?

Mixing the age groups

67 Are older residents, when they wish it, given the opportunity of the company of young visitors?

68 Does someone see that those without family or friends receive occasional visitors?

69 Are younger residents allowed plenty of social interchange with visitors of their own age group, even though their boisterousness may disturb the calm of the ward?

70 Is there a real opportunity for the residents of one ward to mingle with residents of different age groups, or different medical conditions, or of the opposite sex, from other parts of the hospital?

71 Do inpatients and day patients mix freely?

The opposite sex

72 Does the hospital afford the maximum opportunity for men and women to meet?

73 Are there any wards for men and women?

74 Has the hospital authority given clear guidance to hospital staff about the degree to which sexual relationships between long-stay residents are permissible?

75 Is there an opportunity for men and women residents to meet in privacy, and without subterfuge?

Persistence of imagined rules

76 Are the staff or residents working to any hospital rules which no longer need apply?

77 Are residents conditioned or inhibited by rules which do not officially exist at all?

78 Are the confirmed rules of the hospital aimed at developing each resident to his full potential?

Links with former life

79 Are residents, including the disabled or bed-bound, easily able to keep in touch with home by telephone?

80 Is there a planned effort to help residents to keep contact with the world they used to live in?

81 Is transport available for trips home?

Relationships with other residents

82 Are residents encouraged to help other residents, in however small a way?

83 Are residents encouraged to help in small domestic chores, like dusting, washing-up, or making tea?

84 Are residents, particularly the mentally ill or mentally handicapped, given the chance to do voluntary jobs in the outside community?

85 Is there a residents' committee?

86 Are residents encouraged to organise social events amongst themselves?

Relationships with staff and family; counselling

87 Is there a serious attempt to reduce social distance between professional staff and resident?

88 Are family relationships developed by staff as a possible therapeutic strength?

89 Are members of the family encouraged to take a hand in caring for their own resident member?

Problems which require medical and nursing intervention

90 When specialist medical or nursing procedures become necessary, are these explained in advance to the resident, in understandable terms?

91 When the resident becomes more frail, or incontinent, is he helped to discuss with understanding staff his anxiety, insecurity, and feeling of demoralisation?

92 Even when a resident is quite helpless, do staff still respect his dignity and his personality, and avoid treating him as a baby?

Staff morale

93 Does the health authority, through its members, its officials, its rules, and its decisions, consistently and constructively try to uphold the morale of staff in their difficult task?

94 Are there good and continuous arrangements for study days, inter-hospital visits and other forms of relevant inservice training?

95 Does the health authority listen to the views of staff and take account of them?

96 Is there genuine machinery through which staff of all grades and professions can arrive at a collective view?

97 Are junior staff encouraged to discuss their problems frankly with seniors?

Influence of the management system

Does the hospital's management system encourage—

98 participation by staff of all grades?

99 development of the multidisciplinary approach?

100 When decisions which affect residents have to be made by the health authority or its staff, are these decisions designed to help make the utmost of the potential of residents?

Plan for action

There can be no standard plan for action: from area to area, from hospital to hospital, needs, priorities and staffing standards, all vary.

But for all that, every area needs its own plan of action. Most of the social needs of people in long-term care can be met by changes in attitudes, or by a number of small actions, applied on an individual basis: but as the reorganised NHS struggles to plan and finance the entire health care system, the social needs of long-term patients, if not embodied in a plan for action, are likely to go down before the onrush of more dramatic service demands. A health authority wishing to meet the social needs of long-term residents is unlikely to achieve lasting results without a concerted plan.

At area and district level, in health care planning teams, and in the ranks of the community health councils, members and officials need to

recognise the central therapeutic importance of meeting the social needs of long-term residents, and to bear this in mind when making planning decisions and financial allocations

look at the hospitals for themselves

encourage action at hospital level; be ready for requests of a non-routine nature

ensure that influential visitors see the service as it really is

review the situation in each hospital at least yearly.

At hospital level, managing team, professional executive, or similar group needs to

recognise the central therapeutic importance of meeting the social needs of the long-term resident

decide what needs to be done, and who is to be responsible for action

review results ward by ward, at least twice a year.

It is likely that there will be two broad areas of action

that concerned primarily with nursing practices, customs and attitudes (for example, the daily timetable, dining arrangements, privacy, choosing your neighbour, staff/patient relationships)

that concerned with wider social issues (for

example, recreation, further education, links with former life, religious affiliations).

Responsibility for the first should certainly be that of a senior nurse.

Responsibility for second could also be that of the same senior nurse, but might with advantage be included instead in the duties of the organiser of voluntary services. In a large hospital, if the individual needs of each resident are to be met properly, then both action areas would be a substantial part, if not all, of the work-load of one member of staff.

Inservice Training–Some Suggestions

Gain the commitment of the ward staff: it is important for staff of all grades to feel genuinely convinced of the need for action.

Have a team from ward A to score ward Z, and vice versa: compare notes, and use the resultant discussion as the basis for remedial action.

Take one or two topics at a time, to permit examination of problems in depth. Some remedial action can take place within the ward, there and then; other action will need approval, or may need agreement with other wards or departments, or with other sections of staff.

Use the unit nursing meeting for wider discussion of these problems, and to identify constraints. This way, key issues can get up to the hospital's management team, or if necessary, to the district or area teams. Be sure to report back to the original staff on what has happened to their proposal or idea.

Remember that this book has a two-way use; senior staff can use it to explain to ward nurses why changes are necessary; ward nurses can use it to explain to administrators why they want to change established procedures.

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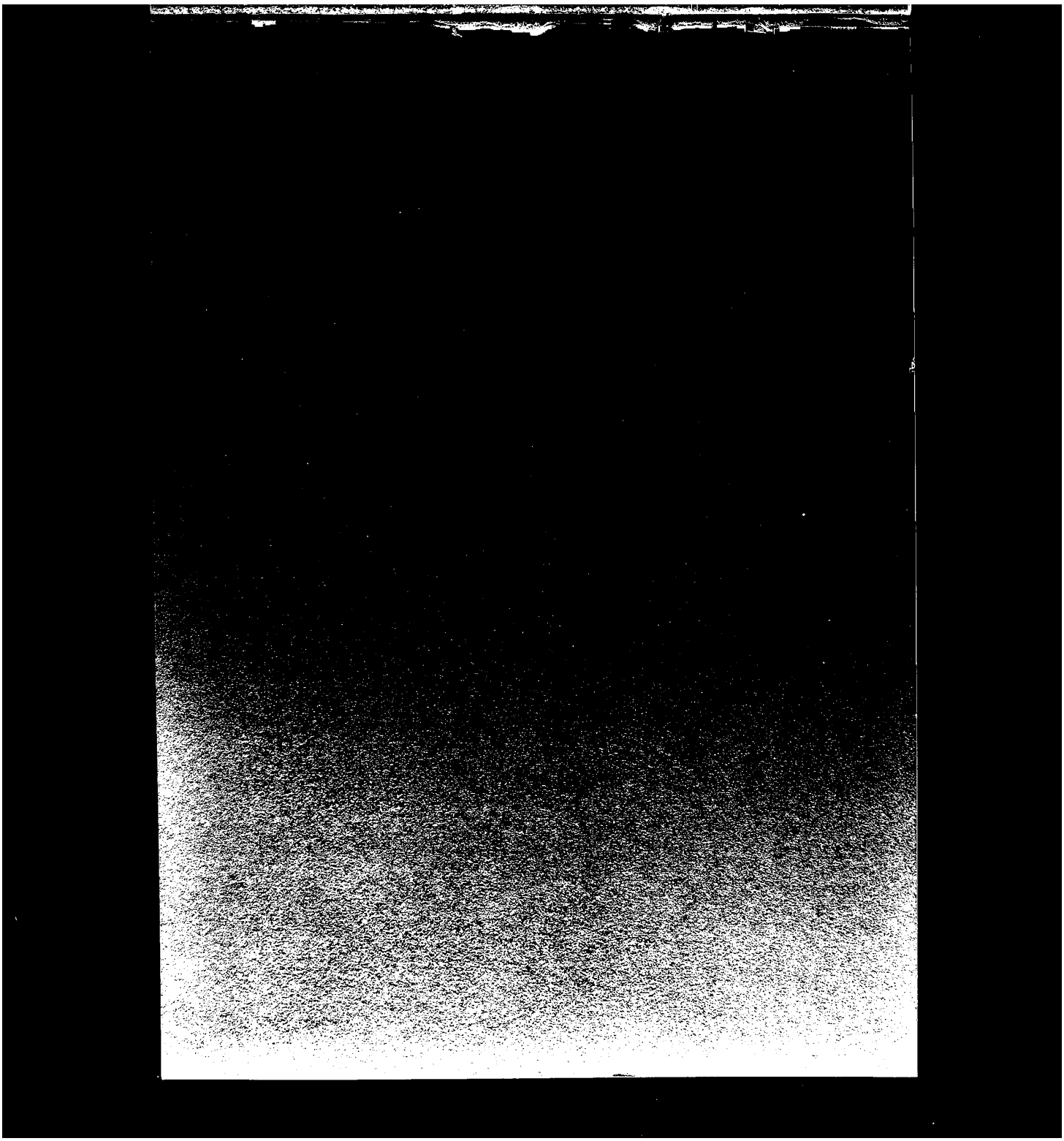

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