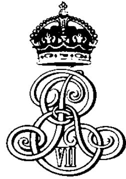

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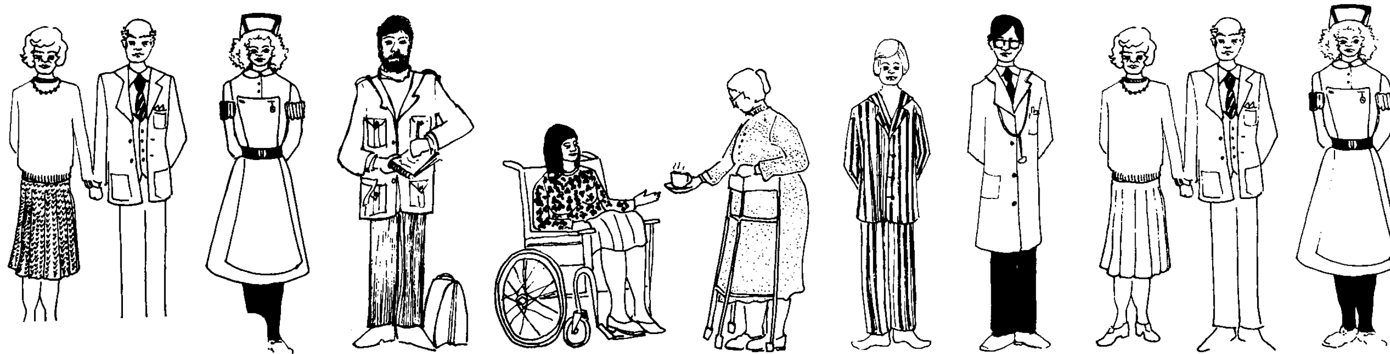
PROJECT PAPER

Number 23

November 1979

# CHC VISITING



HOQH (Gor)

guide to visiting long-stay hospitals and units

Gor

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The King's Fund Centre was established in 1963 to provide an information service and a forum for discussion of hospital problems and for the advancement of enquiry, experiment and the formation of new ideas. The Centre now has a broader interest in problems of health and related social care and has excellent facilities for conferences and meetings. Allied to the Centre's work is the Fund's Project Committee which sponsors work of an experimental nature.

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# CHC VISITING

A guide to visiting long-stay hospitals and units

Written by Pat Gordon
Illustrated by Anita Sutton
Designed by Neil Baird

November 1979 Price: 50p

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# Introduction

Community Health Councils have the right to visit hospitals and other health care premises and to comment on what they find. This sounds straighforward enough, but in practice can be much more difficult and time-consuming if the visit is to be worthwhile and get beyond the 'cracked walls and peeling paint' stage. This booklet is an attempt to suggest some guidelines and good practices which can make the effort involved in these activities more satisfactory to all concerned.

The ideas presented here draw heavily on the experience of a small group of CHC members, Secretaries and others who met at the King's Fund Centre to discuss problems and offer advice on what should be in this booklet. We are grateful to all those who contributed: Mr. G.G. Callaghan, Mr. David Downham, Mr. Tom McAusland, Miss Joan McGlennon, Mr. Morris Malin, Miss Joanna Murray, Mr. Fred Peachey, Mr. D.R. Preston, Mr. L.C. Softley, Mrs. Elizabeth Spector, Mr. Brian Thomas. We owe particular thanks to Pat Gordon who translated these discussions into a clear and readable form. Support to the whole enterprise has been provided by the Centre's Long Term and Community Care Team.

We recognise that views about how CHCs can best carry out their tasks vary; indeed that there is still much to be learnt about the most appropriate and useful approaches in different local situations. We expect, therefore, that the suggestions here will be examined critically by people using this booklet in working out how best to go about things in each locality. While the views expressed are not necessarily those of the King's Fund, we hope that in publishing this booklet we will be providing a useful resource for an important CHC role.

David Towell
Assistant Director, King's Fund Centre

# Why Visit?

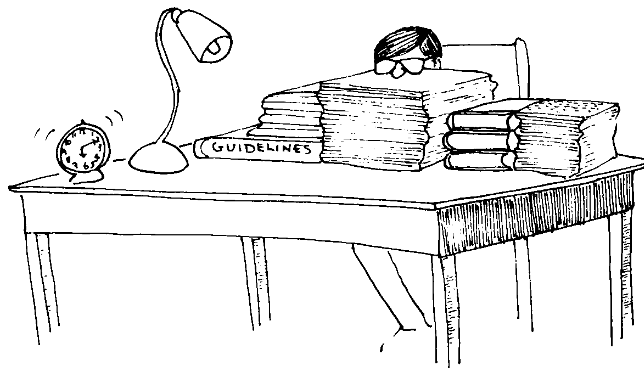
People who live in long-stay institutions are particularly vulnerable members of society. They seldom find it easy to represent their own interests. They badly need spokesmen to be active on their behalf. For this reason many community health councils believe they have a special responsibility towards those who need long-term care. Part of that responsibility is to visit the hospitals and other units where they have to make their homes – and that means everything from purpose-built hostels for young disabled people to vast mental handicap hospitals on the outskirts of towns.

Until you go and see for yourself you cannot possibly understand what life is like in a long-stay hospital. But plodding around on your own two feet does not automatically bring enlightenment, as Maureen Oswin shows in her recent book:[1] "A group of Committee members was visiting the mental handicap hospital. In the spastics' ward six-year old Shirley played with her tears, whirling her fingers disconsolately around in them as they puddled on the bare table in front of her. Her action epitomised a bleak existence. One of the visitors said: 'These children are cabbages' and the others agreed with him, but perhaps it had not occurred to them to look at Shirley and consider that cabbages don't cry."

CHC members are in a special position as visitors. They are not managers. They are not experts. They have not grown accustomed to hospitals and institutional living. They are in a position to question assumptions and to bring a different perspective to support staff who may have been battling for years to win improvements. Above all, they are in a position to make the links between health policy and housing policy, home help services, education, and all the other social agencies whose policies are intended to be complementary but, in practice, seldom are. In other words, CHCs may be able to ask *why* do so many people have to live in institutions – is it because they need that kind of care or is it because there is nothing else?

# Homework

A visit achieves little unless you know what you are looking for, what standards to apply, what comparisons to make. Like most people active in public life CHC members are chronically short of time, but someone has to do the homework if anything of value is to be achieved. This means finding out local facts and figures; reading reports of earlier CHC visits; checking the relevant sections of the District Plan; reading any recommendations the Health Advisory Service may have made about your hospitals.




If we are to get beyond looking at buildings and furniture, it also means finding out about the whole range of facilities for long-term care. What is the relationship between community services and the hospital? What arrangements are there for short-term care of those who live at home? What support services are there for families? Are there residential units outside the hospital? Is transport available?

It sounds daunting but at least there are some good reference places to turn to for help — there is no point in everyone starting from scratch! Further information is given on page 23.

# Who Should Visit?

In deciding who should visit, CHCs have to learn quickly how to make the best use of their members. One CHC whose hospital had a case of a patient dying by scalding learnt far more in a shorter time when they visited because one of their members was a heating engineer. Similarly, a school teacher member may be able to guide others in what to look for in a visit to classes for handicapped children. Remember too, that CHCs have the power to co-opt people from outside onto sub-committees.

There is a tendency in all CHCs to leave the visiting of long-stay institutions to those members who belong to relatives' organisations, such as the National Society for Mentally Handicapped Children. But it is important that members who are not familiar with hospitals should also become involved. This is not always easy. Most of us have to work through mixed feelings and apprehension about the people we might meet. This is hardly surprising when we remember that these large institutions were built deliberately on the outskirts of towns so that we, the community, could avoid having to face the people we had decided to discard. Now we have to learn how to respond when we see a severely handicapped child endlessly banging his head against a wall, or we come across someone walking wearily round and round in a circle, or we are shown into a none-too-fresh smelling day room where a group of old ladies are parked around the walls gazing vacantly into space. We have to remind ourselves that many of the disturbing habits of people in long-stay institutions have been caused by their poor environment. The monotony and boredom in many long-stay hospitals is overwhelming.

It is easy to believe in the stereotype of a 'race apart' but many of the people who have grown old in institutions would nowadays live at home, possibly sustained by modern drug therapy. All of us grow old and some of us, for one reason or another, will require long-term care. Seen in this way, the contrast between the bleak, impoverished atmosphere of some hospitals and the energy and stimulation in others becomes very frightening.

Just because there is so much to be done, however, trying to improve conditions in long-stay units can be the most rewarding work of all for CHC members. It may take patience, and persistence, but there is a lot of scope. One CHC 'found' two young disabled people when plans were made to move them into the wing of an infectious diseases hospital: they had spent many years isolated in different hospital wards. The discovery triggered off a study into how many other young people were scattered throughout the district (40 were found in geriatric wards alone) and what kind of services they needed. As a result of the CHC initiative, the local statutory and voluntary bodies involved, were brought together to work on a plan for improved services. Action so far has included a two-year pilot scheme for care attendants, better dental and chiropody services and a re-appraisal of the plans for a hospital unit.

Sometimes it is easy to see how improvements can be made. One CHC suggested that long-stay geriatric patients be transferred from the top floor to the ground floor to enable them to enjoy the gardens without the hurdle of lifts and stairs. The management readily agreed and readily acknowledged that there was no good reason, except habit, for the previous arrangement. Sometimes improvements come unexpectedly.

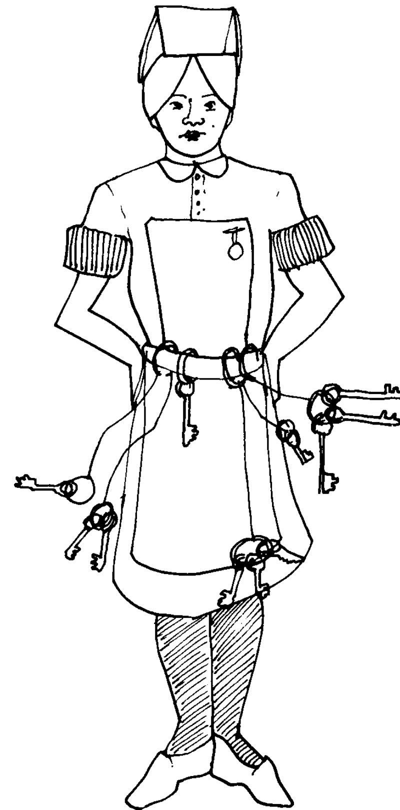
*...the suit had been sent to the hospital laundry for washing.*

One CHC was given a Burton suit which they presented to a patient, who was highly delighted. When next they visited they were horrified to discover the suit was ruined: it had been sent to the hospital laundry for washing along with all the other ward linen and patients' clothing. This led the CHC to look into the whole matter of personal clothing and its care and to put forward a number of ideas for improvements. The gift of one suit led to unforeseen benefits for all.

## When to Visit?

Deciding when to visit will depend on your reasons for visiting. If the aim is to familiarise yourself with buildings, the timing is probably not very important. If you want to end your visit with a discussion with staff, then that may dictate the timing. But if you are concerned with standards of night nursing, for example, you will learn a lot more by visiting at midnight than by getting the information second-hand from senior staff. Similarly, if you are interested in whether patients have to be put to bed at 4pm you will learn more if you are there to observe what happens, and why. One CHC secretary had an eye-opener of a visit when he accompanied the Duty Nursing Officer on her evening round. She had to unlock and re-lock innumerable doors because she had only 17 staff on duty for the whole hospital of over 500 patients. The locking and unlocking brought home the meaning of staff shortages in a way that no amount of talking or reading could have done.

Another important point about timing is to visit the same department at different times on different days. Remember that the people we are concerned about live their whole lives in hospital — it is their home 24 hours a day, seven days a week. You are likely to gain a misleading impression of the level of activity on the ward if your visit coincides with the one morning a week when the hairdresser and the library trolley arrive. By the same token, you have to resist jumping to conclusions about the food, for example, if there is a particularly unpopular pudding on the day you visit.



*She had to unlock and re-lock innumerable doors...*

# What Kind of Visit?

The most common form of visit seems to be the 'Cooks Tour', a spectacular example of which is the regional health authority who invited each of its 22 CHCs to send ten members to visit a mental handicap hospital on the same day!

CHC members obviously have to familiarise themselves with their hospitals and it is very much easier to talk sensibly about old people in hospital if you do at least know where your local geriatric hospital is, what the wards and day rooms look like, and where the gardens are. But orientation is probably the only value of a 'Cooks Tour'. It is not very taxing on the brain or the temper, however hard it may be on the feet. It seldom gets beyond the superficial, and often leads to a false sense of job accomplishment. It can also leave a bad impression with ward staff:
"Some of the children were incredibly difficult to feed . . . Meal-time tension was often increased because inexperienced temporary staff were on duty and they were inept at feeding difficult children . . . In some of the hospitals, visitors were shown round during meal times. Nurses always resented this intrusion; caught at a disadvantage and stared at as they tried unsuccessfully to persuade children to swallow their food, they felt that they and the children were exposed and vulnerable."[1]

The staff who act as guides on a tour take you to all the 'right' places – good and bad – and the visiting group then prepares a report which never fails to say how courteous and hard-working the staff are, to deplore the conditions in which they have to work and to urge improvements to the fabric of the building which the staff have been demanding for years.

CHC members need to develop confidence and independent expertise to get beyond the 'Cooks Tour' — confidence to believe that your judgement as an ordinary, caring member of the public is of value in commenting on the way people live in hospitals; and independent expertise so that you can talk sensibly and realistically with professionals about care and treatment.

Managers sometimes resent attempts by CHCs to do more than tour, and you may have to be persistent if your initial efforts are met with opposition. Formalities have to be observed, at least to begin with, and each CHC will agree its own protocol for arranging visits. Arranging things through the administration however, does not mean that you are obliged to visit only those people or places the administration suggests. If you have decided *why* you are making the visit and therefore who and what you want to see, you should not hesitate to say so and ask for appropriate arrangements to be made. For example, if you do not feel it necessary for the psychiatrist to be present when you talk to the social workers, you may have to say so quite clearly: and that may be more easily and tactfully done in advance than during the visit itself.

One CHC which has solved these problems now visits its large mental illness hospital informally every fortnight. Members make a point of sitting down and talking to patients, not just passing the time of day and rushing on to inspect the kitchens or get to the meeting room to talk. Adopting a particular patient and regularly visiting her is another way of learning about life inside. Spending a whole day on one ward will reveal a lot, and some people have found that taking their toddler with them has broken the ice in a geriatric unit.

One group of CHCs who share several large institutions has devised a successful policy of dividing up the labour of visiting. Each CHC concentrates on certain agreed aspects of life in the hospital. Their detailed reports are circulated to all the CHCs involved to encourage an exchange of ideas. An added advantage is that staff do not have to go over the same ground with each CHC. Their division of labour is set out below:

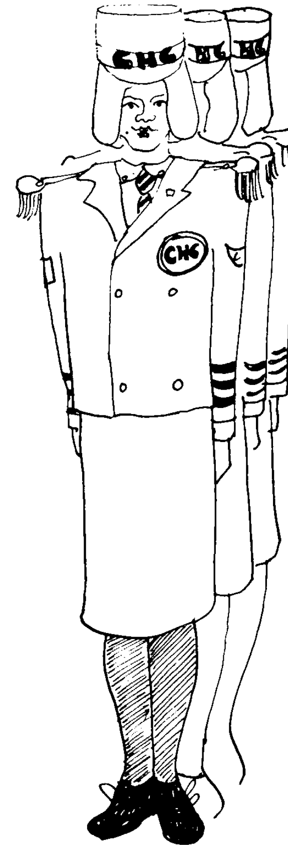
| | |
|---|---|
| CHC 1 | Patient Activities I<br>Work, education, industrial therapy, psychology, occupational therapy |
| CHC 2 | Patient Activities II<br>Social activities, intervention with volunteers, outings, entertainments after 4 pm., holidays, gardens and flowers, pets |
| CHC 3 | Treatment Programme<br>Medical and nursing care, speech therapy, physiotherapy, relations with staff, family counselling |
| CHC 4 | Living Conditions I<br>Wards, age groups, contact with opposite sex, day areas, bathrooms, toilets, privacy, noise, daily timetable, availability of religious services |
| CHC 5 | Living Conditions II<br>Domestic services, catering, laundry, hairdressing, pocket money, clothing |
| CHC 6 | Management<br>Co-ordination between various professions, staff morale, staff training to meet patient needs, influence of management system |

# During the Visit

It may be worthwhile asking for a plan of the hospital and grounds and a copy of whatever information is given to the new resident or his family. You may find there is not much. If you want to experience the place as an ordinary consumer, you should almost certainly travel by public transport and allow plenty of time for wandering around until you find the ward you want.

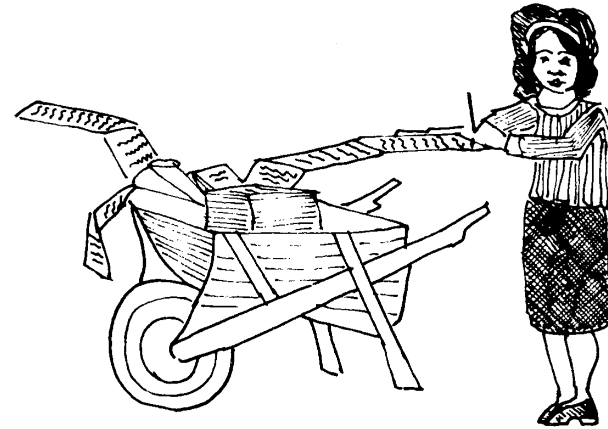
There is no doubt that many CHCs find their most useful conversations are with ward staff but it is not always easy to make this informal contact, especially if senior management are acting as 'guide'. Members will need to be politely firm and insist on having contact with staff away from the scrutiny of mangement. The more you go, of course, the more quickly you learn your way around and become familiar to the staff, which makes informal visiting much easier. Some CHCs favour name badges or identity cards for their members, but for others this smacks too much of officialdom.

Sometimes during a visit a patient makes a complaint to you, or a member of staff tells you of some distressing incident, or you yourself see something which worries you. What do you do? If you actually witness something disturbing you must find the person in charge and seek an explanation. In other cases, the best advice is to take careful note of what has been said to you and follow it up afterwards through the CHC office. Sometimes, of course, a simple action on your part is the answer. If an old lady complains that her spectacles have been removed, for example, you may be able to find the ward sister and solve the problem on the spot.




*...badges smack too much of officialdom.*

You may occasionally find yourself in an awkward situation when, for example, members of staff hold different views on the way their unit should be run and take every opportunity of trying to manipulate visitors to one point of view or the other. You may have to remind yourself when listening to grievances that the CHC is not a staff complaints board. It is wise to say little when faced with these situations but listen carefully and try to have a discussion with other members as soon as possible after the visit.



You will have to decide a means of recording your impressions during the visit. Most people make notes as they go round, sometimes in the corridor between departments, sometimes as they are talking to people. Some prefer to use those little hand-held recording machines. One good suggestion is to appoint one member as note-taker for the visit with the others telling him of points they feel are worth recording: a different person does it each time.

It can be very helpful to have with you a checklist of the points you want covered during the visit. The following questions are based on the 100 Questions found in the book **'Living in Hospital'**[2] which we recommend to everyone thinking of visiting a long-stay unit. References to other useful questions are given on page 24.

# 100 Questions

In using these questions, it is most important to treat them only as a starting point for thought. Some may need to be re-phrased to fit your local situation and you will almost certainly need to devise supplementary questions to make sure you get beyond the simple yes-or-no answer. For example, a question like Are new residents made to feel welcome? can easily be answered Oh, yes, of course! and you will not have gained any real information. You will learn more if you ask: How are new residents made to feel welcome? Who meets them when they arrive? Are they introduced to other residents? Are relatives allowed to stay with them for a while after they arrive? And so on.

*Coming into hospital*

1 How 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 and lie down 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*

15 Are residents encouraged to go to an outside hairdresser?

16 Is there a hairdressing salon in the hospital?

17 Does the visiting hairdresser attend to difficult or anti-social 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?

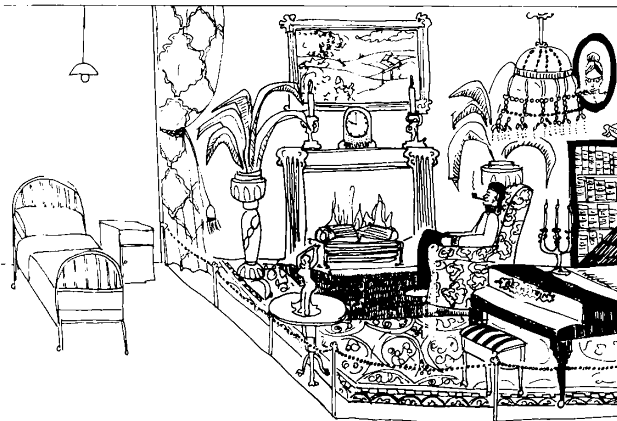
26 Are residents ever permitted to organise for themselves a festive meal to mark some special occasion?

*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?



*. . . furniture or furnishings of their own . . .*

*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?

If so –

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 and encouraged to take 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 Has the hospital exploited fully the basic right of *all* its residents to the whole range of further education services?

48 Do tutors from the local polytechnic/college of art/adult education department come to the hospital?

49 Have residents easy access to the public library service?

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

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?

*Gardens, flowers and animals*

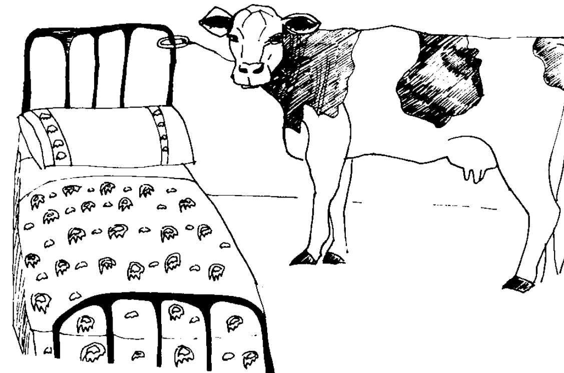
57 Have residents easy access to, and is appropriate seating provided for, a garden, lawn, terrace, or similar area?

58 Are well-behaved pets allowed to visit residents?

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

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

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



*. . . well behaved pets . . .*

*. . . grow their own plants . . .*

*Religious beliefs*

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

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

64 What arrangements are made to cater for different denominations and religions?

*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, is it possible for them to share accommodation if they wish?

*Mixing the age groups*

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

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

69 Are younger residents allowed plenty of social inter-change 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 together in their daily lives — e.g. meals, day room, workshop?

73 Are there any areas of the hospital where integrated living accommodation is available?

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 In what ways are the 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 What planned efforts are made to help residents keep contact with the world they used to live in?

81 How frequently are arrangements made 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 In what ways are attempts made 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, officers and ways of working consistently demonstrate a concern with maintaining the morale of staff in their difficult task?

94 Are study days, inter-hospital visits and other forms of relevant in-service training arranged regularly?

95 Is there genuine machinery through which staff of all grades and professions can express their collective views?

96 In what ways does the health authority listen to the views of staff and respond to them?

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

*Influence of the management system*

98 How far does the management system make provision for participation in decision making by staff at all levels?

99 What methods are used to help staff work together in a truly multi-disciplinary way?

100 What steps are taken to ensure that managers put the interests of residents first when making decisions?

As **'Living in Hospital'** says:

> "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 here?
> 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?"**



# Writing the Report

Most of the information you gain on a visit will be distilled into a report. Some CHCs have tried to devise a formula to help members with things like the length of a report, the difference between comment and statement of fact, whether to name names, how to handle confidential information and so on. This can be very helpful, so check with your CHC office. How you write your report will depend on what you are trying to achieve but there are a few tips worth following:

(a) *check the facts*
It really is unforgivable to write reports with the kind of incorrect information which could easily have been checked — but it happens all the time. The ratio of night staff to patients, the cost of patients' meals, the policy on patients' pocket money — such things are easily verified. Your CHC office may already have the information but if not, will certainly know how to get it.

(b) *do not assume*
One CHC, visiting a hospital for the mentally handicapped, was shown the new physiotherapy department and took it for granted that the physically disabled children they were visiting received treatment. In fact, the hospital's only physiotherapist had decided six months earlier to stop giving the children any physiotherapy at all. The presence of a facility does not necessarily mean the practice of a service.

(c) *have the courage of your impressions*
As an outsider, it is your impression of life inside which can be most valuable. Staff get used to the conditions they work in — we all do. They forget; they know the background problems; they rationalise; they have to keep going. None of this means they don't know what is wrong and want it changed, but it may be easier and more effective for someone from outside to

say 'This is not acceptable.' *How* you say it matters a great deal.

(d) *how you say it*
Few people find it easy to get their ideas on paper and there is sometimes the temptation to retreat into formal reporting in official language which may look right but does not tell you much. The other extreme, of course, is to overdo the emotional descriptions. Maureen Oswin has the enviable ability to describe simply what she sees and allow it to speak volumes. Here she is describing equipment in a mental handicap hospital:
"11 year old Hugh's wheelchair was sent away to be repaired, but nine months later it had still not been returned and nobody knew what had become of it. Hugh had a very large head and his wheelchair had to be specially weighted to prevent him tipping over. Without the chair he could not go to hospital school, nor be taken for a walk around the grounds; he had to lie on the floor of the ward all the time. The nurses were worried that after nine months of lying on the floor Hugh's neck muscles would have lost the ability to support the weight of his head."

"...... there were only three very old broken wheelchairs for 16 cerebral palsied children. Outside the ward there was a rusting pile of broken wheelchairs but no-one knew who was responsible for removing them, and it was said that no new wheelchair could be issued until the old ones were returned to the Region's wheelchair centre."[1]

# Getting Action

Having written a report the next step is to decide what to do with it; how best to use it. Someone in the CHC, perhaps the Chairman or Secretary or an executive, has to decide such things as when information is to be regarded as confidential; whether answers should be sought and incorporated before the report is finalised; when it should go to the full CHC; whether it is first discussed with management, and so on. Your CHC probably has an understanding with the District Management Team on how to handle these matters.

You also have to try to direct your energies to the right place if you want to influence decisions. It is the Health Care Planning Team you should be aiming for; or the DMT's priorities in the District Plan; or perhaps your ideas are incorporated in the plan and you should concentrate on getting it through the Health Authority. How many Authority members are you in contact with; or does everything go through the officers? Does your MP know what is going on? Can you use the experience of other CHCs?

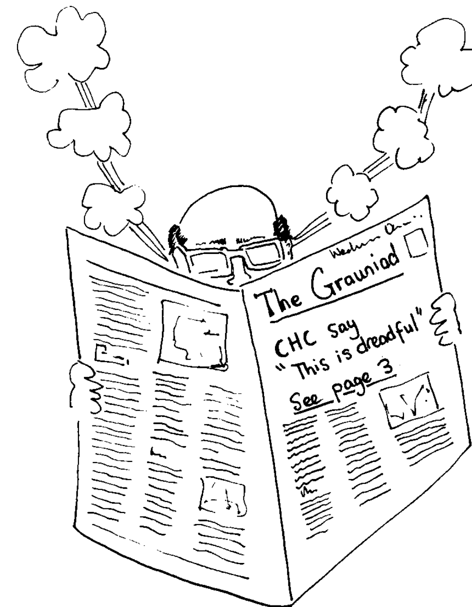
Regular monitoring is undoubtedly one of the CHC's most important tasks: taking some aspect of the service – home laundry service for families with an incontinent old person, say – describing how it works in practice, comparing it with *how it is said to work,* finding out what plans there are for the future and so on. Follow it up six months later. And six months after that. Build up a reliable picture of how the service works locally and use it to argue your case.

There are sometimes other groups in the neighbourhood fighting for improvements, and joining forces can make a lot of sense. The CHC has much to offer because of its access to NHS planning, its membership of Health Care Planning Teams, its contacts with health authority and local authority members

and so on. Relatives' organisations and local pressure groups often have direct personal experience of services and a clear idea of where changes could be made. The CHC knows how to get ideas and information through to the appropriate part of the NHS organisation, which is not so easy from the outside. The CHC can also act as honest broker. In one case, where strong feeling and prejudice were running high because of plans to convert a house into a hostel for people discharged from the local mental illness hospital, the CHC was able to set up a meeting between local residents and NHS staff at which a lot of misunderstanding was cleared up.

CHCs have no executive power so they have to make use of other means of bringing about change. Publicity is one of the most important. There are two aspects to publicity. One is to inform people about what is going on in their health services and the other is to influence health authorities. The two need to be linked, of course. It is too easy to blame managers and staff for deficiencies in a service which is only necessary because of the community's limited capacity for caring. Publicity is often used as a last resort when internal negotiations have led nowhere, and while CHCs cannot expect to be thanked by management for publicising controversial matters, there are those in authority who envy CHCs their freedom, and welcome the opportunity of working with them to get things moving. There are others, of course, who deplore publicity at any price and CHC members may have to develop thick skins to resist the arguments 'You are only lowering the morale of the staff' and 'We are doing the best we can'. Publicity can be a powerful weapon, to be used with care, but CHCs must not fall into the trap of being so frightened of offending staff that they fail to say 'This is dreadful', if they believe it to be so.

Yet despite the publicity surrounding all the enquiries which have been held since the 1960s, the scandals continue. Public concern about conditions has been loudly expressed yet those who fight for improvements still face an uphill struggle. CHC members are now part of that struggle. Somehow you have to get the balance right between fighting for improvements and not expecting too much so that you don't face constant disappointment. Great changes may not be won overnight but throughout the country there are examples of imaginative good practices which demonstrate just what can be achieved. CHCs have the right to visit hospitals. They also have the responsibility, we believe, to exploit every channel open to them in an effort to improve conditions for long-stay residents.



# Further Information

**CHC News and Information Service**, 362 Euston Road, London NW1 3BL – tel: 01-388-4943, has files on general health and NHS matters and on individual CHCs, and files of press-cuttings about CHC activities, and will try to answer any queries from CHC members and staff.
**The Association of CHCs for England and Wales**, same address – tel: 01-388-4814 – aims to present the views of member councils nationally, to respond to calls from CHCs for co-ordinated action on a national level, and to act as a support service to individual CHCs.

**King's Fund Centre**, 126 Albert Street, London NW1 7NF – tel: 01-267-6111 – The Centre is chiefly concerned with promoting new ideas and good practices in the planning, management and delivery of health and related welfare services. Its library and information service are available to everyone. The Centre's Long Term and Community Care Team concentrates on services for mentally ill, mentally handicapped, elderly and disabled people living in hospitals and in the community. One of their main concerns is the day-to-day life of people in long term care.

**CEH – Centre on Environment for the Handicapped**, 126 Albert Street, London NW1 7NF – tel: 01-267-6111 – provides advice and information on the physical environment of handicapped people. It publishes a journal, Design for Special Needs, organises seminars and has a reference library. The services of two consultant architects are available.

**Age Concern**, Bernard Sunley House, 60 Pitcairn Road, Mitcham, Surrey CR4 3LL, tel: 01-640-5431 is the co-ordinating body of some 1,000 local Age Concern organisations which work with volunteers to provide and co-ordinate services for the elderly. Nationally, it provides an extensive information service, conducts surveys into the needs and views of old people; publishes reports and leaflets; promotes awareness of the needs of the elderly; and campaigns on their behalf.

**MIND**, The National Association for Mental Health, 22 Harley Street, London W1N 2ED, tel: 01-637-0741. Among its many activities, MIND runs an information service, an advice centre and a legal and welfare rights service, issues publications and organises workshops and conferences. It has over 130 local groups.

**National Society for Mentally Handicapped Children and Adults** (MENCAP) 117 Golden Lane, London EC1Y 0RT, tel:01-253-9433. Apart from its well-known support services for parents and a network of local offices, MENCAP provides an information service for the public as well as books and quarterly journals.

**RADAR**, The Royal Association for Disability and Rehabilitation, 25 Mortimer Street, London W1N 8AB, tel:01-637-5400, is a co-ordinating body with over 400 organisations in membership. It promotes the education, welfare and rehabilitation of disabled people and their integration within the community. It has departments which deal with mobility, access, housing, holidays, welfare, education and employment. It also operates over 70 REMAP groups throughout the country, which design and provide special aids.

# Publications

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# References


1. OSWIN, Maureen. *Children living in long-stay hospitals.* London, William Heinemann Medical Books, 1978. pp. viii 159. *S.I.M.P. Research Monograph no.5.*

2. ELLIOTT, James R. *Living in hospital: the social needs of people in long-term care.* London, King Edward's Hospital Fund for London, 1975. pp. 84.




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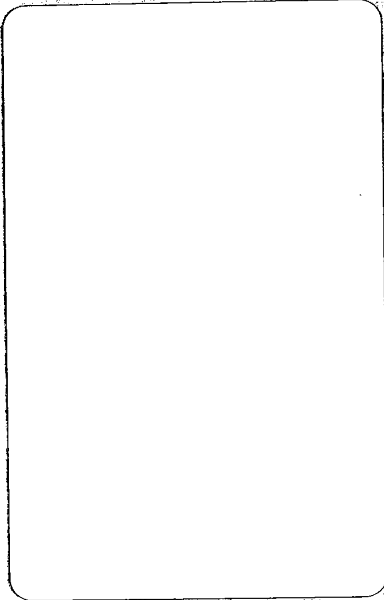

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hospital visiting

community health councils