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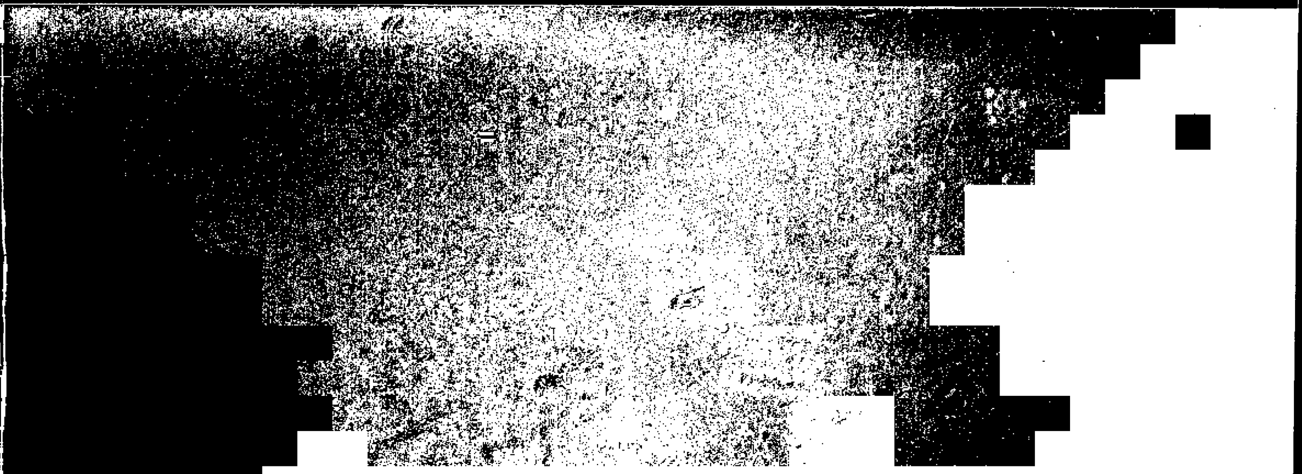

A CARERS' PANEL

ENABLING RELATIVES TO INFLUENCE PATIENT CARE

Brighton ● Camberwell ● Southport ● West Dorset

Nursing
Development
Units

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KING's FUND CENTRE

Published by the King's Fund Centre
126 Albert Street
London
NW1 7NF
Tel: 071-267 6111

ISBN 1 85717 032 6

A CIP catalogue record for this book is available from the British Library

Distributed by Bournemouth English Book Centre (BEBC)
PO Box 1496
Poole
Dorset
BH12 3YD

The King's Fund Centre is a service development agency which promotes improvements in health and social care. We do this by working with people in health and social services, in voluntary agencies, and with the users of these services. We encourage people to try out new ideas, provide financial or practical support to new developments, and enable experiences to be shared through workshops, conferences, information services and publications. Our aim is to ensure that good developments in health and social care are widely taken up. The King's Fund Centre is part of the King's Fund.

Printed by Multiplex medway ltd

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Shouldering the responsibility

We work on a ward dedicated to the care of the elderly. The majority of our patients are admitted to our ward for rehabilitation after initial treatment on an acute medical ward; a smaller percentage of our patients come direct from home, either for respite care or further assessment and rehabilitation. We are situated in the seaside resort of Southport, on the north west coast. Southport is described in a well-known motoring club atlas as 'a seaside resort set on a narrow strip of flat coastline leading off the Lancashire plains.' Maybe it's because of the wide flat promenade and shopping avenues that pensioners have found it a popular place to retire to, leaving behind the younger members of the family.

As nurses working within elderly care, we are very aware of the necessity of good discharge-planning arrangements, particularly when the responsibility for the provision of long-term care falls on the shoulders of the elderly carer.

A different story at home

Nursing Mr Jones highlighted for us the difficulties in identifying the needs of carers. Mr Jones was in his late fifties when he was admitted to the ward for respite care.

In the past, he had held a very responsible job in the Civil Service and had been looking forward to his retirement. Indeed, for both him and his wife, this was going to be a well earned rest. Then unfortunately he suffered a severe stroke, followed by two further strokes, leaving him paralysed and speechless and requiring hospital care for many months. Mr Jones had finally been discharged home with support services after his wife had been shown and allowed to practise various lifting and transferring techniques.

After several months at home, Mrs Jones, almost at breaking point, was finally persuaded by the community nurse to ask her GP about respite care facilities. So eventually her husband was admitted to our ward. We admitted a heavily dependent gentleman who had quite obviously been extremely well cared for. Using our work load indicator, Criteria for Care, the gentleman's score was in the high dependency category. Two nurses were needed to lift and turn him. Repeatedly, the team would wonder how Mrs Jones had managed to care for her husband at home. In talking to Mrs Jones, who constantly told us how good the nurses were, it became obvious the nurses had done all they could to ensure her needs were met prior to Mr Jones' discharge, after his initial hospitalisation.

However, once home the story had been somewhat different. Mrs Jones had had a career of her own, far removed from that of nursing, and could not clearly identify what her needs were going to be, where nursing her husband was concerned. This gentleman, whom she loved so dearly and had vowed to look after in sickness and in health, was now a very heavily dependent patient at home.

Mrs Jones was not entirely alone in Southport; her elderly father, almost in his nineties, also lived with them, and fortunately was able to give help, and to support her by listening.

Many carers we have spoken to remember vividly the endless nights when nobody seemed to care; the longing for an uninterrupted night's sleep; the guilt some have felt at having sworn at or been rude to their relative or spouse when called from their bed yet again.

The physical needs of carers can be somewhat easier to identify and meet. However, in our experience, the more difficult and ever present social and emotional needs are somewhat harder to fulfil.

Ask the carers

Who better to know the problems carers have than carers themselves? We decided to ask them. To achieve this we set up a panel of carers. First we investigated whether such an initiative had been undertaken in other hospital settings. We now know of similar consultative groups but at the time, three years ago, we were unable to find any other places using this method to obtain information. This did not deter us from developing our own.

So our carers' panel was born. At least they could be their own voice and be part of the decision making. We asked carers to sit on a panel alongside other lay people and health service workers. We invited social workers, physiotherapists, occupational therapists, hospital and community nurses. We also involved members of voluntary organisations such as Age Concern, the Samaritans and churches. Here the carers had an opportunity to say what went wrong or what was good, useful and worked well. There was time to discuss what a discharge plan was and to identify areas we had overlooked or been totally unaware of. From this we hoped to gain a clearer idea of what the carers needs were and how we could help to meet those needs once identified.

The information coming back from just our first few meetings was enormous, covering a broad spectrum of care, from carers' views on the initial hospitalisation to their needs at the terminal stage of their loved one's illness, and from the ward environment to the the teaching role of the nursing staff.

Once our carers' panel were willing to voice their opinions and needs, we had the awesome task of prioritising these.

With the carers' agreement, we decided to concentrate our efforts on just five topics:

- developing a teaching programme for carers
- developing a better understanding of medications
- publishing a booklet to be given to carers containing information they identified as needed
- developing a 24-hours Help Line
- better respite care facilities.

A positive role for carers...

We now encourage carers to come into hospital and play a positive role in the care of their relative. This may start fairly simply by coming in to feed the patient and, when the carer is ready, moving on to bathing, dressing, changing catheter bags, applying simple dressings. The carers, if they wish, now become involved with the patient's nurse in all nursing care and are supported by the nurse until they are ready to carry out this care themselves. This also involves other disciplines such as a physiotherapist. A physiotherapist will show the carer how to handle and transfer the patient safely. Some carers may go through all aspects of care in a few days, others may take longer. It is important that the carers are happy with the care they are giving and are happy that they understand the reasoning behind it.

The ward pharmacist gives advice and information to the carer about the medication the patient is prescribed. There is no set medicine round; individual patients receive medication at the time it would be administered at home, thus maintaining a pattern for patients in for respite care or creating a pattern the carer can cope with at home.

Together with the pharmacy department we are in the process of compiling information leaflets on the most commonly used medication in the care of the elderly. Pharmaceutical firms have written many leaflets over the years, but it is vitally important they can be understood by our elderly population and carers. Many examples we have examined have print which is far too small for anyone with a visual problem, so we are producing our own.

We have developed our own carers' booklet and supplement this with information from areas such as the Stroke Association and the Chest and Heart Foundation, thus any supplementary information is given to the appropriate patient or carer.

... tailored support and...

One of the emotional needs highlighted by carers was someone to talk to, such as a telephone Help Line. The Samaritans were only too willing to be the listening service and provided us with a card, which is given out with the carers' booklet, stating how they are there to listen to anyone with a problem or a worry. They are not just there for the suicidal, although we can imagine many carers must at times experience severe stress. The offer of this service provided by the Samaritans has been very much appreciated. Of course, because of confidentiality, we have no way of telling how many of our carers use this service. However, we do feel that this is not the whole solution to this problem.

Many of our carers said how good their GPs were, really having the old family doctor image. However, we feel even the best GP in the world would not wish to be woken in the early hours to hold a counselling session for a carer. So to meet this need, we encourage our carers to ring the ward — there is always someone on duty willing to help and on night duty we have a staff nurse who has undertaken the postgraduate counselling course who can provide the skill needed to cope with this situation.

... a range of respite care

Respite care was an area identified by our carers' panel, although for many years the hospital had offered respite care on a two-weekly basis this did not seem always to be the answer. Carers suggested what they needed was respite care on a there and then basis, not booking and waiting for confirmation.

On further discussion we found that what each carer needed was individual care unique to them. The support we give must be tailored to fit their needs. The solution was not an off-the-shelf package. All patients have individual needs; so do the carers.

For some, two weeks every four months or so was most appropriate. Many others seemed to require respite on an *ad hoc* basis, such as ringing the hospital and the patient being admitted the following day. At the moment, this would be almost impossible to carry out. For others the whole concept of respite was one they could not accept. They told us how guilty they felt leaving their loved ones in hospital and although happy with the care they received, deep down they felt nobody could nurse their relative as well as they did. This was true, they had a one-to-one nursing partnership. Their knowledge of the patient was far greater than that of the nurse, for it went back over many years.

Building up a relationship with the carers and understanding the guilt carers feel is yet another aspect nurses in care of the elderly have to integrate into their nursing practice. The ideal for our carers is a sitter service that would allow them to ring in the morning and book two hours sitting in the afternoon, or possibly to book a full night. So these are areas we feel must be achieved. We do feel that being nursed at home is what the vast majority of elderly people want. 'Home sweet home' or 'home is where the heart is'; these remain true throughout our life, but what is home sweet home to one member of the family must not feel like hell on earth for the other.

'The weekend felt more normal'

Even with the help of our panel it was possible to make wrong decisions and we, I'm sure, are not unique in this. The feedback from the majority of carers was for a range of respite care, so our plan was to make use of the Day Hospital at weekends and offer Saturday respite care. Transport, helpers, meals all planned and arranged — now to advertise our service. This service was welcomed by Age Concern, the local churches and other voluntary organisations. A minister from one church took our leaflet out to his local parishioners whom he felt would benefit from our service. Even with this help, we had no response.

We were very disappointed, as for months we had planned this service. Having asked carers, we still had not got it right. Why did we fail?

On further investigation we found weekends were not the best time. The patient was entitled to the weekend, grandchildren come on Saturday. The feeling of isolation was not as great at the weekend, neighbours were not at work, carers could have a chat over the garden wall. As one carer told us, 'the weekend felt more normal, we were always together at the weekends.'

Recently we have been evaluating the work instigated by the carers' panel. This took the form of semi-structured interviews of the participating carers by an independent researcher. During each interview the carers felt the original points they identified were still important.

The isolation they felt at that time of caring was almost unbearable and yet somehow they had to carry on. We also gained confidence that our initiative is worthwhile, despite the setbacks, as each and every one told us what a good idea the carers' panel was and how much it had helped them. Already this small group of carers had found support from each other.

Listening to all views

Ensuring that the views of all types of carers are represented on the panel is a problem. Membership of the panel is limited to those able to attend meetings. They are carers who have friends or family nearby and are willing to stop by for an hour, or former carers whose relatives have since died but still have an experience to share. As we said earlier, Southport has many retired pensioners living within its boundaries who have no relatives to fall back on. Many spouse carers would not or could not leave their relatives to come to a meeting.

As a solution, we now visit some carers in their homes. This has been a really useful exercise. The interviews carried out to date indicate how each individual's needs vary and also that what is right today may not be correct in tomorrow's world. People's expectations change constantly and we must do our utmost to meet their changing needs, learning by our experience to anticipate a need and, if possible, going some way to meet it. This will be no easy task, but we have learned to listen to the people with first-hand experience.

We are now looking at the possibility of our carers starting a self-help group; they individually may not have all the answers but they have a wealth of experience to share with new carers. Only carers can really know how another carer feels at 2 o'clock in the morning, when they feel the night will never end or that they have no life of their own. We feel that a 'drop in centre' for carers and patients — somewhere to meet and chat over a cup of coffee to ease those feelings of isolation — is essential; maybe a phone link with other carers is a good idea, and a 'buddying' relationship might then develop.

Our work with carers will continue to inform our practice on the ward. Some of our development work can be used in many other areas. For example, the information made easier to understand on medication can be used by anyone in need of such information. The development of our listening skills and our capacity to involve and seek the opinions of our clients are important aspects of nursing. The rapid rate of change in the health service necessitates improved communication.

As a service development we will investigate the possibility of having a night hospital service and will be looking for backing and finance for this venture in the near future. We do know that this work will never stop and must progress rapidly as more and more people find themselves in the carer's role.

'Who can say what's around the corner?'

On a recent visit to a carer whose husband had suffered a severe stroke a short while before, the carer spoke of how confident she felt when her husband was discharged from our ward and how she felt she would now be able to cope. The confidence this carer talked about has taken a long while to build up.

Although her husband was now slowly becoming mobile, he now had severe epileptic attacks. A trained nurse may sometimes find these attacks disturbing; imagine how a loving wife feels seeing her once-active husband in the throes of a fit. Teaching this carer how to cope with her husband's problems took time and understanding. Using information from the Stroke Association, giving her time to read and ask us questions, enabled her to develop the confidence she talked of.

The purpose of my visit was to see if we could have done any more prior to discharge. She felt we had given her the support and information she needed in order to cope, and knowing we were only a phone call away had made a great difference to her. As I turned to go, she said, 'please come again, it's so nice to have someone to talk to and maybe I may need more help in the future, for who can say what's around the corner at my age?' This carer was in her late seventies and had a 24-hour a day job.

Indeed, more help is very much needed for our ever-growing band of carers. This help must be constantly reviewed and improved upon. Our commitment to caring for the carers continues; we are learning to listen and meet the different needs of carers. Working in partnership we are seeking a solution which will, we hope, lead to a brighter future for the many carers in our community. Above all, they need to know we care about them.

Some suggested reading

Kohner N. Caring at home: a handbook for people looking after someone at home — someone young or old, handicapped or disabled, ill or frail. Cambridge: National Extension College, 1988.

Richardson A, Unell J and Aston B. A new deal for carers. London: King's Fund Centre,1989.

Open University. Department of Health and Social Welfare. Working with older people: individual study pack. Milton Keynes: Open University, 1990. (Open University: Department of Health and Social Welfare; P654).

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This series looks at some of the ways nurses in Nursing Development Units (NDUs) have tried to make their nursing more beneficial for patients. The nurses assess to what extent their initiatives really do contribute to patient well-being and what has helped them bring about the changes. Each book will help nurses to introduce new ideas to their work and will suggest ways to evaluate changing practices.

The four NDUs which have contributed to this series have been supported by the King's Fund Centre and the Sainsbury Family Charitable Trusts since 1989 as part of a three-year project. A further 30 new projects have just received funding from the Department of Health and join the growing network of Nursing Development Units.

In this booklet, Jackie Horner, a ward sister, describes how she consulted carers on how to provide effective ward services for elderly people and how the team has set about meeting the carers' needs.

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