

# CARE OF THE DYING & THE NHS

## some carers views

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National Council  
for Hospice  
and Specialist  
Palliative Care  
Services





*Ernie Bray and Fred Norton (top) and Angus and Naomi Jefferies (below) participated in the Consultation Day.*

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# 1. INTRODUCTION

THIS IS A REPORT of a day of consultation and discussion held in July 2002 at St Christopher's Hospice, South London, and organised jointly by the hospice and the National Council for Hospice and Specialist Palliative Care Services (National Council) in response to a request from the Nuffield Trust to gather the views of some carers on Care of the Dying and the NHS.

## Background

This request came in turn from the prompting of Sir William Reid who during his time as Health Service Ombudsman and his experience of receiving complaints from members of the public became convinced that Care of the Dying was an urgent priority within the NHS. He realised that it is crucial to get care right at the critical moments when people do not have the time or energy to "get over" mistakes, incompetence or insensitivity - they do not have the luxury of thinking "oh well, when I get home and get better I'll complain/feel better/ deal with the anger and upset"

"The dissatisfied dead cannot noise abroad their discontent."

*based on Hinton & Oliviere, 2003*

## Background to the day

It was agreed that the views of service users and carers were needed to feed into the Care of the Dying and the NHS Project. The National Council was asked to facilitate this process and worked in partnership with St Christopher's Hospice in South London to arrange a consultation day on the 19th July 2002 with the aim of gathering the views of some bereaved carers on their own experiences.

## Participants — how they were identified

It was agreed that an advert should be placed in the local newspaper (see Appendix A). Letters were also sent to local people known to the hospice who had been bereaved during the previous 12-24 months. 13 bereaved carers attended the day.

## Arrangements for the day

The practical arrangements for the day were very important. It was important to make sure that appropriate support and back up was available. A room was set aside as a "quiet room" in the event of participants becoming upset by the subject matter and by telling their stories. Two nurses were also available for individual support so that there was the opportunity for people to talk and unburden on a one-to-one basis. The choice of chairperson for the day was also important - Frances Sheldon, Macmillan Senior Lecturer in Psychosocial Palliative Care at the University of Southampton, was asked to chair. Not only because the organisers were sure she would do an excellent job but also because she herself was at the time a cancer patient under the care of the NHS. Participants were asked for their permission for photographs of them to be used in any subsequent publications and were assured that any report of the day would be anonymised.

*"The only ... thing to do about peoples' grief is to believe what they say about it."*

*Toynbee, in Oliviere, Hargreaves & Monroe, 1998*

*"We had been married for 55 years – we didn't want to be separated."*

### **Briefing to participants**

*"Why can't they have the same service in hospital as they would have got in a hospice?"*

It was also very important that participants were briefed well on the background to the day. The participants were updated on the work of the Nuffield Trust and the background to the Care of the Dying and the NHS project. The Chair introduced the day to participants as an opportunity for them to "make their voice heard" to tell their stories and to feed their views into the NHS as the NHS wants to learn from service users - people with important experience. Participants were asked to be sensitive as some people's bereavement was more recent than others. Participants were reminded that they were about to share very personal experiences and would hear personal details - they were asked to respect confidentiality.

The Chair explained that the Nuffield Trust would be holding a Conference in March 2003 at which key policy makers from the NHS and Department of Health would be in attendance as well as academics and clinicians and that they would consider the feedback from this meeting and discuss how to educate and influence colleagues in the NHS.

The structure of the day was then explained to the participants - it was explained that after introductions and scene setting there would be a brief presentation by some bereaved carers and then they would move into small groups to discuss the subject; *Our Stories: Good Care/ Bad Care*. After lunch there would be an opportunity for observations and feedback from the morning session and then again small group meetings on the subject. *What do you want to tell the NHS (GPs, District Nurses, Hospital Staff)? - Solutions and Ways Forward*. There would then be further opportunity for feedback and discussion before closing remarks by the Chair and tea at the end of the day.

Participants were asked to think about the care their relative or friend received within the NHS, the good aspects but also the things that didn't work. They were reminded that one of the aims of the day is to identify and develop best practice. The stories that were told were moving, disheartening, encouraging and inspiring.

### **Process of compiling this report**

Four note-takers were present during the day and their notes have been compiled into the section below. There were some common themes emerging from within the small group work as well as the more general discussions and an attempt to summarise some of the discussion and highlight the key issues is set out below.

The key issues have been organised into the following categories:

- |                                       |                                       |
|---------------------------------------|---------------------------------------|
| 1. GP's role                          | 9. After discharge                    |
| 2. Diagnosis and breaking bad news    | 10. Advocates                         |
| 3. Information                        | 11. Going home                        |
| 4. Practical arrangements at hospital | 12. Carers                            |
| 5. Nursing                            | 13. Last days, dying and death        |
| 6. Pain                               | 14. After death care                  |
| 7. Co-ordination and follow-up        | 15. Staff communication and attitudes |
| 8. Spiritual issues                   | 16. Professional support              |

As far as possible the author has tried to faithfully represent the voices of the participants and to use their own words and phrases.

## 2. DISCUSSION WITHIN CATEGORIES

### 1. GP's role

THE KEY ROLE OF THE GP was much discussed during the day. There was a mixture of good and bad experiences related. One participant who cared for her 77 year old husband through a range of illnesses said that their GP didn't go to the house and that he "couldn't care less." "At one time I phoned in desperation. He told me to take my husband to the hospital which I couldn't do as I had no car. We were both awake all night. We had to wait for the next day for a prescription and my husband was in so much pain and discomfort."

It was stressed often how GPs can make a huge difference to patients and carers. They often haven't got time to talk and listen - when they make home visits they are much appreciated and these are missed when they don't take place. Participants spoke about the difficulty of getting past receptionists. The issues that are important to the service users are speed of diagnosis, prompt and efficient referral, good pain management and good symptom control.

Many participants felt that more GPs should specialise in particular diseases like cancer - and that there is a clear need for continuing professional development in cancer and end of life and terminal care. The GP has a very important role in helping patients to access services. Participants spoke a lot about wanting GP's to not 'skirt around issues' and to practice better (more honest, direct) communication.

A key point raised was the lack of consistency in referral, ie knowing who to go to next. Or knowing who refers someone on to the next stage of care within the NHS. One member of the group was particularly concerned about the lack of information available. Some participants spoke about a perceived assumption that the relative knows and understands what is going on so GPs and specialists don't elaborate. GPs who had time and capacity to be attentive, caring, honest, to explain difficult and complex issues and pitch information at the right level were hugely appreciated. More than one story referred to the situation where a patient was continuously going back to the GP as symptoms developed for different treatment, "no one seems to think of the worst case scenario on day one - maybe someone should."

#### *Suggestions for Improvement*

GPs to have more training in specific life-threatening diseases

GPs to be more aware of the information needs of service users

GPs to be more aware of how confusing the NHS system can be to service users

### 2. Diagnosis and breaking bad news

Many participants spoke about delays in getting to see a consultant for a diagnosis.

One participant spoke about the professionals' perceived lack of knowledge about the disease his wife suffered from at the nursing home and the hospital. Another participant spoke about how he pushed for diagnosis himself, doing much reading and research until finally the doctor agreed with him — "I had to take the bull by the horns and work through it but I managed it." Participants spoke about struggles with getting diagnosis in diseases other than cancer. In the case of a relative with Parkinson's Disease one participant spoke about a lack

*"What's important is making them as happy as possible" Maybe we shouldn't concentrate too much on death. The patient knows when the end is near."*

of co-ordination between services after diagnosis - "we were left in the dark - we didn't know what to do next and who to talk to and no one was available to help us with this."

*"We want choice and a partnership between carers, relatives and professionals"*

Breaking bad news came up a number of times - the overwhelming message was that this wasn't done with empathy and a respect for humanity. In one case one carer spoke about "uncaring agency staff" who broke bad news in a particularly unsympathetic way. A common issue that arose throughout the day was around truth-telling - that patients and family weren't told they were going to die. In one workshop out of four carers only one of the relatives was actually told that their loved one was going to die. One participant reported that the consultant never said that the cancer (his wife's) was incurable. "The consultant kept ordering tests without confirming that she was so ill." The participant felt that the consultant just 'needed to use his eyes' to tell that she was seriously ill rather than continuing with inconclusive tests. One participant spoke about the particular problem of doctors not being able/knowing how to break bad news, especially to a young person. Suggestions for improvement included training in communication skills and multi-professional breaking bad news training. It was clear that many people wanted honesty from professionals and that they felt their loved one's did too.

#### *Suggestions for Improvement*

More awareness raising on the massive impact on service users on receiving bad news

More breaking bad news training

More discussion in training on "truth telling" issues - many service users want the truth

More training on using straight language when discussing difficult issues

### **3. Information**

Participants spoke about a general unmet need for information - of all sorts and in all situations. "We need information we can cope with." "We need someone to help us with the information we are given." Information packs on diagnosis - which detail the systems, and processes within the NHS. "We need to know what we're entitled to, where we can get help, where we can get more information."

*"He had a marvellous doctor who had explained everything to the family and was very compassionate. He explained that nothing could be done for my brother."*

A comprehensive range of information is needed. It needs to be part of and able to facilitate good communication between patients, carers and professionals. People need help finding their way around the Internet when researching health and disease related matters. Could people be directed to particular websites and organisations?

Participants acknowledged the fact that appropriate information provision would mean different things to different people. The group agreed that a comprehensive information pack should be provided for people suffering from cancer including basic information that is sometimes assumed to be already known. Such packs should also be made for other diseases (heart disease etc). People need information before they arrive at hospital for appointments and/or treatments to help them prepare at a particularly stressful time.

#### *Suggestions for Improvement*

More appropriate information

Help needed to accompany information that is distributed

### **4. Practical arrangements at hospital**

One participant spoke about her relative who died in hospital. He was in a 6-bedded bay which wasn't ideal for the family. There was an extremely agitated man in the next bed - he

wasn't checked for 3 hours. His son was trying to calm him as he badly needed something. "This was clearly a very difficult situation for the patient and his son - but it was difficult for us too."

"We were initially told that '2 doses of radiotherapy and you'll be all right'. But when we got there things changed - we were told that she had secondaries in her liver. We wanted to try to get her into the hospice but the doctors were very blunderbuss - they did what they could but it wasn't good enough. Dr. . . . (at the local hospice) would have done it differently. She was on a side ward for the last few hours. I was told 'go and stand in the corner while the doctor does his stuff. Then the nurse belted up the corridor and didn't say a thing to me. Hospitals can be very confusing and upsetting places and when your wife is dying that matters. I could have done with a quiet room to get my thoughts together and someone could have explained what was happening."

### *Suggestions for Improvement*

Professionals need help with the practical issues around death and help in communicating these with relatives and carers. Becoming practically involved in care is an area where carers can feel useful and can aid communication with their loved ones but carers need help to make this happen. Privacy becomes especially important and people need space to be able to be properly involved and to avoid them feeling like they have missed particularly important moments and opportunities to be involved. Privacy was raised as an issue by some participants. Side rooms connected to all wards should be mandatory to ensure privacy in situations where this is necessary. In one situation when the carer's wife died, he found the doctor could have been more sympathetic. "As soon as she passed away the nurse asked me to go and stand in the corridor while the 'doctor does his stuff."

Double appointments for patients. Make sure electronic records are available in the system. Shorter waiting times and then longer with the consultant at the time of the appointment. Could information be emailed between specialists so that follow up was immediate.

## 5. Nursing

The importance of nurse cover at night was stressed on many occasions. Many participants agreed that even in the cases where the general care was good little things and details are overlooked and the overwhelming effect when nursing staff are rushed or insensitive cannot be over emphasised at such an emotional time.

One participant spoke about her stepfather who was very ill. The participant felt that there weren't enough nursing visits. She had to ask for a review of the medication herself.

It was agreed that people expect nurses to be all things to all people, pulling together all the threads. They are supposed to be doing the hands on caring. There were comments about "very good ward nurses". But in another case "she got pain control but she was starved and dehydrated." Some particularly bad examples of care were reported. One participant told how her husband fell to the floor during the night while trying to get himself to the toilet as there was no one to assist and he was verbally abused when discovered.

### **District Nurses**

Many participants had had good experiences of district nurses. One participant commented that they were 'very reassuring' and brought 'good experience and humour' at a very difficult time. It was agreed that they play an important role.

*"I'm glad I attended this meeting. I needed this day - to talk about what happened to my brother. Today has helped me and I hope I can make a difference to what happens to some people in the NHS"*

*Suggestions for Improvement*

Nurses need more time

Nurses need more training in palliative care and care of the dying

Nurses need to be aware of the different, complex and urgent needs of the carers

*“Doctors need to talk to us from one human being to another”*

**6. Pain management**

Pain was a major concern for patients and carers. "I wanted it continuously monitored after diagnosis." "No one took responsibility for ensuring my brother's comfort, he didn't get the same level of care throughout the treatment and I didn't even receive a phone call when the end came."

At one hospital - there was not one consultant responsible for care. Pain couldn't be managed and this made the patient very anxious. Expectations need to be managed too - now consultants say: "We want to try to help you *control* your pain."

Some participants mentioned particular difficulties with agency staff not being able to manage pain. One participant spoke about how his relative was told "you never need to be in pain" and that the reality didn't bear this out. Consistency and continuity of care approach was seen to be very important and often lacking.

*Suggestions for Improvement*

Honest and realistic information and planning around pain management. Carers need help with the practical assistance they themselves can offer in this area.

*“He didn't get the 'good end' I wanted for him. I felt out of control – I didn't know what would happen when. I saw him just after death and he didn't look at peace. The undertakers made him look dignified and at peace and I then got to spend 2 hours with him. That helped.”*

**7. Co-ordination and follow-up**

Poor communication between tertiary and primary care was raised on many occasions. "The lack of co-ordination was baffling". There were various stories about a lack of co-ordination between primary and secondary care - as well as stories of patients being sent home alone in cabs after being given a terminal diagnosis or after radiotherapy treatment. There seemed to be no automatic follow-up from primary care and no follow-up into the community. "She didn't want to ask for help" . At a particularly difficult and emotional time vulnerable people had to sort out whether there was Macmillan support at home as well as organising their own medications as this service wasn't provided by the hospital. There were many stories about how long it took to arrange transport as well as stories about long trolley waits after emergency admissions.

There was a story told about a couple who were similarly ill, but in different hospitals. Many participants agreed that there was a particular and distressing lack of co-ordination in the situation where members of the same family are receiving care from different places.

People were often left "stranded" with no knowledge of when particular doctors might be returning - or if they could expect to see particular members of staff again.

Stories about lack of shared access to notes came up on a number of occasions. Vulnerable patients having to go over exhausting histories again and again and left being feeling very unsure as to whether professionals were really getting the best information, and consequently being stressed about the care they would subsequently be receiving was a commonly repeated scenario.

One participant spoke about the frustration of having to keep repeating information to different departments and people. "Doctors can only diagnose on the information they receive and treat accordingly." She was concerned that information might get lost that could adversely effect treatment.



## 2. DISCUSSION WITHIN CATEGORIES

### *Suggestions for Improvement*

Weekly meetings between all departments was suggested as were directories of services and resources. One participant mentioned the 'filofax' system that disabled people have that gives them a personal record of their treatment. There was a discussion about patients having their own notes and opinion was divided on this.

### **8. Spiritual issues**

There was clear evidence of a lack of spiritual support for patients, carers and staff. Staff also need support in talking about death and this is also lacking. People need space to think through the "what was my life about", and "what happens afterwards" questions and they need to know who and what is available to help them with these difficult questions.

"My (relative) felt that she couldn't acknowledge death and spiritual issues because she would be seen as giving up the fight and then possibly not be given any more attention from the NHS."

### *Suggestions for Improvement*

It is important that the NHS is aware of the many different faith communities and understands the different issues that arise for people from each religious group.

People need to know who they can go to for support and to unload about death and ask for spiritual help but they also need choice.

Staff as well as patients and families may need spiritual support.

### **9. After discharge**

Participants discussed what happens after discharge from hospital and a perceived lack of a professional who can take responsibility to ensure the patient is coping.

### *Suggestions for Improvement*

The current system needs to be audited and guidelines put in place.

### **10. Advocates**

On many occasions relatives spoke about a gap that might be filled by a patient advocate or a key worker - to help with co-ordination and information issues as well as practicalities such as discharge planning. This person needs to have a body of knowledge about systems and processes within the NHS but who has the people skills to help when patients and carers are at their most vulnerable and exhausted.

One participant told about an extremely inappropriate consultation when doctors and academics were excited about the type of cancer that one patient had and that the patient had to wait outside the room whilst "the bigwigs decided what to do". In all situations but especially in situations like this it would be ideal to have a patient advocate.

### *Suggestions for Improvement*

Provide advocates for patients

### **11. Going home**

Participants spoke about problems around getting relatives home to die. "Eventually she was moved to a side ward attached near casualty - a small room - for 3 days. There was some talk about arranging for her to come home but on the third day she died. We were trying to organise for her to go home to die but we couldn't organise it. She was in a tiny room - she never got out of casualty."

*"They kept leaving the food for him and the domestic staff kept clearing it away uneaten. I had told them Dad could not eat solid food but they didn't hear. Seven years later I still can't forget Dad going hungry"*

*Suggestions for Improvement*

Need for awareness raising within NHS about the importance to patients and carers of choice over the place of death

More support needed for patients and carers on discharge

*"He had to go to hospital – we couldn't get him into his hospice. All I wanted was for him to "die with dignity". – we were denied that. I just want no-one else to go through what I did."*

## **12. Carers**

All carers present at the meeting would have welcomed more help and advice - at all stages of their relative's illness, dying process and death.

All relatives would have appreciated more space to deal with their own emotional reactions and stress levels - some would have welcomed counselling.

One participant spoke about her membership of a carers support group and found them to be invaluable - practically and emotionally - she had access to a relief carer when she needed one. The group organised £400 for heating and a washing machine when the household one broke.

*Suggestions for Improvement*

A designated member of the health care team should be allocated to deal with issues of particular concern to carers.

Bereavement counselling should be offered to everyone.

## **13. Last days, dying and death**

One participant spoke movingly about his wife's last few hours. He had stayed at the hospital with her for a day and a night and he was told he should go home for a rest and that "she wouldn't know him any way" even if she awoke. He did as advised and his wife died whilst he was away. He felt very strongly that the professionals had failed him when they hadn't warned him how close to death she was. Was it their place to say so emphatically that "she wouldn't know you" anyway. Were they sure about that?

Many participants spoke about what they felt to be "unnecessary" tests while their relative was dying. "The Consultant wouldn't admit that what she had was incurable - this meant that we had some very distressing interventions - just by looking you could see she was seriously ill." "I don't think there was any need for "all those tests." "The only person who ever touched her lump was the GP - he was the first one to use the word (cancer)." It was such a relief when someone finally said, "I can see just by looking at you that you've got cancer." "One of the doctors kept on saying, "you have a mass." She had no idea what he meant and he was never able to say the word 'cancer'.

One participant spoke about her distress when her relative's body couldn't be released for several days and she was given no explanation for this.

*Suggestions for Improvement*

A realisation amongst clinicians that many service users and carers want testing to stop when it is apparent that there is no hope of a cure remaining

A realisation amongst clinicians that carers may need to be present at the moment of death - that this need is strongly felt and cannot be underestimated

## **14. After death**

Participants spoke of difficulties/confusion in dealing with undertakers and other

## 2. DISCUSSION WITHIN CATEGORIES

professionals after the death of their relative. One spoke of being presented with his wife's belongings in a grey plastic bag - this upset him. In one case there was difficulty in getting the body released which added to a carer's distress - there didn't seem to be an obvious clinical reason for this.

Some participants expressed a regret that there was no avenue for contact with any of the clinicians involved in care after the death had occurred.

One participant who had been particularly distressed by the NHS care received by her relative during his life praised the undertaker who was sensitive to her distress and allowed her to sit for two hours with her brother and who helped "make him look nice" as he hadn't previously looked "peaceful" after his death. The Undertaker allowed the carer to have photographs taken of her brother.

One participant spoke about feeling stranded after death - they had been left without instructions after death on practical issues around how to proceed.

### *Suggestions for Improvement*

Awareness raising amongst staff of the intense feelings the bereaved carers are struggling with after the death of a loved one and that every little thing clinicians do or say can have deep and far-reaching consequences.

### **15. Staff communication and attitudes**

"We had asked for a commode twice and someone watched him struggle on to it. This was thoughtless and cruel."

"He had nausea and constipation. The nurse didn't ask if medications were working."

"We felt like we were a nuisance and we found it difficult to ask questions."

A "lovely" student nurse did her best but had limited knowledge. However "her kindness went a long way."

"Another nurse was very defensive."

"Macmillan nurses came back but took a long time to get medication."

"Nobody had told the orderly who arrived with soap and water that he had died."

"No one told us what to do next."

"It's not rocket science that we're looking for -just some humanity and kindness."

### **Communication skills training with doctors**

Some doctors ask for breaking bad news training and don't get it. "In our case the doctor clearly found the situation very difficult - breaking bad news is difficult. Two people can take away very different things from a consultation." "Patients need help with understanding and interpreting consultations and they must not be rushed."

### **16. Professional support**

Participants felt that many of the professional clinicians and other staff needed help and easy to use practical guidance around caring for the dying.

"The Buckinghamshire Declaration needs to be stronger on the training given at medical school."

*"The staff are careless of the knowledge that patients and their families will naturally have questions – often quite basic in medical terms – which, when responded to promptly, will allay anxiety."*

*"I think the staff felt threatened by us questioning what they were doing but they had given her food that they had been advised she couldn't eat."*

*Suggestions for Improvement*

Constructive feedback to professionals

Using case studies and "real" people and their experiences

There needs to be more honest acknowledgement of deficiencies. Training is needed in pain control, dying with dignity, communication and spiritual support. Learning from mistakes and "near miss" meetings should be explored.

Clinicians' should have the opportunity to discuss and examine their attitudes to death and dying and how they might impact on their care of the dying

### 3. SUMMARY

THIS REPORT HAS HIGHLIGHTED some of the ways in which the NHS failed to meet the needs of a group of South London patients and carers when they were at their most vulnerable. Some fundamentally important services were lacking and, in some cases, sensitivity and humanity were also in short supply.

However, organisers of the consultation day also heard about outstanding examples of good care delivered by efficient and compassionate NHS clinicians and other professionals.

District Nurses and the Macmillan Nursing service were singled out for praise in many instances and all participants were acutely aware of the pressures that doctors, nurses and other clinicians operate under within a severely constrained NHS.

All of the issues raised in this report are repeated in "Sian's Story" which is appended to the report. It makes compelling and very moving reading. There are lessons to be learned and Sian as well as all the people who came to tell their story at St Christopher's Hospice in July 2002 hope that highlighting some of the gaps in the care the NHS provides people when they need it most might make a difference for others.

The key themes that are so powerfully reflected in Sian's story are the themes that reverberated throughout the consultation day: compassion, communication, coordination and collaboration.

*“Talk to us,  
from one human  
being to another.”  
A patient's relative.*

## 4. Appendices

**Appendix A** - Advertisement placed in St Christopher's Hospice's local newspaper  
(*The News Shopper*)

### **Care of the Dying and the NHS**

Would you like to take part in a conference on Friday 19th July 2002, at St Christopher's Hospice in Sydenham to discuss care of the dying and the NHS?

The National Council for Hospice and Specialist Palliative Care Services is currently working in partnership with the Nuffield Trust project on Care of the Dying and the NHS. This conference will be part of the project. We are inviting carers who were bereaved between July 2000 and July 2001. We hope to involve about 40 people at this conference and are seeking about 10 through this advert.

We are very interested in your story about the care received by your relative or friend within the NHS either in hospital or at home. Thoughts and recommendations that emerge from the conference will be fed back to the NHS via the Nuffield Trust project. We hope that this will have a real effect on planning care at the end of life within the NHS.

*For more information please contact Jean Levy on 020 8768 4606.*

**Appendix B** - Letter to bereaved carers

Dear

**Care of the Dying and the NHS**

I am writing to invite you to take part in a conference that is scheduled to take place on Friday 19th July 2002 at the Education Centre of St Christopher's Hospice, near Sydenham in South East London. I am the Chief Executive of the National Council for Hospice and Specialist Palliative Care Services, which is the umbrella and representative body for hospice and palliative care in England, Wales and Northern Ireland. We are an independent body with charitable status, set up in 1991 to promote the extension and improvement of palliative care services.

We are currently working in partnership with the Nuffield Trust project on Care of the Dying and the NHS. The project began with a conference held in September 2000. This brought together health professionals and others with varying experiences in and beyond the NHS, in order to generate innovative and practical ideas for improving care for patients and families at the end of life. The conference made recommendations which are included in the enclosed brief: "Care of the Dying and the NHS : The Buckinghamshire Declaration". The Nuffield Trust has now asked the National Council to organise another small conference, in order to gather stories and experiences from bereaved carers. We are inviting carers who were bereaved between July 2000 and July 2001, and St Christopher's Hospice has suggested you as someone who may be interested in taking part.

The NHS has stated that it is interested in a "patient-centred" future and we therefore hope that this conference will have a real effect on planning within the NHS around care at the end of life. Thoughts and recommendations that emerge from this conference will be fed back to the work of the Nuffield Project. This is an opportunity for you to make a real difference to policy decisions for future care of the very ill and dying in the NHS. We are very interested in your story about the care received by your relative or friend. We would like to hear about your experience and understanding of the care that was received (good and bad) in an NHS setting by you, as well as your relative or friend. By NHS we mean a hospital or NHS Community Care (e.g. GP, District Nurse).

The day will start with coffee at 10.30am, and lunch will be provided. There will be opportunities to hear other people's experiences and to relate your own. St Christopher's Education Centre has facilities for those who are disabled, and for those who are hard of hearing, and every effort will be made to make you as comfortable as possible during the day. If you require help with getting to and from the Hospice, we can help with arranging transport. The day should finish by 3.45pm.

If you would like to know more about the conference, please contact Jayne Thomas at the National Council on 020 7520 8299, who will be pleased to discuss the day in more detail. If you know of anybody else whom you believe may also be interested please do let us know. We enclose a reply slip which can be posted back in the postage paid envelope provided. Please let us know if you have any special needs by ticking the appropriate box on the reply slip.

We do understand that this may be a difficult subject for you, and I hope that this letter has not rekindled any unhappy feelings or memories for you. We hope that you will feel able to join us on this day, and that together we can make a real difference to future patient care in the NHS. We look forward to hearing from you.

Yours sincerely

Eve Richardson  
Chief Executive

## Appendix C - Sian's Story

### September 2001

#### Monday

Mum's first X-ray, scan and blood test were taken at Hospital 1 as her GP suspected something serious was wrong and requested this examination as a matter of urgency.

Nevertheless, there followed a six-day wait before the results were ready.

#### Wednesday

A tumour was discovered in Mum's neck, but further tests were needed to determine what course to take.

### October

#### Friday

The consultant was only aware of Mum's case once the results of the tests were available, and they were of such concern to him that he undertook an emergency biopsy. Lymphoma cancer was diagnosed. A morphine patch and steroids were prescribed to control pain.

#### Wednesday

A programme of radiotherapy was begun at Hospital 2. Due to the late detection of the lymphoma, the radiotherapy programme was started in haste and there was a rethink of the area of my Mum's neck that was under treatment. After 9 sessions of a prescribed 20, 4 more treatments of radiotherapy were added to the course.

### November

#### Thursday

A major emotional change took place in my Mum during the last 4 treatments. It manifested itself as a form of depression, which from the literature we had been reading was not an uncommon reaction related to the amount of radiotherapy Mum had received and the resulting loss of taste, loss of appetite and nausea. *None of the medical team made any reference to this emerging condition to any members of our family.*

#### Saturday

There was no official examination or consultation by a doctor before we left which concerned my Mum and me.

A nurse who we had never met before, and from the way she spoke had no in depth knowledge of my Mum's case, packed the numerous tablets and medication into a carrier bag when we requested them. I had to bring up the fact that Mum had been put on antibiotics for the open sores on her neck caused by the radiotherapy, as the nurse was unaware of them and had not packed them.

*No advice or check was made by the Macmillan Nurses or Oncology staff regarding Mum's home situation.* This seemed strange to us. I tried to see it in a positive light, that this was a routine treatment at its end and my Mum was fine to go home and convalesce.

*My Mum felt very bewildered and low-spirited. As we walked off the ward and out of the hospital she said to me: "Is that it, I just go, nobody sees me?"*



**Sunday**

The next day she was still eating very little and had begun a mantra of " I want to die, let me go." This was very distressing to hear. I wasn't sure if the source of it was the desperation of feeling so poorly at the end of all the treatment.

A district nurse visited us and filled out a form about Mum. The purpose of her visit was to change the dressing on Mum's neck. *We talked about the way Mum was feeling and the district nurse was very understanding and suggested some practical ways to generate an appetite.*

**Monday**

There was no improvement in appetite, strength or disposition. Another district nurse arrived to change Mum's neck dressing; the wound was healing slightly.

My sister-in-law phoned to see if we were all right and to check when we were coming. She suggested that it would be a good idea to notify Mum's GP that she had been discharged from Hospital 2 and request that he see Mum before she travelled. He did come and proposed that rather than making the journey to my brother's home, which would need us to register with the doctor there, she might benefit from a period of convalescence in the local cottage hospital, where he could monitor her medication.

Neither Mum nor I had considered the need to stay under his supervision but we recognised the potential advantage of him knowing Mum's recent medical history and she decided to stay at the cottage hospital.

*I state all this because these were very hard decisions we were thrown into making immediately Mum was discharged, yet there was no evidence of a support system, say through the Macmillan Nurses as had been suggested by staff at the hospital. Also, the only reason the GP was aware of Mum's return home was because we contacted him.*

Mum was admitted to the cottage hospital on Monday evening and for that first night seemed quite relieved. Dr Y, Mum's GP advised taking her off the antibiotics for the neck wound and reducing the dosage of morphine in the patch she was wearing to kill the tumour pain. The last instruction we'd been given regarding the drugs was to finish the course of antibiotics and keep up the morphine intake. That was from the nurse on the Oncology ward at Hospital 2 who we'd never met before but was the last person to deal with us before Mum's discharge. This conflicting advice caused alarm in us and so, my sister phoned the radiotherapy consultant to get her opinion. She had no concern about the medication being reduced, so we, with Mum, agreed to such a course. Within two days, the consultant had stopped the morphine altogether.

**Saturday**

Mum was moved from a room on her own to the ward. She was finding it very hard to socialise with other patients, which was not like her, an indication to us, her children that she was feeling very poorly. She still had no appetite, mainly a liquid diet, and very low morale, continuing to say "Let me go, I want to die" and clearly growing weaker by the day. A very real anxiety was growing within her about getting access to water. She was perpetually thirsty due to the effects of the radiotherapy and because of increasing weakness was worried that she wouldn't be able to reach the water.

Also, anxiety was growing about getting to the bathroom and managing her washing and toileting without assistance.

Because she was remaining seated or lying in bed for so long there were potential sore spots coming. A spray had been provided, but all these developments were making her very anxious.

*She sounded like she was experiencing a shortage of breath and took to exhaling rapidly with an "Oh" sound, obviously distressed and literally short of breath. At first, the staff seemed to treat this as panic and something she could overcome if she were to get motivated. But Mum's rapid decline in strength and an inability to take in solid food suggested something other than lack of motivation.*

#### **Thursday**

One and a half weeks later, Dr Y became concerned about Mum's chest sounds and suspected an infection which he thought would be dealt with better at Hospital 2, so had Mum taken there by ambulance that night.

I was very concerned to hear she had been moved without a family member there to support her. My sister had been with her during the day, but couldn't stay, and I was in London. When my sister notified me of these intentions, I phoned the Cottage Hospital straight away, around 7pm, but Mum had already been taken to the city. I drove up immediately to find her in great distress; she was lying on a slipper pan in the assessment unit awaiting examination. She was nervous about wetting the bed so had been allowed to stay on the bed pan, but was 'stuck' to it by the time the nurse came to remove it which succeeded in raising her level of anxiety and caused pain.

*Seeing as her removal from one place to another had been deemed an emergency sufficient to warrant a journey by night, I was alarmed to find that the admissions doctor had not yet examined her. This didn't happen until 11pm. He was clearly snowed under, and without the active request by me and my partner for her examination to be done, I wonder if it would have happened as soon as it did.*

*When the doctor examined Mum, he asked her questions about her lack of appetite and weakness. It became evident that he did not know she had lymphoma cancer; he did not know she had just undergone 24 treatments of radiotherapy. We pointed out that these factors must be related. He hastily checked through her notes and must have found a reference to the lymphoma then. This lack of awareness was of great concern to me.*

*“The failure to notify patients of impending treatment is very distressing for them and it is shocking to witness that this is not understood by hospital staff.”*

He brought up the subject of resuscitation in the event of Mum having heart failure, because he suspected a chest infection; he said he could hear murmurs on her lungs. I wasn't shocked that he was asking us this because Mum was obviously very poorly. The fact that he saw a potential for heart failure suggested that he recognised how ill she must feel.

I was trying to allay her fears and was getting her to settle and sleep, but a porter arrived to take her for X-ray. It was midnight. I went down to X-ray with her. The doctor never mentioned this procedure would be done in the middle of the night and it was another alarming experience for my Mum, as she had not been prepared by any of the staff. I was relieved that I was there to reassure her a little.

Eventually Mum was able to sleep and I left.

*The failure to notify patients of impending treatment is very distressing for them and it is shocking to witness that this is not understood by hospital staff.*

**Friday**

The next evening when I arrived, Mum had been admitted to Ward X where she was to die. I disliked the way the ward was run from my first encounter. I arrived at 9pm to see Mum because I had been at work in London then driven straight there. *The nurses told me visiting hours were over but I could stay for a while. They were not impolite but were not forthcoming, and their disinterest in the circumstance of my Mother being so ill upset me.* Mum had just been admitted to that ward a few hours before, critically ill, with some form of chest infection as yet unidentified. Restrictions for visiting had not been imposed on the oncology ward and this was certainly no time to introduce them. Clearly my Mother was misplaced on this ward and the rest of my account bares this out.

No one came from behind the desk area to give me any information. My Mother was stranded in a bed surrounded by her belongings still in bags. *She was concerned because they had said she had too much luggage and this was upsetting her visibly. I reassured her that I would take some of her things home and unpacked everything else. I left at 11pm, very despondent myself. No one had a supportive word to say as I went.*

**December****Saturday**

I looked at my Mother's notes to see what the Registrar Dr H had prescribed. She was being given an antibiotic for the suspected chest infection and a few things I did not understand the purpose of. For instance, there was a drip tube in her hand, which she told me she had agreed to have during the night when she felt nauseous and they recommended the medication should be administered intravenously. She was sitting in a chair, breathless and anxious. She was too weak to go to the bathroom, so the commode was being brought for her. We both felt alarmed at the lack of information and I asked for clarification about the purpose of the drip. Mum's 'named nurse' was doing something else when I asked another nurse about the drip. She said that Mum's 'named nurse' would come and explain it. She did not come, even though, after waiting some time, I asked again for the information.

Much later, a group of medical staff came to see my Mum. They were mostly trainee staff but included the 'named nurse' and what I would term a Ward Sister. *The purpose of their round seemed to be to do with educating the trainees, but as I had had no joy with accessing information so far, I took this opportunity to raise the question of the drip once more.* The Ward Sister was defensive on behalf of the 'named nurse', and the information was still withheld. *The staff are careless of the knowledge that patients and their families will naturally have questions - often quite basic in medical terms - which, when responded to promptly, will allay anxiety.* This is crucial to the patient's chance of recovery, or at least offers some peace of mind when faced with terminal illness.

Before this round of nursing staff arrived I had read the mission statement displayed on the corridor of Ward X. One of its chief claims was that the staff are committed to the support of the individual patient and their carers. The initial hours on Ward X were spent worrying: My Mother was worried about what was the matter with her now and so was I but there was no one around with any authority to give us some clear information.

*On a note of basic neglect, my Mother, along with at least one other lady in her ward was propped up in bed on those unforgiving iron supports with two thin pillows as cushioning. My request for more was denied due to lack of supplies. I pursued this further by asking for pillows at the service centre on the ground floor where the gentleman I talked to confirmed that each*

*"She was concerned because they had said she had too much luggage and this was upsetting her visibly. I reassured her that I would take some of her things home and unpacked everything else. I left at 11pm, very despondent myself. No one had a supportive word to say as I went."*

*ward had what it had and no more. I bought two new pillows for my Mum and labelled them clearly as belonging to her on advice from a nurse that otherwise they would be lost in the laundry. When she died they asked me if I would like to take them home.*

*On another note of basic neglect, my Mother was put to sit on a chair with a cushion that reeked of the urine of a previous occupant. I was shocked that I had to raise it as an issue and only when I did was a clean cushion produced.*

Mum was experiencing pain in her arm, which could have been breakthrough pain, caused by the lymphoma. She requested oramorph. More than two hours later and there was still no sign of a doctor to see her and authorise this. The ward sister, though very sympathetic, was clearly under pressure and told me that she'd notified the doctor but he was very busy.

This lack of availability of the doctor was in evidence repeatedly. One night, I overheard the doctor on call asking the nurse which patients were a priority, as the less urgent cases may not get seen at all. He did not see my Mum that night and yet she died less than two weeks later. I felt then as I do now that her condition required treatment of the utmost urgency and I remain sceptical as to whether her case was dealt with swiftly enough at this point.

### **Sunday**

My brother and I spent the day with my Mum. She was suffering with low oxygen levels and a nebuliser had been administered with intermittent oxygen. Also, an airbed was brought for her as she was developing bedsores. This was much appreciated, but a pantomime surrounded the instalment of the bed which would have been funny had we not been sitting with our direly sick Mother. Basically, the bed was faulty and kept halting its inflation and when it did so it would begin to beep. By way of alerting staff that there is a malfunction, the beeps get higher in tone. Mum was already distressed and now she had to endure a tortuous sound 3 feet away, a totally unnecessary irritant. Other ladies in the ward were disturbed by the sound as well, since no one returned to the bed in any haste and when they did, refused to accept it was faulty and re-set it. Eventually it was understood that the bed was broken. Positive action was taken to hire a new bed but by now my Mum was very tired and needed to lie down. We requested that they put back the original bed for the time being. This was done.

This 'aural torture' comes in other forms. When the drip bag is nearly empty a warning beep starts. Normally, this would be a good system, providing a swift response to changing the bag but in Ward X no one comes swiftly; no one comes for periods as long as 30 minutes. I timed one of these episodes and it was only rectified by my personal request. It is impossible for a sick person to rest through that noise. It also appears to the patient that no one is concerned about them and they grow more vulnerable.

I was aware that the consultants do their rounds on Mondays, and I knew my sister would be at the hospital on Monday morning and could speak to them. I wrote a letter to Dr X - the lymphoma specialist who had dealt with Mum during her radiotherapy - notifying her of the down turn in Mum's health. It seemed to us that her knowledge of Mum's case might be crucial in aiding a recovery, but we felt that if we didn't draw her attention to it she would be none the wiser. In the letter I requested that she see my sister and took it to the oncology wing and asked one of the nurses for help. How could I ensure that Dr X would get this letter in the morning? *In one of the few acts of compassion shown us, the nurse took me to the offices, which are closed at the weekend, and I was able to put the letter on Dr X's secretary's desk.*

**Monday**

My sister was able to see Dr X and I believe from that point, things were acted upon in more earnest. For a start, Dr X visited my Mum, which I do not believe would have happened if not for my family's intervention. This gave Mum some assurance that the hospital at last remembered she had been a cancer patient there only two weeks before. Until this point, she had been asking: "Why has Dr X not been to see me? She might be able to help me." *This vital need for continuity of consultation was entirely overlooked by this hospital. Had we understood the laxity of communication between departments and indeed between hospital and aftercare services, we would have forced this pace much earlier.*

The combined visit from Dr X and the ward consultant Dr Y meant that Mum received adequate pain control; but this was Monday, she had been in agony since Saturday. I realised something alarming at this point; this hospital has 'a weekend'. There were no doctors with sufficient knowledge of the patient's condition and an extreme shortage of nursing staff at weekends. *I found it astounding and cannot fathom how they allow all staff with the necessary expertise to take off Saturday and Sunday as though suffering human beings can be put 'on hold' like machines.* It means that very sick people who are admitted on Friday must try and survive until Monday for a thorough consultation. This is what happened to my Mother. This is an unacceptable situation.

**Wednesday**

My sister and I were with Mum. Her distress was very apparent. She was concerned about troubling the nurses for a bedpan and also worried that she was going to wet the bed. In retrospect I can see that this may have been the onset of kidney failure, but nobody mentioned this to us or explained whether anything was being done to treat it if it was. Why not? From the start of Mum's treatment in October, we had made clear our desire to be kept fully informed of all medical matters concerning my Mum. *She had requested that we were told everything the doctors knew so that we could help her to understand, since the stress of being ill made her unsure as to whether she had grasped all the information.* We found this very difficult to achieve as interviews with the consultants were limited to Mondays and no one else on the ward ever had the full picture of the situation.

However, it seemed that my Mother had reached a critical stage sufficient to warrant a meeting with Dr Y on a Wednesday. He invited me into an office with a ward sister and prepared me for the possibility of Mum dying of heart failure, as he was concerned that there was no sign of improvement in her chest infection. He thought she was too poorly to undergo a CT Scan which might tell them more about what was causing the infection and allow them to treat it more effectively. *Clearly, the members of staff with knowledge were trying to do their best to save my Mum's life — when they were there.*

*I feel justified in thinking that everybody's sick relative deserves efforts around the clock, if not to cure them, to care for them. The 'caring' side did not seem possible in this ward. For whatever reason, nurses rarely came to the bedside solely to soothe and comfort. They came to take blood pressure, give medicine, answer a patient's buzzer, or deliver food. During the course of Mum's 15 days -360 hours - in Ward X I was present for 180 hours. That includes 5 occasions when I stayed through the night. I feel I am in a position to speak about what I saw as a tragic state of affairs in my Mum's wing of Ward X over those 15 days.*

*My ideal for trained nursing care of a life threateningly sick person is not out of the question. I just wanted my Mum to be shown compassion and cherished as a human being that was suffering pain and terribly frightened by the prospect of the outcome.*

The occasions that I felt the hospital staff demonstrated compassion are so few that it upsets me to recall them. Once there was confirmation from the consultant that my Mum was likely to die from this infection, there was certainly a more gentle approach with the administering of drips and bedpans, but not a distinctive enough shift for my standards, which are no higher than is required for human decency.

It was because of these feelings that I talked to Dr Y about my desire to remove Mum from the ward to a more sensitive and more appropriate environment for someone so sick. His advice was that she should stay in the ward as they were still trying to find a breakthrough with the antibiotics they were using to overcome the infection. I went along with this guidance although I regret it because I think she should have been somewhere where she felt surrounded by people who cared about her. She knew that I felt that way but she also sensed the lack of care from the staff. *The hospital will feel a need to argue this point. I'm telling you how a dying person described her feelings to me.*

*"The hospital will feel a need to argue this point. I'm telling you how a dying person described her feelings to me."*

I do not think that Dr Y was wrong to advise me this way, I think it is wrong that time was unavailable to him to appreciate the circumstances and provide alternatives which might have combined the treatment with care.

For example, by the weekend, I was so distraught about Mum's situation that I contacted the private hospitals in the city, desperate to find a way to get her the attention I felt was necessary. One was an answer-machine response, the other was answered by a member of staff who advised me that in a case like my Mother who is already being treated for cancer and now experiencing complications, we would have to get the consent of the consultants from Hospital 2 to pass her case over, as none of them were registered with the private hospital concerned. *I felt impotent, with no option but to try and compensate for the hostile environment my Mother felt herself to be in, with our family's devotion.*

As Mum was so fretful that day, I stayed with her throughout the night. I dozed when she managed to, but her sleep was fitful and she woke constantly with a raging thirst. By now she needed oxygen almost continuously and great distress was caused by her need to remove the oxygen mask in order to drink. *She panicked about the supply of water, because she needed the cup refilling frequently and didn't have the strength to reach and lift the jug, remove the cup lid or pour. I reassured her that she only had to press the buzzer and a nurse would come to help. She said: "They don't always come, they can't they're too busy." I still reassured her, but to my horror, I found several times when she buzzed in my presence, 10 to 15 minutes would elapse before anyone was able to attend. This commonly happened at night when there was a minimum of staff on duty.*

*I observed the buzzer system failing in its job in respect of other patients too. One lady was put to sit in her chair on the other side of the bed from the buzzer and as she couldn't walk without assistance, it was impossible for her to use it at all. The whole idea of the buzzer as an aid for elderly patients is suspect. Several ladies I talked to did not understand how it could be used and it needed explaining to them carefully. Given the age and possible confusion of being in unfamiliar surroundings, it is possible that even with careful explanation, the patients may still have difficulty understanding this system which is all the more reason why nursing staff should be giving regular bedside attention.*

I had agreed with Dr Y who raised the matter, that Mum would not respond to more invasive treatment, but I did feel she needed constant care, where someone with a degree of medical knowledge would be in attendance at regular intervals over and above the times when she made a direct request.

#### Thursday

Mum's named nurse told me that Mum must have Nil by Mouth, as she was to have a scan that morning. I was thrown into confusion as in the meeting on Wednesday, Dr Y had stated that Mum was too ill to have a scan. Had she improved? Had his opinion changed? The nurse went away to check and returned saying that she could eat, she was not having a scan as she was having an X-ray to compare with a previous X-ray. *The reason I am writing about this incident is not to criticise the nurse concerned, but to criticise the structure where a ward is run in such an incompetent way that the named nurse is unclear as to what is happening with her patient. She was so unclear that she was contradicting the consultant. If I knew what he had said the day before, why had the information not filtered through to the person who has the authority to administer dangerous drugs?*

My sister was with us and we were so concerned for my Mum and feeling so powerless to help, we decided to go and talk to a Macmillan nurse. When we got to that department at 12.30pm there was no one available to talk to until 3pm. Time with Mum was precious and we'd come at this moment because she was sleeping which we knew would be brief. *We really needed the support of the Macmillan nurses that day but found it inaccessible. When they visited Mum during that period they certainly gave good support but the visits were sporadic, were not followed through at the point of discharge and were not automatically re-established when Mum was readmitted. At a crucial point for the family carers, there was no one to talk to. Why? Again I found the infrastructure of the hospital to be weak and ineffective.*

The nurses on the ward were far too busy to confide in. I acknowledge that the Ward Sister who sat in on my meeting with Dr Y was always supportive when she was on duty. However, she went on leave at the end of the week, so I'll never know whether she would have made a difference to the way I feel about how my Mum was treated. *In any case, I don't think Mum's experience should have rested with an isolated demonstration of compassion.*

#### Friday

Dr Y decided that Mum would be OK to have the scan this day. My sister and I accompanied her and knowing how much she relied on regular sips of water, we took two cupfuls with us. As Mum was being taken in for the scan we asked the technician if she was allowed water in there. The technician, not knowing we had brought some with us, informed us that there was no drinking water available in this area. *We were relieved that we had thought of providing it and dismayed to think that no one working on Ward X would have.*

After the scan, we waited 30 minutes before a porter was available to come and take Mum back to the ward. This might be less than the average accepted by hospital policy makers, but I was looking at a person who was seriously ill, lying on a trolley on a corridor on an oxygen supply that was not humidified so that her desperate feeling of thirst was exacerbated. I think any humane policy maker would find this an unacceptable length of time.

At the last meeting Dr Y held with our family he once again explained the risk of Mum's heart failing and suggested that resuscitation and intensive care would not be advised by him. We agreed with this, knowing that Mum's feeling was that she did not want to be resuscitated.

*"I don't write to criticise the nurse concerned, but to criticise the structure where a ward is run in such an incompetent way that the named nurse is unclear as to what is happening with her patient. She was so unclear that she was contradicting the consultant."*

These issues were dealt with thoroughly: We understood that Mum was gravely ill. Being so aware of this made us all the more concerned about the atmosphere in the ward. My sister voiced our feelings of dissatisfaction and anxiety about the lack of care being provided for one so ill through the nursing structure. Dr Y was defensive on behalf of the nurses. He told us he ought not to be brought into this debate, that if we had a specific complaint, we should deal direct with those concerned.

He asked us if we wanted him to arrange a meeting right then with the Sister on duty. We said yes, but the meeting never happened. *As our priority was our Mother we didn't pursue the reasons for the nurse failing to meet with us. In fact, it only confirmed for us the miserably weak line of communication between the hospital and family carers of patients.* If the consultant and registrar will not take responsibility for inadequacies within their team, who will? Surely the link between doctor and nurse is paramount? *As far as the patient is concerned, the nurse has a vital role in providing practical application of the doctors prescription and one would expect this to be accompanied by reassurance and words and actions of comfort.*

One of the glaring problems with the staff structure on Ward X was the paucity of expertise available on any one shift. In my days spent on the ward, the Ward Sister was stretched to the limit. She could only spend brief time with my Mum. I was aware that she had experience and medical knowledge that allowed her to explain what was happening to my Mum. None of the other nursing staff had this capacity, including the named nurse. *It was no wonder that a sense of doom crept over our family, including my Mother, when we were constantly met with: 'I couldn't tell you, you'll have to ask the doctor about that' But the doctor is seldom available.*

### **Sunday**

My Mother was a little calmer in the morning, but very uncommunicative, having to put all her energy into breathing. When the auxiliary nurse arrived she opened the curtains: Bright light poured in and within a few minutes the lady in the bed beside the window felt nauseous. (She suffered with some kind of eye condition where sudden light affected her adversely. Unfortunately this information had not reached the attention of this member of staff, although I, as a mere visitor was aware of it) This account may seem unnecessarily pedantic and not relevant to my Mum. I think it is essential to present the details of all the failings I witnessed in Ward X in order to analyse why nursing staff are so ill informed about the patients in their care. I hope then that someone who is earnest about improving the situation will do something to rectify it.

Opening the curtain might be considered a mistake but what that nurse did next was misconduct. The lady felt sick and asked for something to vomit into. The nurse took a cardboard kidney dish and threw it on the bed, told the woman to use that and left the room. The patient was frail and was having difficulty propping herself up in order to vomit. In the absence of any hospital staff I went to assist her. It only took a few seconds to support her back with pillows and place the dish within reach. I gave her some tissues which were beside her bed but out of reach and I stood beside her for a while to offer comfort. Seeing this treatment of a patient by a member of staff made me even more concerned for my Mother's welfare, considering that by this stage she could not sit up without aid. *Apart from the practical matter of helping a patient function physically I consider what I witnessed to amount to cruelty.*

I stayed with my Mum all day and through to late evening. She had slept a lot during the day



and felt stronger for it. I decided to leave her that night, as I felt I needed to get some recuperative sleep. Her supply of water concerned me. I left an adequate supply at her bedside with a note to the night staff alerting them to the fact that Mum had a great need for water, so please ensure that it was within reach. (*Apparently on nights when I did not stay the bedside table would be moved out of the way when routine checks were being conducted and not replaced.*) There was no system in operation for informing the change of staff of such important needs.

### **Monday and Tuesday**

My sister was with my mother for these two days. Although Mum was sitting up in a chair, she was extremely weak and barely eating.

For all of her time in this ward she had needed assistance to use the toilet. At first it was the commode, soon after the slipper pan, then the staff used a hoist to allow her to sit on the commode again. From the first day, Mum made it clear that whenever her daughters were there, she wanted them with her at all times. She told us that it comforted her to have us with her for the manoeuvring necessary with these toileting appliances. However, this request was never noted and passed on to the different shifts of nursing staff. Consequently we had to go through a traumatic process of explaining her wishes to a nurse who was insisting we left. Maximum distress was caused to my Mother over this sensitive matter. Again I refer you to the ward mission statement, which implies that the individual needs of patients and patients' family carers are of paramount importance to the nursing staff.

*In fact, this absence of sensitivity was taken to a ghastly extreme over this period. My sister - having been sent out during the toileting procedure - remained right on the other side of the dividing curtain and heard the nurse in attendance say to my Mum: "A please and thank you would be nice." This is not appropriate talk. Sarcasm or chivvying along someone who has a life threatening illness is not the right method of care.*

### **Wednesday**

Mum had had a very bad night according to the staff on duty. Someone had alerted my brother just before 8am. He in turn contacted my sister and me. We all went straight to the hospital. Mum's breathing had become very painful. The doctors suggested trying a different type of antibiotic, but were clear in explaining that it looked very likely that Mum would die. *They felt it was better that she went into a side room. I felt that the calm of a private room would have benefited her much earlier, as I have already noted.*

We began a vigil. Mum was wracked with anxiety, distress and awareness that she was likely to die. We held her hand continuously to soothe her and gave her water through a syringe as she was permanently parched. She hardly referred to us again. All her mammoth energy was going into surviving storms of breathlessness.

### **Thursday**

Mum survived the night and naturally, a hope crept in that the tide would turn and the new antibiotic would take effect.

Then followed a chain of actions of unbelievable incompetence by nursing staff.

The water canister that bubbles away to humidify the oxygen was virtually empty. We requested it be replaced as soon as possible. An auxiliary nurse acting with a trainee nurse brought the replacement. She started to disconnect the oxygen feeding my Mum. We tried to

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intercept her, explaining that Mum could not be without oxygen assisted breathing. She told us it would only take a few seconds to change and proceeded. We requested that she first bring a substitute portable oxygen supply to cover the switchover, but she proceeded with the disconnection. The oxygen supply stopped and within a few seconds Mum's breathing became gasping. At this point the trainee nurse revealed that he did not know how to remove the top of the water bottle. Now we were very anxious and instructed the nurse to connect the oxygen without the humidifier. Something broke on the tube she was trying to connect, so Mum still had no oxygen at all. I could be forgiven for panicking. Actually I didn't, I acted quickly and rushed into the corridor and called to one of the nurses to bring oxygen as there was an emergency. The head nurse rushed in with a large canister, tried to turn it on and found it was empty or faulty, whichever, there was still no oxygen and now my Mum had stopped breathing. The auxiliary nurse suddenly connected the 'wall oxygen' and we rushed it to Mum. It got her breathing again. *Later on the staff involved reported to the registrar that I was hysterical. The registrar spoke to my partner who was present at the incident, and suggested that I didn't understand that the oxygen was the only thing keeping my Mum going. My partner explained that on the contrary, I was fully aware, but had not wished to see Mum dying through the incompetence of staff failing to deal with the routine changing of oxygen, and quite rightly had called for emergency help.*

Doctors came and went through the day and night. One doctor refused to let us stay in the room with Mum while he listened to her chest. As a result he came over as very arrogant and insensitive. *This was our Mother who was clearly dying; we had been with her without a break for 36 hours, and nothing he was going to hear through his stethoscope was going to save her; yet he behaved as though his function as pulse and temperature monitor took priority over our support and tenderness.*

We acquiesced to his demand that we leave, but stood on the other side of the door, to make sure his insensitivity was not transferred to my Mother. That is how much confidence and trust we had in the system by then.

*In stark contrast, another doctor came in during the night and exuded the compassion I had so longed to see in other staff. He indicated that we should stay and was positively tender towards Mum. I wondered why he was one of the few.*

*The night shift nurses seemed unaware that this noble woman was breathing her last and persisted in taking blood pressure and giving injections. It was a macabre, laughable, misplaced efficiency and a lack of communication on a grand scale. We requested that they discontinue these treatments.*

#### **Friday**

Mum's waves of survival continued until 8.50 am when she died. *The nurse who attended her body was very sensitive and was extremely co-operative in allowing us to assist in bathing Mum's body. She helped to make it a dignified ritual as was befitting.*

In conclusion: We will never know whether the delay in first examining my Mother and the delay in administering treatment, or the excessive radiotherapy contributed to her death. But what we do know and experienced was the failure of the hospital to look after her properly and sensitively at a time when she most needed it.

“This was our Mother who was clearly dying; we had been with her without break for 36 hours, and nothing he was going to hear through his stethoscope was going to save her; yet he behaved as though his function as pulse and temperature monitor took priority over our support and tenderness.”



