



'Now I feel tall'

What a patient-led NHS feels like

December 2005

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What a patient-led NHS feels like

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Foreword

By Sir Nigel Crisp
Permanent Secretary and NHS Chief Executive

Creating a patient-led NHS sets out our commitment over the next few years to change our relationship with patients and the public, to move from a National Health Service that does things *to* and *for* its patients to one which is patient-led, where the service works *with* patients to support them with their health needs.

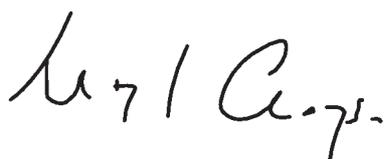
To create a health service that is truly patient-led and genuinely responds to patients, their families and carers, NHS organisations need to have a better understanding of what matters to patients.

Patients often come into contact with the NHS when they are at their most vulnerable. Research and feedback shows that patients' emotions and their negative feelings are heightened at these times. We want patients to have good, positive experiences and to feel valued and cared for throughout their time with us.

To do this, we need to have a better understanding of when and how the NHS can improve how patients feel about their experience of the NHS. 'Now I feel tall' shows how a number of NHS organisations have listened and responded to patients, how they have changed the way they deliver services and how patients feel about the improved service they are receiving. Our aim is that every patient should 'feel tall' when they are cared for by the NHS.

I strongly encourage all NHS organisations to take a close look at how they deliver their services and to ask their patients if their emotional needs are being met as well as their physical ones. They should ask patients if they are:

- getting good treatment in a comfortable, caring and safe environment, delivered in a calm and reassuring way;
- having information to make choices, to feel confident and feel in control;
- being talked to and listened to as an equal; and
- being treated with honesty, respect and dignity.



Sir Nigel Crisp
NHS Chief Executive
November 2005



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"I really, really appreciated them because they were the medical staff. I could say to them, Look I've got an extra pain here or there, is it all right, can I still carry on doing A, B or C?. They would say, "Well let's test your blood pressure", and often it was sky high, we would laugh about it. In the end, I really didn't have any worries."

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"The EPP course has taught me ways of improving my lifestyle. I feel in control again, I am less dependent on others, more confident and fitter. I no longer make frequent visits to my doctor and I have learnt how to control my pain without the use of drugs."

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"Emotionally, you are outside your own body. My emotions were all over the place and I began to think, I'm losing track of this. I spoke to my son and daughter and we tried to piece things together and wrote things down. After this I started to do it on my own and kept a diary."

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Part 1: Introduction

This document is for chief executives, directors and all staff who deliver the National Health Service. It aims to make the NHS more aware of the importance of improving patients' emotional experience and the relevance of this to creating a patient-led NHS.

As well as the drivers identified in this document for improving patients' emotional experience, NHS organisations may have their own specific drivers and schemes. This document shows that improving a patient's emotional experience is not difficult to do but, 'Becoming truly patient-led will require more than just changes in systems. There need to be changes in how the system works and how people behave, and a culture where everything is measured by its impact on patients and the benefits to people's health.' Creating a Patient-led NHS

Changes are beginning to happen. One example of a hospital that has made patient-led changes is South Manchester University Hospitals. It worked with the PALS and Manchester People First to improve access to the hospital for people with learning difficulties. Following these changes, a person with learning difficulties said, "I'm only small, but now I feel tall" (for the full story and other examples see part 3).

Not all patients 'feel tall' and their emotional needs are not always a high priority for the NHS. Current activity mostly relates to achieving the **Public Service Agreement** (PSA) and policy work tends to focus on the practical and physical aspects of patient care. There is relatively little understanding about patients' emotional responses to their experiences, and little attention is paid to the expectations of patients at an emotional level.

What do we mean by a patient's emotional experience? This is about how a patient feels about their experience of using the NHS and what they value. For example, a patient kept waiting for an appointment in an outpatient clinic may have a good emotional experience if they feel someone cares about them (that is, they are given regular information about why they are being kept waiting and an update on how long they will have to wait). The same patient left to wait without any information is likely to have a negative experience because they feel abandoned and neglected. Improving patients' emotional experience is about treating people as we would want to be treated – with dignity and respect.

Defining the emotional experience of patients

As part of the national consultation Choice, Responsiveness and Equity, the Department of Health carried out a piece of research to explore the emotional experience of patients. It collected views of recent patients, the public and NHS staff through a series of workshops, focus groups and face-to-face interviews.



Patients and the public said that they tend to come into contact with the NHS when they are at their most vulnerable and emotional, which makes their emotions, and particularly their negative feelings, stronger. They continually referred to feeling 'emotional', and there was a strong feeling that the NHS did not always meet these emotional needs. People had different opinions and experiences, but there were some consistent themes in terms of typical positive and negative feelings.

The most commonly identified negative feelings were confusion, disappointment, annoyance and frustration. The main causes were poor communication, long waiting times, patronising staff attitudes and feeling lost in the system. Most patients felt isolated, overwhelmed by the experience and treated like a number instead of an individual. Numerous people in the study mentioned feeling scared, afraid or anxious. They often said they thought these feelings were linked to their situation and medical condition, but some felt that they were made worse by their NHS care (particularly care in hospitals).

People involved in the research shared the same opinions about what a positive patient experience at an emotional level should feel like. They said patients want to feel reassured, confident, cared for, informed, safe and relaxed. Being reassured was particularly important, they wished to feel safe and 'in good hands'. Central to an ideal experience was feeling that they are important and 'special'.

Staff descriptions of the ideal situation for patients were very similar to those described by patients themselves. They appear to be aware of how patients are feeling but are limited by time, resources and the culture of the NHS itself, to create a more positive emotional experience.

When asked for suggestions on how the ideal emotional experience may be achieved, many people were cynical about this and felt it was unlikely to be achieved but gave numerous practical suggestions on the way forward. These were based on how patients are communicated with (in terms of both quality and quantity of information) and changes to the environment (particularly waiting rooms).

The final report on the results from the research, carried out by Opinion Leader Research (OLR), says that:

'An alternative way of portraying the ideal emotional experience is separating those emotions that participants would like to feel as they go through the process and a secondary layer – those that they would like to feel as a result of their experiences. Some key emotions do cut across both.'

Feelings during the patient journey

Reassured
Respected
Cared for
Listened to
In control
Safe



Feelings resulting from patient experience

Satisfied
Relieved
Cared for
Confident (in treatment and in the NHS as a whole)
Pride

The findings were quite clear – the quality of a patient's emotional experience was a major factor in their overall satisfaction with the NHS. Building on the Best, the report on the Choice consultation, included a 'patient experience definition' that covered the main parts of a good patient experience, as defined by the people involved in the research.

(For the full OLR report, e-mail enquiries@opinionleader.co.uk)

The patient experience definition

'We want an NHS that meets not only our physical needs but our emotional ones too. This means:

- getting good treatment in a comfortable, caring and safe environment, delivered in a calm and reassuring way
(see the examples in part 3, from Dorset County Hospital, Royal Brompton Hospital and West Dorset General Hospitals NHS Trust);
- having information to make choices, to feel confident and to feel in control
(see the examples from Greater Manchester and Cheshire Cardiac Network, North and East Cornwall Primary Care Trust, Royal Berkshire Hospital, Royal Brompton and Harefield NHS Trust and South East London Cancer Network);
- being talked to and listened to as an equal
(see the examples from Central Manchester and Manchester Children's Hospitals, Dorset and Somerset Coronary Heart Disease Collaborative, The Modernisation Agency, PALS and Manchester People First, South Manchester University Hospitals and St James's Hospital, Leeds); and

- being treated with honesty, respect and dignity' (see the examples from East Devon Primary Care Trust, East Sussex Hospitals NHS Trust, Ellesmere Port and Neston Primary Care Trust, and Halton Primary Care Trust, Newcastle, North Tyneside and Northumberland Mental Health NHS Trust and York Hospitals NHS Trust).

This document contains some positive and inspiring examples, but the NHS is not always delivering the experiences patients say they want. So it is important that PCTs and NHS trusts are aware of the importance that patients place on a good emotional experience and the effect this may have on meeting the PSA targets and the core standards (see part 2).

The main drivers for improving patients' emotional experience

The NHS Plan, published in 2000, reinforced the importance of 'getting the basics right' and of improving patients' experience of the NHS.

Essence of Care, launched in February 2001 by the Modernisation Agency, provides a tool to help practitioners (any healthcare employee delivering direct patient care) take a patient-focused and structured approach to sharing and comparing practice. Patients, carers and professionals worked together to agree and describe good-quality care and best practice. This resulted in benchmarks (a process of comparing, sharing and developing practice in order to achieve and sustain best practice) covering eight areas of care. In July 2002, further work was done on these that focused on communication between patients, carers and healthcare staff.

The Essence of Care toolkit includes:

- an overall patient-focused outcome that shows what patients and carers want from care in a particular area of practice; and
- a number of factors that need to be considered to achieve the overall patient-focused outcome.

The NHS Improvement Plan, published in June 2004, set out the way in which the NHS needs to change to become truly patient-led. It says that the next stage in the NHS's journey is:

'to ensure that a drive for responsive, convenient and personalised services takes root across the whole NHS and for all patients. For hospital services, this means that there will be a lot more choice for patients about how, when and where they are treated and much better information to support that.'



It also says that:

'From the end of 2005, patients will have the right to choose from at least four to five different healthcare providers, and the right to choose from any provider as long as they meet clear NHS standards.'

The growing importance of 'patient choice' means that there has to be a better understanding of what makes a good emotional experience for patients, as well as greater flexibility and growth in the way services are provided. In the future, resources will be given to those hospitals and healthcare providers that are able to give patients what they want.

'There will be incentives for healthcare providers to offer care that is efficient, responsive, of a high standard and respects people's dignity.'

'**Creating a Patient-led NHS**', published in March 2005, sets out the major themes for delivering a patient-led NHS. It outlines how the NHS will need to change and what services will look like.

- Every aspect of the new system is designed to create a service which is patient-led, where:
- people have a far greater range of choices and of information and help to make choices;
 - there are stronger standards and safeguards for patients; and
 - NHS organisations are better at understanding patients and their needs, use new and different methodologies to do so and have better and more regular sources of information about preferences and satisfaction.

Extract from 'Creating a Patient-led NHS'



Where this happens, everyone involved makes sure they:

- respect people for their knowledge and understanding of their own experiences, their own clinical condition, their experience of the illness and how it impacts on their life;
- provide people with the information and choices that allow them to feel in control;
- treat people as human beings and as individuals, not just people to be processed;
- ensure people feel valued by the health service and are treated with respect, dignity and compassion;
- understand that the best judge of their experience is the individual.

Patients who are treated considerately, who are not left to endure anxiety and worry, who are treated attentively, who are given full and prompt information, who understand what they are being told and who are given the opportunity to ask questions, are more likely to have better clinical outcomes. A good patient experience goes with good clinical care – and patients need both.

Extracts from 'Creating a Patient-led NHS'

The national patient survey programme (see page 16) and other social research shows that patients are telling us they expect more from the NHS on getting the basics right and that they want a positive emotional experience. NHS trusts and other healthcare providers will need to have a better understanding of what matters to patients, what makes them feel good about their experiences, how to improve patients' emotional experience, and how this is measured in the Public Service Agreement (PSA) (see part 2).

The Healthcare Commission now manages the patient surveys. These focus on issues that patients say are important to them and provide information on how the NHS can improve the quality of care it provides. The assessment of the patient experience is based on the five areas (dimensions) that patients have identified as being of the greatest importance.

The five dimensions of the patient experience

Access and waiting

The extent to which patients are able to reach required services and treatments when needed and get around within them. This includes waiting times; patients' ability to find out about, get referred to and physically get to services; accessibility for diverse populations, and the range of services provided. How people are kept informed while they were waiting, and the amount of notice given for admissions/elective care and changes to admission dates, are also included here.

Safe, high-quality, co-ordinated care

This is about assuring patients of technical safety and minimum standards. It also assuring the quality of staff through training, longer consultations and demonstrating the ability to work in a co-ordinated way. The extent to which users move smoothly between the necessary service providers throughout their health care journey are also taken into account. This encompasses the co-ordination and integration of care, appropriate education for and communication between professionals, and the quality of health care transition and continuity.

Better information, more choice

This is about giving individuals (and communities) more quality information about services in their area, about their diagnosis and their options for treatment, so that they are supported to make informed choices. It is about asking patients about their experiences with services and letting them know how their feedback will be used to make improvements (accountability).

Building closer relationships

This covers issues around the interpersonal skills of medical staff in relation to patients and their family. It is about communicating effectively with patients before, during and after care, and taking into account their individual and social needs, values and preferences. Customer care and courtesy is included here.

Clean, comfortable, friendly environment

This is about providing an environment where patients feel cared-for and cared-about from the moment they arrive at an NHS provider. It is about the physical environment and the message it gives, the facilities management services (e.g. cleaning, food and linen) and the messages they give; and the people who lead and deliver services and the culture they promote. The extent to which the physical setting within which care is delivered is safe, comfortable and appropriate to both the clinical needs and the client group, and issues around privacy for discussion, examination and treatment, mixed-sex facilities and whether patients are treated with dignity and respect.

Part 2: Why improving the emotional experience of patients matters

The Healthcare Commission – getting the basics right

Over the next few years, the Healthcare Commission will be changing the process for assessing health services to promote and drive improvements. It wants to know:

- what **matters most** to patients, carers and the public;
- what **makes people feel** that a healthcare organisation is well run;
- what patients would expect to see in an organisation that really puts them first;
- how **patients will feel** if they are really participating in their care and treatment; and
- what **makes patients feel** that the organisation they are treated in is well designed and maintained.

Each year, the Healthcare Commission will ask every trust to look at its own performance, and assess the extent to which it is getting the basics right. This is the new health service annual health check. There will be four components to this, one of which will require trusts to make public declarations on how far their organisation meets the core standards. The declarations will include the views of patients and other partners in the local health community. The Healthcare Commission will check them against other available information and follow up where there are concerns.

The theme running through the basic requirements is how **patients feel** – these feelings relate to their experiences of the NHS which is why improving them is so important.

Standards for better health – compliance with core standard 13

The Department of Health's 'National standards, local action' sets out a common set of requirements to make sure that all healthcare organisations 'drive up standards by identifying areas for improvement' in relation to the safety and quality of services. The Healthcare Commission believes these standards are the basics that all trusts should be achieving. The assessment will show how far NHS organisations are in fact doing this. The Commission expects most NHS organisations to be meeting the basics, or to have plans in place to make sure that they soon will.

The Commission intends that the declaration on the core standards should become part of the local accountability of trusts and should provide a mark by which to measure current performance.

To make the declaration, trust boards will need to have systems to assure their compliance with the core standards. On the basis of the trust's own declaration and the Commission's subsequent checks, it will classify the trust's compliance.

The core and developmental standards for the NHS (see page 14 and 15) are set out in seven domains – the fourth of which is patient focus. The expected outcome of this domain is that health care is provided in partnership with patients and their carers and relatives, respecting their diverse needs, preferences and choices, and in partnership with other organisations (especially social-care organisations) whose services impact on patients' wellbeing.

Core standard 13a) requires healthcare organisations to have systems in place to make sure that staff treat patients, their relatives and carers with dignity and respect. Elements of the standard which trusts are expected to show compliance with are:

- that the healthcare organisation has taken steps to ensure patients, carers and their relatives are treated with dignity and respect;
- and, the healthcare organisation monitors its performance with regard to treating patients and carers with dignity and respect.

Development standard D8 within the patient focus domain is:

Health care organisations continuously improve the patient experience, based on the feedback of patients, carers and relatives.

The core standards relating to improving patients' emotional experience

Safety	Governance	Patient focus (working in partnership)	Accessible and responsive care	Care environment and facilities
<p>C1 Healthcare organisations protect patients through systems that:</p> <ul style="list-style-type: none"> a identify and learn from all patient-safety incidents and other reportable incidents, and make improvements in practice based on local and national experience and information derived from analysis of incidents. 	<p>C8 Healthcare organisations support their staff through:</p> <ul style="list-style-type: none"> a having access to processes which permit them to raise, in confidence and without prejudicing their position, concerns over any aspect of service delivery, treatment or management that they consider to have a detrimental effect on patient care or on service delivery b organisational and personal development programmes which recognise the contribution and value of staff, and address, where appropriate, under-representation of minority groups. 	<p>C13 Healthcare organisations have systems to ensure that:</p> <ul style="list-style-type: none"> a staff treat patients, their relatives and carers with respect and dignity b appropriate consent is obtained when required, for all contacts with patients and for the use of any confidential patient information c staff treat patient information confidentially, except where authorised by legislation to the contrary. <p>C14 Healthcare organisations have systems in place to ensure that patients, their relatives and carers:</p> <ul style="list-style-type: none"> a have suitable and accessible information about, and clear access to, procedures to register formal complaints and feedback on the quality of services b are not discriminated against when complaints are made c are assured that organisations act appropriately on any concerns and, where appropriate, make changes to ensure improvements in service delivery. 	<p>C17 The views of patients, their carers and others are sought and taken into account in designing, planning, delivering and improving healthcare services.</p> <p>C18 Healthcare organisations enable all members of the population to access services equally and offer choice in access to services and treatment equitably.</p> <p>C19 Healthcare organisations ensure that patients with emergency health needs are able to access care promptly and within nationally agreed timescales, and all patients are able to access services within national expectations on access to services.</p>	<p>C20 Healthcare services are provided in environments which promote effective care and optimise health outcomes by being:</p> <ul style="list-style-type: none"> a a safe and secure environment which protects patients, staff, visitors and their property and the physical assets of the organisation b supportive of patient privacy and confidentiality. <p>C21 Healthcare services are provided in environments which promote effective care and optimise health outcomes by being well designed and well maintained, with cleanliness levels in clinical and non-clinical areas that meet the national specification for clean NHS premises.</p>

The core standards relating to improving patients' emotional experience – continued

Safety	Governance	Patient focus (working in partnership)	Accessible and responsive care	Care environment and facilities
		<p>C15 Where food is provided, healthcare organisations have systems in place to ensure that:</p> <ul style="list-style-type: none"> a patients are provided with a choice and that it is prepared safely and provides a balanced diet b patients' individual nutritional, personal and clinical dietary requirements are met, including any necessary help with feeding and access to food 24 hours a day. <p>C16 Healthcare organisations make information available to patients and the public on their services, provide patients with suitable and accessible information on the care and treatment they receive, and, where appropriate, inform patients on what to expect during treatment, care and after care.</p>		

National patient survey programme

The Healthcare Commission co-ordinates the national patient survey programme. Each trust and PCT is responsible for organising its own survey (carried out in line with guidance) and for submitting the information to the NHS Advice Centre. The surveys are carried out on a rolling basis and relate to a number of specific user groups and settings. They provide important feedback about the experience patients have of health services. The results contribute to the performance ratings of all NHS trusts and PCTs.

The survey responses provide more detailed information on how patients feel about the service they receive, they form part of the assessment of trusts against the healthcare standards. The acute, mental health, primary care trusts and the ambulance survey programme indicators are mainly included in domain four of the healthcare standards – patient focus. However, there are indicators for how patients feel about different aspects of their care included throughout all the core standards. (see page 14)

Individual trusts and PCTs are expected to use the results to identify how they can improve services for patients.

The answers to the 'dignity and respect' questions and other related questions, for example in the sixth domain – Care, environment and amenities, C20 b, asks acute services and PCTs whether they have taken steps to provide services in environments that support patient privacy and confidentiality, provide feedback on the patient's emotional experience and relate to overall patient satisfaction.

A further example of questions that provide feedback on patients' emotional experiences are those in the inpatient (adult) survey 2004 – patients were asked the following questions.

- Q4 How do you feel about the length of time you were on the waiting list before your admission to hospital? [Waiting list only]
- Q9 Did you feel that you had to wait a long time to get to your room, ward or bed?
- Q43 Overall, did you feel you were treated with dignity and respect while you were in hospital?

Link: www.healthcarecommission.org.uk

The Public Service Agreement (PSA)

Public Service Agreements (PSAs) are an integral part of the Government's approach to achieving better public services. They are a clear statement of what the Government is trying to achieve and are the basis for monitoring what is and what isn't working. Focused on outcomes, they inform national standards. What happens at a local level must connect to the ambitions at a national level.

The patient experience PSA target for 2005 – 2008 is a key strategic driver. The target is to 'Secure sustained national improvements in NHS patient experience by 2008, ensuring that individuals are fully involved in decisions about their health care, including choice of provider, as measured by independently validated surveys.'

The experience of black and minority ethnic groups will be specifically monitored as part of these surveys.

The PSA target requires sustained national improvements in patient experience by 2008, as measured by the national patient survey programme.

Measurement of the PSA

A number of 'core questions' have been identified for each survey. National results are calculated by aggregating the scores for all trusts and PCTs taking part in the survey. Progress against the PSA target is defined as recording an increased national score for each survey, relative to a baseline score. The performance of all trusts and PCTs will contribute towards the PSA target.

Monitoring and managing performance

The patient experience PSA is as important as all the other PSA targets.

To help the strategic health authorities manage performance, the Department of Health is rolling out a Patient Experience Information System (PEXIS) that brings together different pieces of patient survey data and statistical information in an easy-to-use 'traffic-light' system, to better understand and improve the patient experience.

PEXIS is a performance assessment tool to assess and improve patients' experience locally. It can be used to look at the performance of trusts under each of the five dimensions of a good patient experience and brings together a wide range of data-sets in one system. The results are aggregated to produce an index score for each dimension.

As a performance assessment tool, PEXIS:

- is **patient focused** – to help shift the delivery from a target culture to patient-centred services
- provides **peer review** – for greater understanding of the national position and comparison at a local level, and
- provides **knowledge management and high quality information** – supporting local management information systems, providing relevant information in one place and increasing people's confidence in the information and the system.

Link: <http://nww.unify.dh.nhs/unify/interface/homepage.aspx>

Important messages

PCTS and NHS trusts need to understand why improving patients' emotional experience is important and how this may affect their ratings.

The PSA is measured nationally but entirely depends on the contribution of each trust.

Targets can only be met if all trusts improve.

It is not enough to focus on low-performing trusts.

All trusts need to be clear on how the PSA is measured and how they can contribute to achieving it.

To secure sustained PSA improvements activity needs to focus on the core questions that relate to the five dimensions of the patient experience (see page 11).



Are you clear what you need to do to understand and improve patients' emotional experience, and how this will be measured for the PSA?

There are many good examples of how the NHS is improving patients' emotional experience (see part 3). However, organisations do not always recognise the impact this type of activity has on delivering a patient-led NHS.



Part 3: How the NHS is improving patients' emotional experience – examples of good practice



The examples in this section reflect the following area of 'the patient experience definition'.

'Getting good treatment in a comfortable, caring and safe environment, delivered in a calm and reassuring way'

They also reflect the following 'dimensions' of the patient experience.

Access and waiting

Building closer relationships

Clean, comfortable and friendly environment

Arts in Hospital project

Dorset County Hospital

The Arts in Hospital scheme was founded as a voluntary project and is supported by the West Dorset General Hospital Charitable Fund.

The project, 'Bringing the outside in', aims to:

- bring a wide range of high-quality contemporary art to Dorset Hospital;
- raise the patients' spirits and give pleasure to everyone involved with patients' welfare – helping Dorset to feel better.

The artwork livens up the environment, provides distraction and stimulation, and improves the experience of being in hospital. It is the largest and most exciting collection of contemporary art in Dorset, housed in a hospital which has around 200,000 people passing through its corridors every year, many of whom have never had the opportunity to visit art galleries and museums.

As well as providing artwork, the Arts in Hospital project does many other things, including the following.

- There is a resident artist who runs workshops for patients and members of the public. Patients come from different wards including the children's ward, and patients aged 50 to 80 with chronic pain have taken part in the workshop. One patient said, "I can't imagine the hospital without all the art, it would be so bleak and empty".
- There is a programme on the long-stay and elderly-care wards where many patients are unable to provide a healthy level of mental and emotional stimulation for themselves. The programme includes reading to patients who cannot read for themselves. Wordsworth's poem, Daffodils, has helped to focus people's memories and has visibly reawakened interest in the outside world. The reader noticed that even patients who are lost and confused seem to 'come together' suddenly during a reading, most particularly of Daffodils. One woman was calling "Joan, Joan" continually in a very distressed state and was clearly also hallucinating. When Daffodils was read to her she became quiet and at the end said, "I learnt that at school". The reader said, "Such a momentary stay against confusion is surely a worthwhile experience for such a patient".

- There is an exhibition of animals around the hospital, which includes a life-size wooden carthorse called Agnes. Agnes became the focus of a campaign to raise money to buy her so she could stay at the hospital permanently. Staff said, “She has become a focal point for our pain-management patients to walk to and discuss, she is very therapeutic for staff and patients alike”.



Agnes by Mike Chapman

The pre-operative home-care team

Royal Brompton Hospital

The Royal Brompton Hospital has a team of nurses who provide home-care visits for patients waiting for heart surgery. This is an extract from one patient's story told in a 'discovery interview'.

"When I first saw the consultant and he said "Yes, I think you will be good for the operation", I was absolutely delighted. I knew this was the next step as I had already had a failed plasty, and I thought, please let's hurry up and get this done, because I didn't feel I wanted to live the rest of my life in this way. I asked the consultant how long I would have to wait and he said, "Probably three months". I thought I could stand it that long knowing it was coming and I was looking forward to it, at no time at all did I dread it.

The week before I went in for the operation I was a bit anxious, apprehensive I suppose. I got a little bit nervous but there were plenty of people to talk to you so it didn't matter.

Now in all this time between seeing the consultant and going into hospital I was having the home-care team and boy did I ever appreciate them.

I really, really appreciated them because they were the medical staff. I could say to them, Look I've got an extra pain here or there, is it all right, can I still carry on doing A, B or C?. They would say, "Well let's test your blood pressure", and often it was sky high, we would laugh about it. In the end, I really didn't have any worries.

I did get apprehensive towards going into hospital, especially as it was several months since it was first suggested to me. There was always a worry that I might have a heart attack, and I didn't want to damage my heart. So I got a bit jittery and I would say to people just let me walk around a bit, don't worry about me, and they would laugh and that would be fine and it would break the ice.

The home-care team were coming about once a month and phoning in between. I had to lose some weight before I could have the operation and make sure my blood pressure had evened out. It would have been nice to have seen the home-care team more often but I know they are busy.

So off I went to hospital, full of promises – the marathon next year. I didn't have a worry whilst they were there, and afterwards I remember that was my one big complaint when I first came home.



My daughter and her husband came to live with me for a week but when they went home, I didn't see the home-care team for three months after the operation and I wished I could have seen them every month. After about two weeks, I saw the rehabilitation team and they told me they would let me know when there was a vacancy to start the exercises. She gave me a booklet that told me what I should be able to do after three weeks, six weeks and 10 weeks, and when I could drive again, that sort of thing, but at that point I really felt frightened of doing anything to hurt myself.

The home-care nurse told me about the helpline person, and sometimes I thought I had cause to ring but I thought what if the nurse is busy on the ward and you don't know what emergencies there are. I'm not going to be the only one to worry about calling them. Then the home-care nurse explained that this was her job and that I wouldn't be interrupting her.

I didn't know that I could ring the home-care team after they had finished visiting. There must be lots of people like me who hold back from calling and saying I would like another visit, because in my case, saying I wanted another visit is only because I wanted company, medical company, so I could say about this pain here and there.

The team was certainly a godsend to me. I wouldn't have been without them."

Room with a view

West Dorset General Hospitals NHS Trust

Leukaemia patients in isolation rooms at Dorset County Hospital are now able to watch a live view of nature 24 hours a day, seven days a week. A camera, with a view of the lake and gardens at Kingston Maurwood House, is connected by a wireless link to the hospital that is three kilometres away. The view is transmitted to large screens in the rooms used by patients who are isolated for several weeks while they receive treatment for leukaemia and other blood disorders. This low-key sensory stimulus provides a soothing and healing experience for the patients who are unable to leave their rooms due to the high risk of infection.

There has been some significant research into the effects of viewing nature on stress and recovery rates. The arts co-ordinator for Dorchester County Hospital said, "The treatment for leukaemia is traumatic and stressful. We hope that a live view of nature will allow patients to think about, and experience, the real world outside their isolation rooms and this will contribute to their increased wellbeing and quality of life while confined to isolation in the hospital". She said that the first person in the room said it was very relaxing and when he had seen the sunrise it had made him feel very alive.

Over the next two years, a planned medical research project will assess the benefits of 'Room with a view' on the patients' psychological and physical stress levels.



The arts co-ordinator went on to say, "We hope that evidence from the research project will provide extra support for developing the project further. This is a pilot scheme and we hope to develop the project with other cameras in different locations around Dorset".



The examples in this section reflect the following area of 'the patient experience definition'.

'Having information to make choices, to feel confident and to feel in control'

They also reflect the following 'dimensions' of the patient experience.

Better information, more choice
Building closer relationships

Heart to Heart – a video for patients waiting for a coronary angiogram or angioplasty

Greater Manchester and Cheshire Cardiac Network

Patients waiting to be transferred to specialist facilities that carry out cardiology procedures are often cared for on general medical wards in district general hospitals, and hospital staff do not always have the necessary background knowledge to tell patients what is going to happen to them. Also, no information was available locally or nationally that covered all the stages of the patient's journey. The result of this was that patients were afraid of the unknown. These feelings were expressed during a 'discovery interview' held with a patient who had been transferred from secondary to tertiary care for angioplasty.

"I said to the sister on the ward, "What is happening tomorrow", but she wasn't sure at all – she didn't know.

No-one told me what to expect when I came over to have the angioplasty done – there was not talk of it at all – I didn't know what to expect."

Nursing staff reported that one patient was so anxious he refused treatment at the tertiary centre because he didn't know what he was there for.

To prevent patients feeling anxious, it was decided to produce a video to provide accessible, accurate information for patients who are being treated for acute coronary syndrome. The audience for the video is patients and their families and it will give the nursing staff referring patients to centres enough information to answer their questions.

The Cardiac Network decided that because nothing was available nationally, the video would not be tied to any one hospital. In this way, many patients in the north west could benefit from it.

A project team of health professionals and a patient agreed the content for the video and the objectives of the project. The producer of the video was a member of the cardiac network's patient and professional partnership group who had undergone coronary-artery bypass surgery some years before.

Patients have been involved with the video at every stage of its production. The action in the video is centred around a radio phone-in. All the people in the video are healthcare professionals and patients talking about their experiences and asking questions to the



phone-in panel. The video shows an angiogram and angioplasty being performed and explains each part of the procedure. It also covers risk factors, healthy living and the importance of cardiac rehabilitation.

Feedback has been very positive. Patients have said that if the video had been available for them at the time of their treatment, they would have been less anxious and more prepared for what was ahead of them.

Every hospital across the north west now has a copy of the video. A series of roadshows are also planned, with specialist nurses and patients involved in the video, giving out free copies of the video and giving general educational talks on acute coronary syndrome.

To assess how effective the video is against the original objectives, a questionnaire has been developed for patients and staff, and patient-led research is planned to assess whether the video has helped to reduce the anxiety in this group of patients.

Expert Patient Programme

North and East Cornwall Primary Care Trust

North and East Cornwall Primary Care Trust have introduced the Expert Patient Programme (EPP) to help patients who are living with a chronic (long-term) condition to come together and develop skills to help them cope with the difficulties of long-term health problems.

The course is made up of six sessions of 2½ hours, every week for six weeks. The topics covered during the course include dealing with anger, fear and frustration. The course aims to develop healthy lifestyle habits and to complement, rather than replace, any existing medical treatment. The goal is that people will achieve the greatest possible physical capability and pleasure from life, despite living with a chronic health condition.

The EPP courses are led by tutors who themselves have chronic health problems. Patients reported improvements that included:

- less severe symptoms;
- a significant decrease in pain;
- improved activity;
- improved life satisfaction;
- a reduction in the pain-relieving medication needed;
- feeling in control of their own life;
- a greater understanding of how to cope with day-to-day problems;
- more effective use of limited energy;
- raised self-esteem and confidence; and
- the ability to move forward in life.

Clinicians are also beginning to see an increase in the potential of patients with long-term medical conditions, who go on self-management courses to:

- get involved in their own care;
- work with health professionals;
- make decisions about their treatment;
- express their preferences for care; and
- monitor and report their symptoms more clearly, helping clinicians to diagnose and identify effective treatments.



One of the outcomes is that when symptoms get worse, people are learning techniques to cope with negative emotions and difficult phases in their lives. They can recognise the things they can do for themselves and those with which they need help.

One person who went on the course said:

“Before my occupational therapist recommended I go on the Expert Patient Programme I was quite withdrawn and low, emotionally. My physical recovery from a stroke had slowed down since I came out of hospital. I had what I now call ‘four wall syndrome’ and I was dependent on others for my daily needs. My confidence levels were low.

The EPP course has taught me ways of improving my lifestyle. I feel in control again, I am less dependent on others, more confident and fitter. I no longer make frequent visits to my doctor and I have learnt how to control my pain without the use of drugs. I am now able to take exercise unaided and do almost all of my own domestic tasks. I have a social life and I have met new friends. I am now confident enough to be able to do voluntary work, helping others with similar problems. In short, the EPP has given me a quality of life that I thought simply not possible.”

Another patient with multiple sclerosis said that he had found the course beneficial. He said, “I had been going to the GP every three weeks but since doing the course I now only go about every three months. I am not reliant on the doctor to live my normal life, I am a lot better in myself and a lot more confident and feel 100% better. The course programme book is brilliant, it helps to go deeper and to understand, it’s really, really interesting.”

He went on to say that, “Because all the tutors are also patients, it helps me to see what I can do. I will consider being a tutor when I’m not so busy. I would like to be able to pass on my experiences from the course to other people. People will feel big benefits and keep away from the doctors. It’s given me a big boost.”

This shows how the Expert Patient Programme supports positive change within the NHS. It gives patients the power to make real choices and they can develop the confidence, communication skills and insight they need to work with their healthcare professionals, and get involved in planning and monitoring their treatments.

Intensive-care diary

Royal Berkshire Hospital, Reading

This is one man's story of how keeping a diary helped him to get through the ordeal of his wife being in intensive care for 49 days.

We will call him Mr B.

Mr B came home from work to find his wife unconscious on the floor. Until then she had always enjoyed good health. She had suffered acute respiratory distress syndrome and was admitted to intensive care on a ventilator. Her condition deteriorated and Mr B was told to prepare for the worst. Her health took on a pattern of small improvements which did not last long before she deteriorated again. For Mr B, the emotional rollercoaster was spinning out of control. He said, "Emotionally you are outside your own body. My emotions were all over the place and I began to think, I'm losing track of this. I spoke to my son and daughter and we tried to piece things together and wrote things down. After this, I started to do it on my own and kept a diary."

Mr B noted down the time of his three daily visits to the hospital, who was on duty in the ward and changes in his wife's condition. He said the diary helped him to get his mind in order when he went back to the hospital the next day to talk about things, although there were times he could not write anything at all. The diary became a companion with whom to share his thoughts and feelings.

Mr B's wife made a full recovery.

The hospital's intensive-care unit encourages relatives to keep a diary and to go to the follow-up clinic sessions for patients. Staff complete diaries for long-stay patients so that they have information on the treatment they have received during their stay, which is often a gap in their lives, and diaries are used as a reference point to discuss patients' care during follow-up sessions at the hospital.

Fit-for-surgery programme

Royal Brompton and Harefield NHS Trust

While waiting for coronary artery bypass graft (CABG) surgery, many patients receive little or no medical and nursing care, at a time that is very stressful for them and their families.

The Royal Brompton and Harefield NHS Trust has carried out a pilot programme to assess whether home-based, nurse-led support and education for patients waiting for heart surgery reduces their anxiety and improves their quality of life while they wait and whether they have a smoother recovery from their operation. The programme also looked at whether the risk factors for heart disease could be reduced during this time and whether it is cost-effective to intervene during this period to improve physical and psychological fitness.

The time spent waiting for surgery is an ideal time to tackle risk factors and to provide information on surgery and recovery. For example, there is good evidence that a reduction in blood pressure and cholesterol is of short- and long-term benefit to patients. Staff considered that it would be of benefit to patients if they were supported during this difficult time and encouraged to plan lifestyle changes.

During the pilot programme, a group of patients received monthly visits from a cardiac home-care team over a four-month period.

Specific aims included:

- to evaluate by questionnaire a new local manual for patients who are waiting for surgery; and
- to assess the usefulness of the pre-operative support programme offered in patients' homes and at nurse-led clinics in the hospital.

The outcome measures included:

- levels of anxiety;
- length of stay in hospital;
- changes to blood pressure;
- smoking rate;
- cholesterol; and
- quality of life.

At the end of the programme, the evaluation was carried out and the nurses involved took part in two focus groups. The patients had phone interviews one month after their last contact to find out their views of the overall programme.

42 patients took part in the programme.



Patients and their families generally found the manual helpful.

“I think it is the bible for heart patients and it is like a reference book.”

They found the programme of visits helpful, useful and reassuring, and appreciated the one-to-one contact. Some patients would have liked more visits and some would have liked them to continue after their operation but considered they could be reduced to once every two months.

About half the patients involved in the programme felt that they had made changes to their lifestyle, including changes to diet and their level of exercise. Half of those who had not made lifestyle changes felt this was because they had no changes to make as their risk factors were under control.

Outcomes

The nurses felt the programme fitted in with the National Service Framework for Coronary Heart Disease but that it would need adapting as GPs become more involved with managing risk and running local clinics. The pre-operative screening aspect proved very important and provided information that could be used to measure problems that, if undetected, would have led to surgery being delayed. The visits also highlighted worsening symptoms. However, the nurses found the programme involved a lot of work, although patients did appreciate it.

Patients and their families provided useful feedback on how the manual could be improved, for example, coloured tabs separating sections, a more user-friendly risk-factor assessment sheet, and more pictures for patients who cannot read well.

The nurses thought that the manual:

- helped patients to know what questions to ask;
- gave a focus for discussions with the nurses;
- gave patients control over their own lives; and
- encouraged responsibility for their health.

Recommendations

The manual was well used and should be made available, with one-to-one support, for all patients with raised risk factors.

The format of the manual needs to be changed to make it more user-friendly.

The programme should be expanded to assess and manage the risk factors for all patients waiting for coronary surgery. Those patients with increased risk factors should be regularly assessed.



Conclusion

The fit-for-surgery programme built on previous work that had highlighted a need to provide more support for patients waiting for coronary artery bypass graft surgery. The pilot programme and new manual were intended to provide psychological support and risk-factor management, and both nurses and patients felt this had been achieved.

This example is taken from an article in the *European Journal of Cardiovascular Nursing* (2002) and the research project proposal.

Palliative care services

St Christopher's Hospice South East London Cancer Network

At St Christopher's Hospice, the staff are trained to communicate with families and couples, not just individuals. This makes a big difference to the quality of care experienced in a healthcare setting. The following examples show some ways in which attention is paid to the emotional care of the patient and their families.

Admission to the home-care service or inpatient unit

The process of admission into either the home-care service or inpatient unit often takes patients and their families by surprise as they are not expecting the level of detailed interest and concern in themselves and their families. The aim of the interview is to find out what matters to both the patient and their main carers, who are usually the family. A simple way of finding out this information is to draw a diagram showing the patient and those close to him or her. By asking questions like, "What do you understand about your illness?", it is possible to find out who in the family knows what and who would like more information. Through this simple tool, the staff can find out the patient's view of who is struggling emotionally to manage the current situation. The patient can then help to make a plan of who else in the family would benefit from being offered more emotional support. The staff are also careful to find out what patients want to achieve and help them to prioritise.

Information

Staff have a range and style of written information that is easy for patients, their carers and families to understand. It includes material for young children, teenage children and carers. For example, there are leaflets on:

- why the hospice uses morphine;
- what a syringe driver is; and
- some practical information for carers on topics such as what to do if someone cannot eat and how to recognise when your loved one is dying.

The children's information includes workbooks and the staff work with the parents so they can do the workbook with the child.

A multi-professional team

The multi-professional team (nurses, doctors, social workers, physiotherapists, occupational therapists, a psychiatrist, a pharmacist and welfare workers) all work from the same notes, which means that patients and families do not have to keep repeating information and telling their stories over and over again. Working in this way makes patients and their families feel secure and confident.

The day unit

The day unit helps patients who, because of their illness, have experienced what has come to be called 'social death'. Their world has become smaller, friends have lost contact and they cannot do the kind of activities that they used to enjoy. The range of programmes available to patients includes horticultural therapy, arts and crafts, remembrance groups, music therapy and an opportunity to make their own video about their local area. These types of project seem to give hope to patients who are feeling hopeless.

Attention to care around people who are dying

Families are encouraged to stay around the bedside or in one of the family flats. The staff work out with them how much or how little physical care they want to be involved with. The complementary therapists often teach carers simple hand massage – having something to do while keeping vigil can help. The staff rehearse with the family exactly what they would like to do when the patient dies, deciding who they might need to ring and what they would do in the coming days.

After a death, families are invited back to the ward the following day for a meeting. Part of this is to receive the death certificate and belongings of their loved one, but the major aim of the meeting is to review the impact that the illness and death has had on them. If they wish to, they can see the body in the viewing room, accompanied by a nurse.

A variety of approaches to bereavement care is offered, from a one-off meeting to ongoing one-to-one support. Families are invited back to a remembrance service on the first anniversary and several thousand people come to the hospice every year to light a 'candle' on the remembrance tree.

This kind of emotional support gives families the experience of a well-managed death which, over time, gives them the ability to move on to new experiences.



The daughter of a patient said:

“Thank you St Christopher’s for making the death of my father bearable. I was terrified of death before my father was admitted to you. I can now understand the phrase ‘live until you die’. My father came in despondent and with no hope. You were able to help him live again, even in the three short weeks that he was with you. He so enjoyed the creative therapists who came and worked with him at his bedside. A week before he died he made a silk scarf which he gave to my mother.... she will treasure it always. The nurses and doctors made us feel like important human beings again and not just a number in a system. What was important to us was important to you. Thank you from the bottom of my heart.”



The examples in this section reflect the following area of 'the patient experience definition'.

'Being talked to and listened to as an equal'

They also reflect the following 'dimensions' of the patient experience.

Access and waiting

Building closer relationships

Sickle-cell support group

Central Manchester and Manchester Children's Hospitals

A mother raised several concerns with the Patient Advice and Liaison Service (PALS) about the care of her 11-year-old daughter, who has sickle-cell disease. The main point was the lack of support both she and her daughter had from other families going through the same experience. In the outpatient clinics at the sickle-cell centre, there were rarely any other children and no-one of the same age spoke to her daughter – they sat quietly and did not mix. This was resulting in strong feelings of isolation and frustration. The mother and daughter came up with the idea of a support group and this developed into a party.

The mother said, "There were many times that she asked me to see, meet and play with 'like her', meaning other children with sickle-cell disorder. Even at the hospital's clinic day where it's just for children with sickle-cell disease, she said that it didn't feel the same, as everyone was passing through and they were keen to return to school."

The mother often contacted the PALS officer and expressed her concerns about her daughter's health and the support that was available for a child of her age. "For many years I have felt alone and very much frustrated that I couldn't do more for her in her early years, where she could see that she was not alone."

The idea for the party came in January 2004 when the daughter had an operation. "The reason why I wanted to have a party for the children is because I felt the children need to be brought together with the parents, to see that they were not alone and we could share experiences."

The daughter designed and printed flyers and invites to the party. They were sent to all families who had a child under the age of 11 who attended the Thalassaemia and Sickle-Cell Centre, consultants and healthcare professionals.

The party was held in July and there was music, face painting, a clown, toys, games, balloons and food. Information about sickle-cell disease was displayed in the room. There was a fantastic turn-out with 15 families attending – children with sickle-cell, their brothers and sisters, mothers and fathers. The children's ages ranged from babies on bottles to about 11 years old and included an unborn baby already diagnosed with sickle-cell, whose mother came along to talk to other mothers.



At the party there was fun and laughter – parents met other parents for support and children played together, seeing other children who had the same condition. It was very successful, with parents commenting on how valuable it was to have this type of event. Sickle-cell disease did not dominate the conversation, it was enough to know that everyone was there for the same reason. Socialising and meeting people was very important. Parents supported each other, which is an essential part of how families cope psychologically, and it was important for the children to feel part of the 'bigger picture' where life is fun and normal.

After the party the mother said, "I was totally overwhelmed by the response that I received on the day and even now, five months after. At the age of 11 my daughter has a permanent disability but is now very much focused on the future. So much has improved now but I feel that there is so much more we can do for our children with sickle-cell disease".

The mother has many ideas for improving the care of children with sickle-cell disease. She has asked her consultant for a letter to tell other doctors about her daughter's individual needs when in sickle-cell crisis. This is a great help and puts her daughter at ease from the pain and discomfort. She has many other ideas and says she would be more than happy to help put them together and she knows it can only be of benefit to others in the future.



Hearing and responding to the needs of heart-failure patients and their carers

Dorset and Somerset Coronary Heart Disease Collaborative

The Coronary Heart Disease Collaborative in Dorset and Somerset carried out 'discovery interviews' with both patients and carers. These highlighted the intense emotional aspects of being diagnosed with heart failure – the importance of a timely diagnosis, the strong feelings of anxiety and the depression that can result, the need for better communication between healthcare professionals, patients and the professional carer, and the need for good information at the right time.

This is one patient's story.

"My lungs were filled with water, I was being sick, I lost three stone in weight, I couldn't eat, I was just sipping water, I lost my taste for a cup of tea, I was at my lowest ebb. I have never before, ever contemplated taking my own life but I didn't want to live anymore, I just wanted to curl up in a corner and die.

After I had had the heart scan they told me what was wrong, you can imagine. We went from being up there to plummeting to the depths. It was a terrible shock and as the realisation of everything sunk in we both felt very cross because it hadn't been picked up. We just felt it should have been picked up with all the times I'd been in and out of hospital.

There were all these emotions going through both of us. My husband would visit and he was working so he'd come in the afternoon and the doctors had invariably been round in the morning you know.

I was in hospital for a month, the water came off but the depression hit me really, really bad. Because, it's that thing, when you're told it's your heart, it was frightening, scary for my husband, scary for me. I'm the type of person who has to know what the outlook is, I have to know. It's my body and I have to know what's around the corner and what's happening and I'm afraid that it's a struggle to get any information.

I would like to know from A to Z really. I'd like to be able to read the facts and figures and have a bit more knowledge at my discretion. It wouldn't be a question of false hope, it would be some hope.

It's been a total change around to how life was and it's taken a lot of adjusting and I cried and cried because I couldn't come to terms with how much life had changed and how much I'd changed."



This story revealed the huge emotional impact of a delayed diagnosis. Having listened to this story, the team:

- recognised the need to develop further existing guidelines for managing heart failure that would include specific information for people with symptoms that are not typical;
- produced a communication checklist which will make sure patients have understood the information provided about their condition;
- provided in-service training to raise nurses' awareness of heart failure and linked physical and emotional needs; and
- felt there was a lack of consultation time on ward rounds and that people may feel intimidated and may not 'hear' what is being said. It was agreed that after the ward round, nurses with expertise in heart failure would sit with the patients and their families to follow up information provided by the clinical staff to make sure they understand what has been said and reduce anxieties.

This story not only inspired the local heart failure team to review their practice and make improvements, but also led to further improvements in other areas providing heart care.

Children's services

The Modernisation Agency

Staff at the Modernisation Agency talked to young school-aged children about what makes children happy in hospital and their ideas for improving hospital care. They used an imaginary person called Mo and asked the children to draw pictures to describe their ideas and experiences as well as to talk about them. These answers and drawings belong entirely to the children.

A five-year-old boy who has been in hospital, describes how minor injuries are not a reason for going to the accident and emergency department.

"I would like it best if it was mostly boys of all ages and there's a train in the waiting room of the children's hospital."

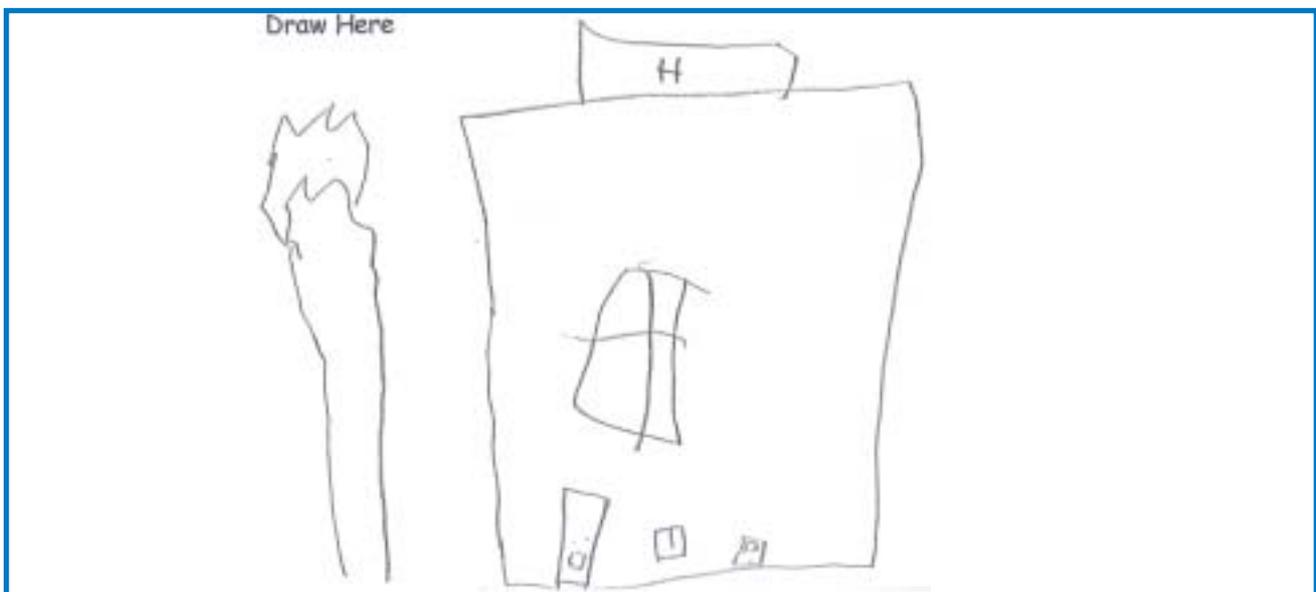
Are the doctor and nurse wearing uniforms?

"The nurse is, doctor isn't."

Would you like the doctor and nurse to wear uniforms?

"Yes, you know they're a doctor and not a burglar."

Hospitals – "They would like to have a big window so they could fit lots of patients in the windows. If they're really poorly there's a drink machine outside. If it's just a little cut that's bleeding you can come to the entrance and press the button to make the plaster drop down and all the bandage – you can choose which button to press for a plaster."



A five-year-old girl who has been in hospital would prefer it if there were mostly girls in the ward but she is happy for them to be of different ages. She says, "It's not nice in hospital but the doctors make you better. There's tissues and sick bowls". She would prefer it if the doctors and nurses "just wear an apron to keep the germs off", rather than uniforms. She would like a chair to sit on, a little table with flowers and a teddy, little presents and a cake.



A six-year-old boy thinks that Mo is a girl. "It's her birthday and she's going to get a present from under the bed, she gets to have all those treats and chocolates." He would prefer it if there were boys and girls on the ward, and they were all different ages – 16, 20, 6, 11. He would also like the doctor and nurse to wear uniforms "because then you know they are doctors and nurses, otherwise you might think they were visitors". He would like the outside of the hospital to look nice and inside "bunk beds, nice nurses and doctors, toys, TV, cars, cakes, lollies, a guitar, drum, toy puppet, a watch to wear and a whole board to draw pictures on".





A visit to an acute trust can be a terrifying experience for people with learning disabilities

PALS and Manchester People First South Manchester University Hospitals

A carer of a patient with learning disabilities highlighted to the Patient Advice and Liaison Service (PALS) the real problems around communication, getting consent and the treatment of patients with learning disabilities. The PALS worked with Manchester People First, a self-advocacy group for people with learning disabilities and staff from Manchester Learning Disability Partnership, to identify the problems and ways of overcoming them.

Together, they organised a day to which people with learning disabilities could come to tell their stories. The day was advertised across the whole of Manchester. Over 50 people with learning disabilities came and said they felt ignored, scared, bullied and uncared for. They said the following.

- Medical staff spoke about them, not to them.
- Staff did not listen to them.
- Staff were not explaining medical conditions or treatment in a way they could understand, so they often left the hospital feeling worse, more frightened and confused.
- It was hard to find their way around the hospital.
- They often did not go to the doctor when they knew they should, as there seemed little point.
- They sometimes felt bullied, emotionally and physically, into giving permission for treatment.
- There were problems with the accident and emergency department and theatre, and these were particularly frightening places.

They wanted explanations, "What an illness means, what needs to be done. You leave the hospital worrying and feeling more ill because you haven't understood what is wrong with you, what it means or what to do!"

Many people with learning disabilities have communications problems. "Give us time – we might be scared and it might take time to reply."

It emerged that people were finding the hospital experience so frightening that they were not going to appointments. There were real horror stories about accident and emergency and people not being treated because staff just did not know how to communicate with them.



People from all over Manchester came to the day so these stories were not just about one particular hospital.

The PALS also started to receive calls from carers to say there were people with learning disabilities who were finding it just too frightening to come to the hospital. As a result of this, they began to invite people to the hospital for a coffee, followed by a walk around the hospital and a visit to outpatients, x-ray, accident and emergency and other departments.

People with learning disabilities said they would like:

- information with pictures they could read through with their carer;
- all staff trained in treating people with learning disabilities, with particular training in the areas of theatre and accident and emergency;
- guidance for staff on getting consent for treatment – “They sent me home because I hadn’t given consent, I thought I had!”;
- assertiveness training on how to talk to doctors;
- health events when people would come and talk about specific areas of health care;
- open days at the hospital and the chance to come and see around the hospital before being admitted;
- an opportunity to meet the staff, look at the accident and emergency department, the theatres, and x-ray;
- an opportunity to talk to the trust board – “Let us talk to your hospital bosses and tell them what it’s like to have learning disabilities!”;
- to be involved in improving the signs at the hospital;
- messages on the hospital system explaining what someone’s needs are so they do not have to keep repeating themselves; and
- not to cancel surgery.

People First advised on the way forward. Some people were not sure about the early work of the project, and only two members of staff went to the first meeting arranged to discuss the issues. Following this, the PALS manager met everyone to raise awareness and identify ‘champions’ – the champions were the Medical Director, the Head of Training, the Clinical Governance Manager and the Chief Nurse, and with their help changes began to be made.

- PALS worked with the speech and language therapists from Manchester Learning Disability Partnership to create pictorial guides to accident and emergency departments and theatre. These books illustrate the patient journey through these areas and are specifically prepared for people with learning disabilities.

- People First assessed the hospital signs and people with learning disabilities made recommendations to the board.
- General training is given to staff on the induction programme and specialised training around getting consent is given to medical staff.
- Alerts are now on the hospital's computer system in accident and emergency for patients who are known to the learning disability services.
- Health events have included eye care, sexual health and giving consent for treatment.
- A day for people with learning disabilities, their carers and health professionals was organised. They worked together to draw up plans to improve health care and access to healthcare services for people with learning disabilities. Over 150 people came, which was a big improvement to the two who came when the work was first started.
- There are now visits every three months around the hospital to accident and emergency, a ward, outpatients, x-ray and a theatre – these are well attended.
- PALS has negotiated more time in outpatients for patients with learning disabilities, and will support the patient if necessary.
- PALS has also negotiated 'protected admission' for patients with complex needs, which means that these patients should have some protection in terms of their surgery not being cancelled.
- At a recent event, drama was used to explore ways in which these patients can be helped to have choice, in terms of both giving permission and the new booking system called Choose and Book.

Some of these schemes are helpful to other patients, for example, the picture booklets are also useful for people who have difficulty reading English.

Patients who previously were so frightened of hospital that they would stop eating tell us that they now like our hospital, the 'Did not attend' (DNA) rates have dropped and staff are coming forward to help with the training.

Two of the comments we have received show the difference these changes have made to the emotional experiences of patients with learning difficulties who visit the hospital. We still have a long way to go but we are encouraged to keep trying.

"Now I can hold my head up high!"

"I am only small, but now I feel tall."

Supporting cancer services

The Robert Ogden Macmillan Centre, St James's Hospital, Leeds

The Robert Ogden Macmillan Centre is a purpose-built cancer information and support centre at St James's Hospital, Leeds. The centre was opened in 2000 with the main aim of providing cancer information to patients, relatives and staff. However, following a series of open days it became clear that patients and relatives wanted much more than the information provided.

Three open days were held – one for the patients and the public, one for hospital staff and one for primary care staff. Everyone who came received a questionnaire to fill in about the type of services they would like to see provided at the centre. There was a stark contrast between the views of the health professionals and the patients. Patients asked for quite simple things such as comfortable chairs, proper cups and saucers, staff who had time to listen, background music and so on. Health professionals asked for a variety of clinical services. We listened to the patients' views. The philosophy of the centre has become that if one person asks for something, then it is worth doing.

Four years on, the centre has a range of non-medical services that have all been developed in response to what the patients have said they need. They include:

- reiki healing;
- reflexology;
- art therapy;
- look good, feel better;
- Indian head massage;
- cranial sacral therapy;
- head art therapy (using hats and scarves to disguise hair loss); and
- ABRACADABRA (a bra-measuring and supply service for people who have had a breast or breasts removed).

The centre has set up a number of support groups, and between 8,000 and 9,000 people contact it every three months. It also provides an 'outreach service' to oncology wards and departments, and usually sees around 100 patients a week.

Patients believe that the services provided by the centre are an important part of their care and treatment. Many of them tell the staff they would not have coped without the support of the Robert Ogden Centre. They said:



“The complementary therapies help to take away some of the clinical chemo side effects you go through. They show you how to relax and help you to feel better about yourself.”

“I have gained great calm through healing, and talking to my healer.”

“The groups give me a sense of not being the only one.”

“The feeling of wellbeing you get from people who work here when you come in is so uplifting. People really care – you feel that it makes a difference.”

“When I came into the Robert Ogden Centre I was at rock bottom. I couldn't see any way forward, any point in carrying on. Staff here got me back on my feet. They turned me round.”



The examples in this section reflect the following area of 'the patient experience' definition.

'Being treated with honesty, respect and dignity'

They also reflect the following 'dimension' of the patient experience.

Building closer relationships

A joint induction programme and developing PALS champions

East Devon Primary Care Trust

The PALS manager and training team at East Devon Primary Care Trust (PCT) developed a joint induction programme for all new staff involved in delivering healthcare services within the PCT. This included domiciliary care workers, some private-care-home workers and social services directorate staff. The course is compulsory for all new staff. For staff who handle patients, it lasts for two and a half days, and for others one and a half days. In each case the half day focuses entirely on the patient's experience, patient 'vulnerability' being the main theme.

The PALS champion course is for any member of staff – anyone who comes into regular contact with patients, relatives and carers. This includes hotel services, administration and clerical, occupational therapy, qualified and non-qualified nursing staff and therapy assistants. Patients and carers were involved in designing the training programme. Past PALS clients were asked about their emotional needs during their time as patients, relatives or carers. They formed the backbone of the course by relating their experiences, exploring needs and identifying skills in a blame-free and non-judgemental setting. This was a powerful experience for staff, patients and carers.

Involving patients, relatives and carers was crucial as it underlined the importance of 'the little things' and how these pile up, feelings of helplessness and hopelessness, and the grief of losing your health.

The course was run by ex-PALS clients, a volunteer, carers and several patients. The information about pensions and freedom of information was provided by the 'experts'. Some people were worried about having 'nothing to offer' and 'what can I possibly teach them?', but ground rules were negotiated and concerns explored.

The course has helped staff to change their way of working, rather than accepting 'it's always been like that...'. They now act as advocates for the patients and have more confidence in what they do. Some PALS champions have become involved with Essence of Care projects, something which, they say, they would not have done before doing the course.

Feedback from patients is positive. Patients said the following things.

"You couldn't change anything, but at least you took the time to explain why I had to wait so long. No-one had before."

"We're moving to east Devon and we needed to make sure things went smoothly [for my child]. Until I talked to you, it was as if everyone was assuming that someone else was doing something, and no-one was doing anything. All I needed to know was who to talk to, to make it all happen for myself."



East Sussex Hospitals NHS Trust

The pain-management team on the Eastbourne site already run pain-management programmes and pain support groups. However, for various reasons, these groups are difficult for some people to go to. Difficulties around literacy, social confidence and spoken English were stopping patients having the kind of group experience that may prove beneficial to their long-term pain management.

To give as many people as possible the benefits of being part of a therapeutic group setting, the team decided to run a pilot group and have art as the focus for the programme. Art encourages people to express their feelings and talk to each other about their lives. It is a pleasurable activity that has been found to distract people from their pain.

Everyone who went to the pain clinic held at Eastbourne District General Hospital was given flyers and posters. Twelve patients agreed to join the group. There were three men and nine women and their ages ranged from 30 to 79.

The plan was that using art in a therapeutic way may help people to move forwards positively, towards a long-term approach where they manage their own treatment.

Funding for the programme came from the League of Friends and the Pain Management Trust Fund. A print maker and collage artist was employed as artist in residence. The artist is an experienced teacher who has worked in the health service and has some understanding of the complex nature of long-standing pain. The team that supported the artist in residence and ran the pain-management programmes and support groups, included a clinical psychologist, a senior physiotherapist and a clinical nurse specialist.

Art was regularly put into patients' diaries and the team encouraged them to make friends with other members of the group.

The environment was chosen deliberately to be uplifting and non-threatening. There was a flexible approach and the team was open to suggestions and contributions from group members, who, for example, suggested having music in the sessions. An important factor in the success of the sessions was that the staff took part in the activity and produced pieces of work themselves. The overall emphasis was on respecting the patients' different abilities.



The pain-management collage workshop

The work was monitored and evaluated through questionnaire packs that patients were asked to fill in. The team was particularly interested to see if there were any:

- improvements in the quality of people's lives;
- improvements in their moods; and
- decrease in anxiety and levels of pain.

Outcome measures showed no significant change, which was not surprising given that no physical or psychotherapeutic treatment was given. However, feedback suggested signs of improved moods (patients looked forward to future sessions).

The artwork produced by the group has been framed and displayed in the outpatient pain clinic area, and inspires other patients who go to the clinic.



Patients said the following.

“It is very difficult to put into words the benefits it has done for me. I get very little sleep at the moment and never get a pain-free night hence getting up in the morning and being somewhere by 10am is very hard. Each week I have done it and each two-hour session feels like 30 minutes.”

“I find that this work has been such a help to me not only mentally but I have made new good friends and the people who run the course have been so helpful towards me. They helped me to express myself through art and it's really good to meet new people who have similar problems as myself.”

“Without realising, I have been spending a lot of time at home not knowing what to do or not having any enthusiasm to do anything. Along with this, I have forgotten how to socialise with people. This course has made a great deal of difference to me. It has been very interesting to do. It has given me something else to think about and most of all it has given me something to look forward to each week. You do feel at times that you are the only one going through it and that nobody else understands. This makes you realise that this is not the case. I have seen how other people are and got inspiration from doing so.”

Living with cancer project

Ellesmere Port and Neston Primary Care Trust and Halton Primary Care Trust

The aims of the 'Living with cancer' project were to:

- help patients and carers to become more involved in their care;
- improve the communication skills of professionals; and
- improve the quality of life for patients living with cancer.

A member of staff thought these aims might be achieved by using Neuro-Linguistic Programming (NLP) methods. Three focus groups, attended by patients, carers and health professionals, were held to influence the early stages of the project. These highlighted the need for:

- good communication between patients, carers and professionals, and within services;
- good relationships between patients and professionals;
- relevant, accurate and appropriate information being provided and delivered sensitively;
- carers and health professionals being able to handle their own emotions to make communication easier and more effective; and
- psychological and social support for patients and carers at certain stages such as diagnosis, during palliative care and in bereavement.

The 'Living with cancer' project joined a Macmillan project that had already set up a drop-in information centre at the local library. This provided easy access to information and raised awareness of the services available. Support groups also met every week which had educational input from qualified NLP trainers. They offered relaxation techniques, self-help coping strategies, and ways to improve communication and relationships. 62 patients and carers attended the groups.

A patient's account

"I needed something there and then because I had reached such a low point. I had kept myself positive through all the treatment for breast cancer, and then suddenly my confidence was swept away as my friend and neighbour, whose experiences seemed to mirror my own, became terminally ill with secondary tumours. We had been through so much together, even having our operations on the same day. It was a great shock. I was frightened and very, very upset.

So I joined the support group, and although it seemed strangely unfamiliar at first, the atmosphere was relaxing. I especially liked the tai chi. I noticed how the music lightened the mood and I found I could let myself go in the group. People were talking and sharing their different experiences.

The facilitators taught us how to relax and now I'm able to just shut off for five minutes whenever I want to, and it gives me the oomph to carry on. Being able to relax can make so much difference.

I can handle difficult situations much better now, I think first. I've got more confidence to talk to people. My relationship with doctors has changed. I used to say they weren't listening to me. I was brought up in awe of doctors, to show respect, never to ask questions, just to do as I was told. These days I find myself unconsciously mirroring their body language, I ask questions and I don't forget the major points. And my doctor tells me things, gives me more details, explains more. I feel consulted.

Having a better relationship with medical people has given me more confidence in them. I can trust them because I know I've had a proper examination and discussion, mind and body working together, and the doctor, the specialist and myself are all sharing control and are all taking responsibly for my wellbeing. I feel better about myself."

A carer's account

"NLP has added another 20% to my communication skills. I can talk to people in bad situations now and I'm aware of how important it is to focus on the positive. My advice if you are talking to a cancer patient is to ask, 'Where do you want to be in 12 months time?' You need a target. It's important to have a positive attitude. I am much more confident talking to professional people. There were health professionals there and they were interested in what we had to say and wanted to learn. I can talk to consultants now, matching, mirroring, thinking about the aspects that I want to find out about, and asking questions. NLP helps me think clearly and sensibly, and be aware of the language I use.

For me personally, NLP has made a difference by putting me more in control of my own emotions. Following my illness 10 years ago, I was having mood swings and suffering depression. NLP has helped me out of that depression, I am a lot calmer."

Staff accounts

Diane was getting more and more anxious about the gastroscopy and colonoscopy she was waiting to have for suspected cancer. She had heard that the tests were very unpleasant and was worried about the possible outcome. She was very anxious during the day and this was disturbing her nights. With guidance from a member of staff who was doing the NLP training with the project, Diane learned how to calm herself down. She found NLP techniques helped her get back to sleep more quickly. She was much calmer and very positive when she went for her tests and operation.

Another story

District nurses were finding it difficult to cope with treating a man who had severe facial disfigurement caused by cancer. The situation improved after one nurse, who had done the NLP training with the project, taught her colleagues how to manage their own feelings.

The reception nurse

Newcastle, North Tyneside and Northumberland Mental Health NHS Trust

Newcastle, North Tyneside and Northumberland Mental Health Trust has formed very positive links with patients, some of whom have been keen to carry out patient-led audits of services. A number of these patients completed training in interview and audit skills, and a senior nurse supported them while they completed the audits.

As part of a consultation to identify ways of improving services, patients visited the acute inpatient areas. They agreed a set of questions and filled in questionnaires with other patients who had given their consent to be interviewed. Group sessions were organised for people who did not want to complete a questionnaire.

A number of issues emerged from this exercise. A particular theme was that patients felt that during the initial stages of their admission to hospital, staff were too busy to be approached, they were seen by different staff who asked similar questions and they found it difficult to get information they and their carers needed. Staff said they were often not aware of what information had been given to patients because a number of staff carried out different jobs throughout the admission process and important information was overlooked.

A project was developed, driven by patients working with a Modern Matron. The aim was to provide a more caring and informed admissions process for patients and staff. The solution to this was to trial a dedicated reception nurse on three sites in the Newcastle area. Their role would be to:

- greet new patients;
- put them at their ease by talking them through the admissions process;
- show them around and introduce them to staff and other patients; and
- make them feel more comfortable about being in hospital.

The Modern Matron said, "In any healthcare setting, the first contact with patients and carers is critical. It dictates how healthcare professionals, patients and carers engage and work together. Patients need to feel at the centre of the process. Having a friendly face to meet them on admission and stay with them until they are settled makes them feel cared about and this is really important".

Patients agree that the reception nurse has improved their experience of the admission process and reduced feelings of isolation. A patient representative said, "A reception nurse is important, they help to lessen the distress of being admitted to a ward and help new patients to settle into a strange environment".



Staff at the trust are just as positive as they have seen the benefits it brings to patients. Having a central process cuts out unnecessary duplication and reduces patients' and carers' frustrations.

The role of the reception nurse is to:

- identify themselves to each patient and carer when they arrive at the hospital to be admitted;
- where appropriate, make sure a room is identified ready when the patient arrives;
- greet the patient and aim to help them feel at ease, for example, by offering drinks, staying with them throughout the admission process and offering explanations and information;
- show the patient around the ward and introduce them to other staff and patients;
- show the patient their bed area and organise locker keys and welcome packs; and
- carry out the property check with the patient.

Maternity services

York Hospitals NHS Trust

At the beginning of the year, the trust developed new guidelines for caring for parents experiencing a stillbirth. This is a situation which as well as being heartbreaking for the family is also very sad for the staff. The labour and delivery process is often a complicated procedure and there is an enormous amount of paperwork to complete correctly, which involves communicating with many different agencies. The aim was to produce a clear document, which followed the parents' journey and included practical tips relieving staff of some of the worry and stress and so freeing them to support the parents.

Over recent years, the trust has chosen mementos of parents' babies to give to them. One of the aims in writing the guidelines was to make sure that in future the parents choose these themselves. The staff try to support parents as they create their own memories, rather than creating memories for them.

Through links with the Stillbirth and Neonatal Death Society (SANDS), the staff were able to identify areas that caused particular concern. The initial diagnosis of a stillbirth is traumatic for both parents and staff. Now, whenever this is suspected, the mother is moved straight into the side room specially furnished by the local SANDS group. The radiographers have agreed to scan mothers in this room instead of in the busy antenatal clinic. Following diagnosis, mothers who are able to are encouraged to spend some time at home before labour begins, so they can choose their own clothes and toys for their baby and maybe bring other things in from home. When they return home, these objects will hold special memories of their baby.

The staff have written a new booklet which gives a brief description of what will happen before, during and after labour and the choices the parents can make. There is also room for parents to record these choices.

The local SANDS group has contributed to refurbishing a room on the labour ward so that these babies are delivered in a much more homely and less clinical environment. After the baby has been delivered, parents may:

- bath their baby;
- take photos (the staff will take photos of the family, if that is what they want); and
- take hand and foot prints and locks of hair.

If the family wishes, a memento booklet is provided. Parents can also choose from a selection of clothing and knitted blankets so that there are extra articles that can be left with their baby or taken home in a box that is provided to keep all the mementos safe.



When parents feel able to say goodbye to their baby, they may push the baby to the mortuary in a pram, where they are met in the lounge by the mortuary staff. For many parents, the parting is easier if they know where their baby is and who will take care of him or her.

If needed, the hospital chaplain is always available and the patient affairs officer visits parents on the ward to help with funeral arrangements. There are two remembrance books in the hospital chapel – one is for recording the names of the babies who have died and the other is for parents to write in themselves.

Parents said the following.

“I don’t think I would have got through that night without my midwife. She spent all night with us, talking about what to expect and going through all the possible things we could do with our baby once it was born. Some of these things had never occurred to us or we would never have expected to be able to do, like bathing our baby, and making sure we had a family photo taken. This helped us try to gain some control over what was to happen. Looking back now I am so grateful for that time, knowing we made our own choices, created more memories and we were encouraged to spend time with our son.”

“I was 23 weeks pregnant and came to the delivery ward feeling unwell. It was a shock to find I was in advanced labour and it was unlikely that my baby would survive at this early age. We had not brought any baby items to the hospital and anyway they would not fit, no camera or any personal items, and there was no time to get any and we were totally in the hands of the medical staff. Our son was stillborn and we were in shock but the midwife encouraged us to spend time with him, they took photographs and gave them to us an hour later, they provided clothes for us to choose what to dress him in. They gave us a Winnie the Pooh box to put all the items in and encouraged us to create as many memories as possible of our son. I often take down my memory box and think of my son, I look at the tiny clothes and hand and foot prints and am thankful for the memories and the help we received.”

The midwives recognise that nothing they do can really improve this emotional experience and feel it is inappropriate to question the parents about how they feel, but all feedback they have had suggests that these changes have helped in an unbearable situation. They are currently carrying out an audit of the new guidelines. The trust will make sure that staff understand the guidelines and fill in all paperwork and check sheets correctly. The trust will also ask the midwives involved to measure the extent to which they were able to fulfil the parents’ requests within the limitations of staffing, budget and so on, and whether they felt that they had enough support.

Epilogue

While preparing this document, the editor went into hospital for emergency surgery and had her own patient experience – some of which was good, but some not so good.

This is her story.

Experiencing abdominal pain and anaemia she was investigated for over a year at a major London hospital. This included going into hospital for two weeks for urgent tests. All the tests were negative except for the last one that showed symptoms of a long-term condition. From early November 2004, she was treated with steroids for this condition but her health did not improve.

In January, she was told by her GP to take a month's rest leave to give the drugs a better chance of working. As head of patient and public involvement for a London strategic health authority, there were several important deadlines to meet in the forthcoming weeks so she negotiated the start date for her leave. However, two weeks later, acute anaemia forced her to go on leave earlier than planned. A week later, she was admitted to hospital through the accident and emergency department and underwent emergency surgery.

Before the operation, the surgeon mentioned the word 'tumour', but as the tests had been negative she did not consider this a possibility. Following the operation, a registrar told her that an inflammatory mass had been removed. A few days later, the consultant came to the ward and told her she had cancer. He did not follow any of the guidelines used by the hospital for giving bad news and she was alone on the ward with no privacy. During that day she was given several conflicting pieces of information about what would happen next.

So what would have improved her emotional experience?

Getting good treatment in a comfortable, caring and safe environment, delivered in a calm and reassuring way

"There needs to be a better understanding of what makes patients feel cared for and safe. For example, in order to meet the four-hour target in the accident and emergency department, an elderly inpatient on my ward was woken up at 11pm and asked to pack her belongings as she was being transferred to another ward. The next night two more patients were asked to do the same thing. The result of this was that the patients who had been asked to move became very distressed and the other patients were anxious for them. None of the patients understood or cared about the accident and emergency targets, and the staff seemed oblivious to how this affected the patients' care."

Having information to make choices, to feel confident and to feel in control

“On the day the consultant told me I had cancer, none of the staff on the ward had been told. When I told them what the consultant had said they expressed some doubt as to whether the information was accurate. This caused confusion and a lack of confidence at a particularly traumatic time. Over the following two days, there was more confusion. There appeared to be poor communication between the consultant and his team of registrars that resulted in mixed messages about what would happen next.”

“No information was offered about what to expect when attending for treatment, for example, the long waiting times, first for your drugs and then for the treatment, and there was no advance warning that I would need to provide a bag to carry round the chemotherapy pump for the treatment to continue at home. It would have been helpful to know how other people had coped with their pumps at home, for example, how they kept them dry when trying to wash their hair. I have since discovered that vets’ gloves, that come up to my armpit and can accommodate the pump when strapped to my arm with cling film, greatly improve bathing and hair-washing procedures.”

Being talked to and listened to as an equal

“During my treatment, I had to attend the day unit for an endoscopy. A nurse took me aside to go through a form. When asked about any drugs I was taking I told her I was a cancer patient at the hospital, that I had a PICC line in and was therefore taking warfarin. She immediately told me that I could not have the investigation. I was most upset that nobody had told me to stop taking the warfarin, and that although I was a patient at the hospital, the staff in the day unit knew nothing about my medical history. I did not feel I was either talked to or listened to as an equal or that the staff cared. I felt like a pawn in a game. In the end, it was only because I happened to see my nurse specialist that the procedure went ahead.”

Being treated with honesty, respect and dignity

“Although my consultant thought he was doing the right thing by informing me of his conversation with the pathologist as soon as he could, I would have felt that I was being treated with more respect and dignity if he had followed the hospital’s existing protocols for giving ‘bad news’. Then I would not have been left sitting by my bed, all on my own, trying to come to terms with what I had been told.”

These experiences highlight the importance of creating a patient-led NHS where: ‘NHS organisations are better at understanding patients and their needs, use new and different methodologies to do so, and have better and more regular sources of information about preferences and satisfaction.’

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