



# Contents

Foreword.....	3
Executive Summary.....	5
Acknowledgments.....	7
Introduction.....	8
PATIENTS' CONCERNS – KEY THEMES.....	10
Overarching Theme: Being human – caring for others .....	14
Theme 1: Real concerns about care .....	15
Theme 2: Informing and communicating .....	35
Summary of findings .....	45
PATIENT STORIES OF FAILINGS REGARDING THE NHS CONSTITUTION .....	47
PATIENT STORIES OF GOOD CARE.....	62
CONCLUSIONS.....	63
COMMON THEMES/FINDINGS.....	65
2013 STORY UPDATES “ONE YEAR ON”.....	68
TRUST RESPONSES TO OUR 2014 STORIES.....	79

## FOREWORD



The themes and examples discussed in this report demonstrate that many of the principles and values underpinning the NHS Constitution regarding the rights of patients, are not fully enshrined in NHS delivery or within NHS staff culture. Overall, if the pledges and rights outlined in the NHS Constitution are adhered to by NHS organisations and staff, the majority of concerns and complaints raised by patients would be alleviated. As a result, **we urge all NHS staff to understand, respect and follow the NHS Constitution.**

The NHS was set up to provide health care from the **cradle to the grave**. Yet from our National Helpline we hear very worrying trends regarding the care of older people, care of the dying and those who are struggling to access mental health services. The most vulnerable members of society appear to be those failed the most, at a time when they deserve the very best care and compassion.

The word we frequently hear from the thousands of patients who contact us yearly on our National Helpline, is **why?** Why is no one listening and why does no one care? All too often it is as a result of the stoicism and determination of patients and their relatives, that things change and patients receive the quality of service that is their right and of which the NHS can be proud.

In October 2014 the Patients Association published a report into complaints handling in the NHS. This report highlighted how families who raise concerns are frequently met with barriers and defensiveness from the health and social care provider. Complaints are like gold dust: they are telling a Trust that something is not right, whether that is in the acute or primary sector. Complaints should be welcomed, not rebuffed. Many of the themes and personally written stories highlighted in this report demonstrate the need to listen to what patients and their relatives are saying.

As a result of the calls and correspondence we received on our National Helpline, the Patients Association identified significant flaws and weaknesses in the handling of complaints by the Parliamentary and Health Service Ombudsman (PHSO). In November 2014 we published a report into their significant failings. Since publishing that report, our Helpline has been inundated on a daily basis with people contacting us for support. The majority of those cases are very complex and could have been resolved at a much earlier stage, had the processes been right and the concerns truly and openly investigated. People tell us of the deep sense of despair they feel trying to ensure that others do not suffer as they have. They tell us how the PHSO, instead of supporting them achieve this goal, actually put massive barriers in their way, directing them into a maze of false hope, only to find more dead ends.

The theme of poor complaints handling both at a local and PHSO level is without doubt the greatest category of call we receive today. Why, when we have the NHS Constitution and so many high profile enquiries, is the NHS still failing patients and staff who raise concerns?

A handwritten signature in blue ink that reads "Katherine Murphy". The signature is written in a cursive style with a large initial 'K'.

Katherine Murphy  
Chief Executive  
The Patients Association

## EXECUTIVE SUMMARY

For nearly 52 years the Patients Association has campaigned tirelessly and publicly on behalf of patients and service users. Through our National Helpline, campaigns, focus groups and increasingly NHS Whistleblowers, the Patients Association has access to thousands of day to day experiences of patients, their relatives and carers who have accessed health and social care services. Sadly, far too many of those experiences are poor, demonstrating a lack of compassion, openness, care and communication. In the last year, the complexity of individual cases to our Helpline has increased considerably. This is mainly as a result of the mismanagement of complaints or concerns raised at a local level and then at Parliamentary and Health Service Ombudsman (PHSO) level.

In November 2014 the Patients Association published a report in respect of the significant failings of the PHSOs handling of complaints. This was directly in response to the calls and correspondence we received on our Helpline. During the last year, the number of people worried about speaking out or complaining about the PHSO has increased significantly, because of a fear that their complaint against the NHS will be adversely affected.

This resonates with our experiences nearly four years ago. It was as a result of the analysis of calls to our helpline in 2011 that we launched the Care Campaign. At that time, we were receiving an unprecedented number of enquiries regarding poor care. Now we are inundated with enquiries and complaints regarding the significant flaws and weaknesses in the PHSO handling of complaints. The very organisation that should be the organisation of last resort for those affected by poor care in the NHS is failing on so many levels. This can only lead us to conclude that the NHS is failing to learn and the cycle of poor care is not being broken. Action plans are tick box exercises, it is real, physical and visual changes that people want to see.

As well as analysis of the data from our National Helpline, this report presents the findings collected from the information received via focus groups, listening events and surveys in 2014. The themes highlighted illustrate the main concerns of patients, and are linked to the principles and values of the NHS Constitution.

To illustrate these themes, we have included some patient stories in order to help the NHS gain a better understanding of the concerns of patients. All the stories have been written personally by patients and their relatives. The Patients Association is very keen to ensure learning takes place as a result of our feeding back episodes of poor patient experience. For this reason, we have also included a look back on the stories featured in our *Patient Stories 2013: Time for Change*.

Our findings show a huge gap between the commitments set out in the NHS Constitution and the reality of being a patient in the health and social care system today. The NHS is failing many of the most vulnerable members of society. To plug this gap, there are two crucial themes that need to be addressed:

- **Concerns about care:** inconsistencies in the provision of care and poor standards of care and compassion.
- **Information and Communication:** lack of openness and transparency in communication between health and social care staff, patients and their families.

These themes can be summed up as a desire to be treated in a humane and caring way with compassion and dignity, openness and honesty.

Key experiences reported to the Patients Association suggest:

- Patients want to be treated humanely, with compassion and listened to. Far too often this is not people's experience;
- People are anxious about raising concerns or making a complaint about their health and social care experience because of fear of recriminations;
- What motivates people to raise concerns is an overriding desire to ensure that others do not share their negative experiences;
- People want to be kept informed about events affecting their health and social care, but all too frequently this is not the case;
- People accept that health and social care staff may not be able to answer concerns that patients raise directly for a variety of reasons. However, it is important that health and social care staff address such matters directly with the patients and/or their family to avoid ambiguity.

The conclusions from this report give further evidence of the need to adopt a patient friendly complaints charter as published by the Patients Association in October 2014.

## ACKNOWLEDGEMENTS

The Patients Association would like to thank all the members of the public, patients, relatives, carers and health professionals who shared their concerns and experiences with us. This includes individuals who called our Helpline, together with those who participated in focus groups, listening events and responded to surveys in our e-newsletters. We are very proud of the support we offer, and that this often leads to improved experiences for patients, as shown by the examples below.

We would also like to express our gratitude to those patients and families who have written accounts of their experiences and given permission for their stories to be published in this report.

The Patients Association has also worked tirelessly on projects across the country, ranging from improving care for older patients to providing development programmes for Patient Participation Groups across Devon, Cornwall and the Isles of Scilly.

The Patients Association is working with over 60 Trusts and other organisations to deliver patient improvement projects. We are also working with a growing number of Clinical Commissioning Groups (CCGs).

We would like to take this opportunity to acknowledge all of the NHS Trusts, CCGs and external organisations that have worked in partnership with the Patients Association to improve services for patients and to ensure that the patient voice is represented.

The Patients Association would also like to thank those who featured in our Patient Stories 2013: *Time for Change*, for writing an update “one year on”. We are also grateful to the NHS Trusts who have given us their perspective of a complaint, after it was published in Patient Stories.

## 1. INTRODUCTION

The Patients Association is a national, independent health and social care campaigning organisation for patients, carers and the public. Established almost 52 years ago, the Patients Association occupies a unique position in the UK health and social care landscape as the only major non-disease specific charity for patients. This is an identity that has enabled us to develop a high media profile and role in stakeholder engagement.

Through our philosophy of “listening to patients, speaking up for change,” the Patients Association campaigns on issues that are brought to our attention through patients, carers and members of the public. One of the methods used to support this role is through our National Helpline.

The Patients Association deals with thousands of enquiries a year to the Helpline which enables capture of stories about health and social care across the UK. We offer a listening ear and vital information, highlighting what needs to happen to ensure that patients and their relative’s access and receive safe, high quality and compassionate health and social care. Through the Helpline and other work undertaken with service users, a large database of stories about patients’ experiences is generated.

Each year, millions are treated by the NHS, but still too many mistakes are made. When this happens, many vulnerable people make the significant effort of raising a concern, often with the ultimate intention of ensuring that lessons are learned and steps taken to prevent the incident happening again.

Each concern should be a learning opportunity; a chance for a Trust or provider of health and social care to genuinely apologise. It is also essential that Trusts are committed to their statutory obligation of openness and accountability, demonstrating a willingness to learn and bring about change. This is overwhelmingly what patients and their relatives want.

Following complaints and incidents, those raising concerns are always told “there is an *action plan*”. Action plans are all too frequently becoming tick box exercises, giving false assurance that things have improved. Patient outcomes and experiences, not a piece of paper on a board table, are the only way to evidence good practice and deliver real, effective change.

Since the initial analysis of data for this report, the Patients Association published a [report](#) into the failings of the Parliamentary and Health Service Ombudsman (PHSO). That report was written as a direct result of the evidence gathered from our National

Helpline. We became increasingly concerned that many of those contacting us for support were desperate for help, as a result of failed local resolution of their complaint and poor experiences when taking their complaint to the PHSO. As a result of that report, the Helpline has been inundated with an unprecedented number of people contacting us in relation to their experiences with the PHSO.

The majority of people who make a complaint do so in a desperate attempt to prevent a recurrence of an incident or episode of care. If the PHSO fails to investigate properly and to identify learning, the NHS will never change. In the words of Sir Liam Donaldson, *“To err is human, to cover up is unforgettable, to fail to learn is inexcusable”*.

The Patients Association strongly believes that in line with the principles of *Being Open* when things go wrong, patients, their relatives and carers should be properly involved in investigations, in order to give new insights and learning. The information we receive from patients and the public supports this viewpoint.

This report has five aims:

1. A plea to listen to what your patients are telling you and be honest, be transparent, show compassion and don't be frightened to speak out.
2. To highlight current themes and the concerns of patients reported to us.
3. To use our understanding of these themes to help influence policy makers and service providers to improve patient support and care appropriately.
4. To demonstrate our commitment to continue building partnerships with the NHS, in order to bring about positive change.
5. To continue to work with the NHS in the hope that our report and stories will improve the experiences and outcomes for patients.

## 2. PATIENTS' CONCERNS – KEY THEMES

Calls received by the Helpline are often one step in part of a long process. Issues raised by callers can take a considerable amount of time to unpick and pursue. As previously mentioned the complexity of cases brought to our attention is increasing enormously. We have to question, is this indication of failings in the NHS reaching an all-time high? Topics of concern included the following categories:

**GP services**, which included difficulties registering with a GP, getting an appointment with a GP, communication around diagnosis and access to medical records, failure to refer, mis-diagnosis and postcode lottery.

- ❖ *My husband and I have been seeing the same GP for the past 20 or so years. She is part of the only GP practice in our village. She knows our past histories so we have chosen to stay with her rather than have to explain everything to a new GP. I have a physical problem which has an impact on my husband's well-being, and he has mental health issues which have an impact on my well-being. However our GP consistently refuses to discuss one in the absence of the other in spite of repeated (verbal) consent. She won't even listen to me during my appointment with her if I need to discuss the impact that my husband's problem has on me.*

**Quality of care-** whilst in hospital, including unsatisfactory medication or diagnosis and cancellations and delays.

- ❖ *Sue's mum had her operation cancelled at least three times; the last being due to the fact that when her chart was checked on the morning of the operation they noticed she was on a blood thinning tablet that she should have had stopped 10 days before the operation. Sue's mum is diabetic and had been unable to eat from midnight as she thought she was going to theatre; then she was told it was to be postponed.*

**End of life care**, including communication about Do Not Attempt Resuscitation orders and the Liverpool Care Pathway.

- ❖ *Julia refers to the care of her late father who she feels was mistreated by the NHS. She said that he was taken off the Liverpool Care Pathway (LCP), which was later reinstated. This was despite the medical consensus that he was coming to the end of his life. She also claims that she was not informed that her father was to be taken off the LCP at any point. She also believes that Palliative Care should have been more involved sooner. Her father's syringe driver had been changed and incorrect dose administered. This error was only realised 6 hours after the incident.*

- ❖ *“Sara was kept alive by machines in the intensive care unit. We were then present whilst they carried out some tests to ascertain that she was really only being kept alive by machines before these were switched off. This is also when Sara’s little heart stopped beating. This was it, my Sara was gone for real and forever! There was nothing I could do to have her back and keep her with me. It is heart breaking to imagine how unloved, frightened, uncared for and alone she must have felt whilst in so much pain in her last hours of life.”*

**Access to mental health services**, poor levels of compassion and provision of services for those requiring support.

- ❖ *“I have suffered from severe depression since 2011; have had numerous referrals and assessments, but still waiting for treatment. I have just this week received a letter for an appointment for yet another assessment, which may put me on a waiting list for treatment. However, I will have to travel for over an hour one-way. I often can't drive safely due to my condition and in addition just can't afford the petrol to do this regularly.”*

**Complaints handling process** within the NHS, including a culture of defensiveness and lack of transparency.

- ❖ *“My wife died in hospital and there were serious questions that I raised with the various health agencies involved in her short illness. I was messed about for over two years, particularly by the hospital Trust. Obtaining all of her medical records was an ordeal in itself that was never completed, some even having been destroyed under retention policies after my request. I remain convinced that she was seriously let down by the NHS for a number of reasons. I was so totally dissatisfied with the way in which it was handled and with the unfinished and unsatisfactory outcome but I was physically and emotionally drained and had to give up for the sake of my own physical and mental health. The file became so large and complicated by what I considered to be procrastination, prevarication and obfuscation that the task became overwhelming.*

*To prepare a file for the Ombudsman was a daunting task. My contact with the CQC had been uninspiring. I reluctantly concluded that I couldn't continue even though I desperately wanted to for the sake of my late wife and other patients, something that in itself leaves me with a feeling of guilt.”*

**Parliamentary and Health Service Ombudsman-** handling of complaints and outcomes.

- ❖ *“The PHSO responses from their ombudsmen have been nothing short of pathetic. Wholly lacking in any investigation, delayed, quite off hand and complicated. They have insisted in breaking my complaint into two, narrowing the scope so that there could be very little recompense or penalty or anything*

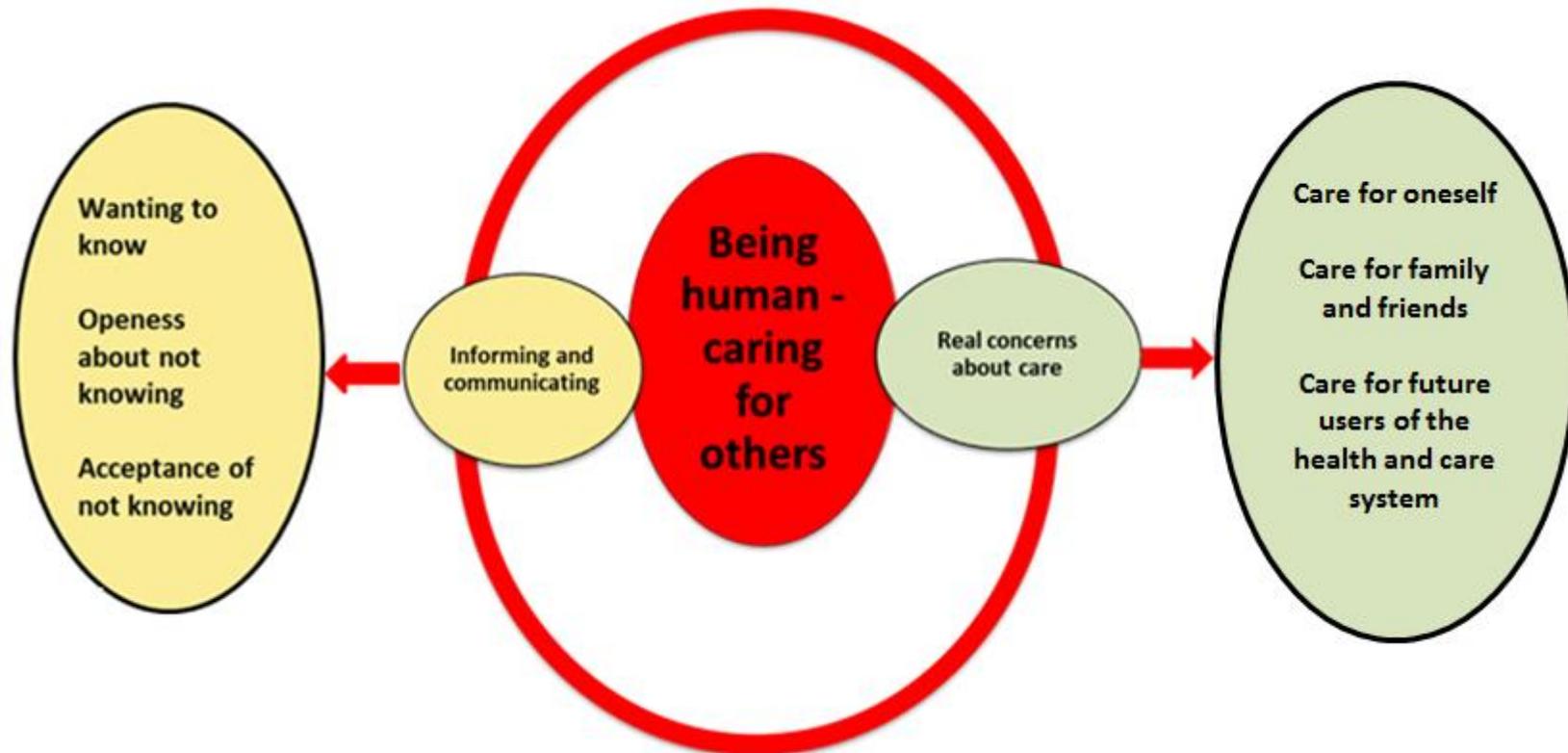
*required, and they are massively biased in my opinion in favour of those they are 'investigating'. I have to say they appear an extension of a very mistake-denying NHS. I love the NHS. I also know how complex and inefficient and ineffective it can be."*

- ❖ *"The whole process relies heavily on the complainant being able to formulate and present complaints almost to evidential standards. There appears to be no recognition that most complainants are laymen, unlike hospitals, who have lawyers crawl over everything, the cost being carried by the tax payer."*

During 2014 a large volume of Helpline queries recorded on our database, film clips and sound bites were drawn together and analysed thematically to produce themes around the principal areas of concern for patients and members of the public who engaged with Patients Association services during this period.

There were two key themes and these had a number of areas for discussion. These are illustrated in figure 1. There was also a single overarching concern which came up time and again; a desire for people to be treated in a humane and caring way within the health service. We have described this as '*Being Human – caring for others*' equating to a deep sense of caring for each other humanely. In other words back to basics - treat *people as you would want you or your relatives to be treated*. This includes the complaints process both at local level and PHSO level.

Figure 1: Diagram of themes from the data analysis



### 3. OVERARCHING THEME: BEING HUMAN – CARING FOR OTHERS

A wish to receive humane treatment from the NHS came up as a consistent concern amongst people contacting the Helpline. Sadly the experience of too many people was that the treatment they received was anything but humane. On too many occasions people who were vulnerable were not being kept informed about what was happening about their (or their relatives') treatment, and were often left with profound concerns about their future welfare. Being 'human' also means that health and social care professionals and patients, carers and members of the public are all equal, and when accessing health services, people want to *feel* equal and cared for and listened to. Those caring for patients in health and social care services must be conscious of treating patients as people not as a number or disease.

Often it is the way in which a patient or their relative is communicated with that makes the difference between a good experience and one that is less than satisfactory. Albert's case below offers an example:

- ❖ *Albert's wife had been in hospital for over two months and this was nearly 40 miles from their home. He has mobility problems and can require a wheelchair taxi to take him to the hospital to see his wife. This is arranged when his daughter can help him on one particular day of the week. Albert and his daughter wanted to speak to the consultant looking after his wife but Albert has been told that the consultant is only available on Wednesdays and the consultant refuses to offer a telephone call to discuss his wife's care.*

Similarly, a bad experience can result from a person simply not being treated 'as a human being', i.e. without dignity, respect or compassion as borne out by these case examples:

- ❖ *Lucy told us she was not happy with her doctor's surgery. She went to see a nurse who was quite rough with her when taking a blood sample and while she was there another nurse walked into the room while she was half dressed. Lucy felt vulnerable but when she wrote to the practice manager about her concerns she was told "Well, you can leave the practice if you are not happy." This made Lucy really anxious and worried.*
- ❖ *Pippa was due to see an NHS specialist after a referral from her GP. She was told it would probably be about a four month wait which worried her. Pippa was so frightened she decided to go and see someone privately first, whilst she waited for her NHS appointment. She called the surgery to check details of her appointments to be told that her GP surgery had now cancelled the appointment because she had told them that she was going to see someone privately. She was upset that her surgery never called her to discuss their intentions or advised her once they had cancelled the*

*appointment. She did this because she was unsure whether she would have to wait for four months or longer for an NHS appointment.*

- ❖ *Colin told us of his uncle who had been in hospital for four months. His uncle's house was not prepared for his return as there was no heating and rubbish had not been collected for months - the place was dirty. Colin believed there may have been a discharge meeting but the family was not involved and did not know the details. Colin was not clear what to do and wanted to know if he needed to pay privately for the rubbish to be collected and the house made safe for his uncle's return. The hospital had not communicated with him. Colin lives a very long way from his Uncle.*

## **Real concerns about care**

The first key theme '**Real concerns about care**' arises from the importance people placed on the basic principle of feeling cared for and to experience considerate and thoughtful care. Frequently, callers to the Helpline were motivated by a concern for other people who would use health and social care services in future.

## **Care for oneself**

People wanted to be fully informed and knowledgeable about their condition including the systems and processes that they needed to access to help them manage or treat their condition. Many of the patients in touch with the Patients Association lacked knowledge about their rights as a user of health and social care services. Examples included:

- ❖ *Mary wanted to know more about her illness that was diagnosed following 18 months of investigations, numerous visits to the GP and investigations at a hospital. She was worried for her own family and whether or not they should have investigations. The GP did not seem concerned and would not advise whether her son and daughter should have a blood test to check for the rare condition.*
- ❖ *Alice was told by the practice nurse that she would need cardiac monitoring for 24 hours but she was not told why she was having it and when she would be having it. She wanted to know if she should ring the practice nurse but was afraid she might get "angry" with her.*
- ❖ *George who is 92 was told that the chiropodist could no longer visit him and his elderly wife and he would now have to pay for a private service or arrange to visit the chiropody clinic twice a year. George's wife has not been out of her flat for almost 2 years and he is very concerned as she is a diabetic.*

## PATIENT STORY

### Peter Woolliscroft – In his own words



I am a 68 year old male – still working full time and with over 40 years' experience of working in the NHS, including as a Board level Director of an NHS Trust, so the inner workings of hospitals are no mystery to me.

My account documents my recent personal experience.

It all started in the early hours one morning with the sudden onset of severe bouts of sickness and diarrhoea and extreme stomach pain – painkillers had no effect and it continued throughout the following day. By 17.00 hours I decided I needed to present to the local hospital, thinking it might be food poisoning, which might now need investigating.

I was taken into the A&E department itself where I waited to be seen. Although I had been allocated to a particular nurse, they unfortunately were dealing with another patient so there was a wait, which although not long because I was in great pain, it seemed an age. After examination, a doctor was called and after another examination I was given a morphine injection for the pain. I was later admitted to a ward for overnight observation.

On arriving on the ward, I actually thought I was on the set of the 1950s Carry On film. The beds were very old and far too close together. There was only one power point between 2 -3 beds and trailing extension cables, the ward environment itself was poor, there was no TV and even the ward clock in the bay wasn't working. As my own expensive watch had been taken away with my possessions, I had no way of knowing how much time was passing and when you don't know this you lose much of your sense of time and reality.

During the night my condition became worse and I was transferred to the Intensive Care Unit (ICU). At this point the hospital informed my family that I was seriously ill and that they should take my possessions home. It was then discovered that my watch was not with my belongings. I reported this to the staff on both the ward and the ICU but was unable to follow it up due to my deteriorating condition. It is fair to say that they appear not to have been able to do anything about it. I asked my family to mention it to the Patient Advise and Liaison Service (PALS) but they simply

advised me to submit a claims form. I got the impression that no one seems to think it was important enough to take action.

Once I started to make a recovery, I was able to observe the way that parts of the hospital worked at close quarters. I would like to make it clear that the medical care I received was good, and the medical team took time to explain what was happening and I can only thank them for getting me to a point where I can write this account.

Even in such a key department where most patients are confined to bed and with very limited movement, the staffing numbers were less than I would have expected from my own professional experience. When I raised the issue of the apparent shortage I was told the planned staffing level did meet the required standard but that due to sickness and other reasons this standard had not been met – they were short staffed. On asking, I was informed that the standards were: one qualified staff member to two patients. However during the day this went up to three patients and at night to a minimum of one member of staff to five – and this was on intensive care!

Patients in intensive care are very often unable to carry out the most basic of functions without help due to their conditions, the impact of drugs and being immobile – they depend on staff coming to their assistance and the need for help is very often highly unpredictable and urgent. Everyone will be able to understand why a rapid response is important to patient dignity and comfort, sense of wellbeing and to creating the sense of a professional, caring environment. However, there were many times when no one came for at least 10 minutes and at times it was much, much longer.

I could plainly see that they were unmoved by a call bell, preferring to finish their personal conversations before responding to patients. This was not a one off – it happened time after time and was clearly the culture: patients appeared not to come first with some staff.

Whilst I did meet some very caring staff who did take the trouble to talk to me and made an effort to consider my perspective and needs as a patient, these were very few in number. Because so many of the staff were so busy and uncaring, I found it very depressing indeed to find out that the good staff would not be on duty the next day, and one was forced to rely on people who have apparently little interest in their job or their patients and have lost the ability to empathise or show compassion.

I was eventually transferred from intensive care to another ward. To my disappointment this was just as primitive as the first except that there were more modern beds. The space between the beds was even more cramped, even though it is well known that bed space is important in terms of infection control.

And yes, there was another broken clock. Again there was no TV – having nothing else one can do has a very negative impact on wellbeing and recovery. One would

expect something as basic as this to be provided given patient wellbeing and speed of recovery should be a priority.

I found my stay on this ward extremely depressing. As I was unable to get out of bed without assistance, this placed a strain on the already stretched nursing staff and it had a major impact on my morale and the speed with which I was able to recover (and free up a bed for someone else).

Having been treated at the hospital around two years ago for a lower back problem I found my pain had returned. When I discussed this with the consultant I was told the nature of my condition had back pain as a side effect and that it clearly aggravated the original condition. He kindly advised me he would request the Acute Pain team paid me a visit. A few days' later two nurses announced themselves as "pain specialist nurses" and "what was the problem". I explained what I was told which was greeted with a statement that this is nothing to do with them as they only dealt with pain directly as a result of the hospital procedure and I should make an appointment with the community Pain Service!! On asking how they suggested I did that, I was told my recovery in hospital could be up to a further ten weeks! This was met with a "don't know just take some paracetamol!" If this response is correct and complies with standard practice then it is about time the guidance is reviewed.

Two weeks and two blood transfusions later the condition that had landed me in hospital in the first place was now under control and I could have gone home had it not been for my continued lack of mobility. I was still unable to get out of bed without help or walk without a frame. Staffing levels were just not adequate. At most there were two trained staff at any one time, up to 15 patients per nurse at night, with the remainder of the ward team made up of Health Care Assistants (HCAs) of varying levels of experience.

Not only did this impact on patient care, but it also undermines the staff that do want to do a professional job. There were however very good staff, which tended to be one or two per shift but even these were frustrated by the low staffing numbers, but also the casual attitude of some of their colleagues.

Being in hospital for long periods means that mealtimes often become a highlight of the day as they are often the only things that break the monotony. Although the food was not bad when it was produced, distribution on the ward was not of a good standard. In the six-bedded bay where I was, every single day at least one patient got the wrong meal or there was something missing despite having named individual menu cards. To be fair, the staff tried to reorder or provide something else but all too many times the moment had gone and the anticipation of the meal was lost.

As I began to recover, I asked some of the HCAs for their view of the issues. Needless to say inadequate staffing levels was the first and major item but there were other practical issues which could be dealt with more readily and would have

an impact not only on patient wellbeing but also on the efficiency with which the hospital can run. These included:

1. Some means of raising their concerns with “senior management” as they felt that every attempt they had made to raise issues with local managers had come to nothing.
2. TVs or other entertainment or the “patient power system”. This is a particular issue when one is too ill to read and it helps to pass the time. There was nothing available unless the patient brought their own and in such cases the equipment understandably had to be checked by the hospital staff – and this took a long time.
3. Patient wash kit: it is inevitable and readily foreseeable that patients admitted as emergencies will arrive on the ward without essential items. I am not sure what happens, but I guess the staff used materials left behind by previous patients.

Once I was medically fit for discharge, the Physiotherapy team was now charged with enabling me to be sufficiently mobile to leave the hospital. However, the team was also short staffed. I saw a physiotherapist for 30 minutes every couple of days which was not enough to make a difference; it was supposed daily The Physiotherapists assumed that the Health Care Assistants would help me to practice the exercises but this simply did not happen; the HCA did not have time.

I found the whole experience extremely depressing, detrimental to my overall health and a poor use of resources – I simply could not see myself getting any better while I remained there. I therefore requested a discharge to a rehabilitation unit and was later discharged to a privately owned facility, as a state funded patient. More of my possessions went missing during the transfer from hospital to rehabilitation unit. The quality of the accommodation was very high and the staff care and attitude was high quality and focused on supporting patients to regain their independence as quickly as possible. However, I still required some clinical support that was beyond their resource particularly at night where one carer was looking after 15 to 20 patients. My history, care plan and treatment were incomplete.

Although one of the major purposes of the unit was to enable patients to regain lost muscle mass so that they could regain mobility and independence and go home, the amount of physiotherapy was inadequate for a speedy recovery. I was there for three days before any initial assessment, and the treatment plan consisted of a sheet of exercises and being told the physiotherapist would return in about 4 days. After the next visit, I successfully argued that for all the good it was doing me I might as well be at home and it would be cheaper for the NHS; this was agreed. I went home 10 weeks after the original admission to hospital.

At the point of discharge from the hospital I was told my GP was being sent all my files and a “Care Plan” as I was no longer the responsibility of the hospital and my care would be transferred to my GP.

Once home, I expected that there would be some form of follow up to the discharge letter, sent to my GP informing them of the required on-going medication and my general physical condition. A Care Plan from the hospital had been sent, but had not arrived. Two weeks after discharge no one had been in touch. I rang my GP, having been told that they had the notes but my GP had done nothing. The GP suggested a blood test to determine my prescription but it was a week before a nurse came to take it.

As the medication given to me at discharge had now run out I rang the GP to be told by one of the practice managers that the GP had not been passed the results, but she would now have the GP issue a prescription – which would be ready in a week. A further 2 weeks passed and I was still waiting.

Six weeks post discharge I attended my follow up appointment at the hospital and looked forward to clarification on my diagnosis and Care Plan, as the GP had failed to fulfil this role. I was advised that although I seemed to have started to recover well, the original trigger for my problem remained a mystery and I should take great care with diet and general lifestyle, however my GP should advise further.

I made an appointment with the GP to follow up on this advice, however there was very little that could be done, I even struggled to get a decision as to how long I should continue to take the drugs I was prescribed. When I remonstrated over the lack of community physiotherapy and follow up care etc, he agreed the service was not as it should have been.

Whilst staff are professionals in their own right and should act on the hospital’s standards and practices, in my experience these issues arise because the hospital has allowed this culture to develop and has not been effective in dealing with the issues causing it including listening to staff concerns and suggestions. In many cases, unnecessary costs are incurred through poor practice and shortsighted cutbacks. It is not always about money, but about senior managers having the will to find out what is happening at ground level. There are plenty of staff at middle level, but not enough on the frontline.

I have shared this story because I think it is important as means of keeping the issues at the very forefront of everyone’s mind. Everyone should speak out about their experiences – good and bad – as a means of keeping the issue on the agenda. It brings about change and, importantly, supports those staff who still put their heart and soul into caring for patients and upholding the standards which the NHS should have consistently as its focus.

## Care for family and friends

Many callers to the Helpline did so on behalf of a family member who lacked the confidence or knowledge to make the call themselves. Some were hesitant to call because they were worried that it might affect their future care if they complained about a health professional they would need to see again in the future. The following examples illustrate some of the issues described by relatives. The following two moving accounts have been written by Joanna Wragg in relation to the care her grandfather and father received whilst patients at Whipps Cross Hospital.

### PATIENT STORY

#### Frederick Tolhurst - written by his granddaughter Joanna Wragg



Frederick Tolhurst was admitted to Whipps Cross University Hospital, Leytonstone, on Saturday 1st March 2014 and was placed on one of their three winter pressure wards, Mary ward. Due to the substandard care he received he passed away on that ward, with no family present, fourteen days later. This was the first and only time he had been admitted to an NHS hospital.

My grandfather was born in Hackney on the 9th September 1920, one of eight siblings. He loved cricket and football, whether it was to participate in school or college or try to score goals from his armchair later in life. He was keen on cycling and was still riding a bike up to the age of ninety. Grandad Fred

as I always called him, was intelligent and determined. He was awarded a scholarship to Regent Street Polytechnic and gained a good, all round education whilst also learning the trade of tailoring. He served in the Second World War as a Royal Engineer. He was one of the first to be enlisted and one of the last to be demobbed.

He married my Grandmother Ellen Donovan in 1942 and they had almost fifty years of marriage until she passed away in 1990 of ovarian cancer. As a family they raised my mother Anne and her younger sister Linda. He worked hard first as a tailor and when he could no longer find work in that field he trained and took exams to become a counter clerk for the Royal Mail. When I think about my grandad I think of a man that was clever, who got up and did four crosswords in the morning, loved computers and new technology. A man who enjoyed the simple things in life, a cup of tea and a

slice of cake or talking to the lady in his local paper shop when he walked to collect his daily newspaper. Fred was loyal, shy, kind, and inquisitive, a man that was always level-headed, he never smoked and only drank a glass of bubbly at Christmas, enjoyed a roast dinner and loved his family. He never hurt anyone, found joy in watching nature and the seasons pass; he was our family's own personal weatherman, always knowing if a storm was coming with no help from the Internet or fancy meteorological machines.

I think that is why I found his death so hard to take. He was given so little compassion, and completely dehumanised in the days leading up to his death. Even though a number of months have passed since he died, the loss and circumstances in which he died are still as raw as if they happened yesterday.

On Saturday 1st March 2014 my grandfather was admitted to Whipps Cross University Hospital after falling down a couple of stairs inside his own home; he had fallen backwards and hit his head and his back on a metal radiator cover. He had been subject to blackouts in the past due to epilepsy but in this instance my mother believed he simply lost his footing when going from downstairs to upstairs. He was assessed in A&E and found to have a mild urine infection which would need antibiotic treatment and observation due to the fall but he had been cleared of any major broken bones or bleeding. He was also assessed to have lower oxygen levels due to cement on his lungs because of work he had carried out on Mulberry Harbour to advance our troops during the war.

My grandfather was placed on an Acute Assessment Unit (AAU) and our family were satisfied with the care that was being delivered to him. He seemed at ease, if a little reluctant to stay in hospital. My mother requested could she take him home as my own father had already had bad care on a respiratory ward some three weeks earlier. She wanted to be notified if my grandfather was to be moved to any other ward within the hospital, no matter what time of day or night. We were assured he would remain in AAU for at least a day or so and not to worry, he would be safe. We were soon to find out just how wrong this information was.

In the middle of the night my granddad Fred was moved onto a winter pressures ward with half agency nursing and half employed staff. By the time we finally located where my grandfather had gone to, telephoned the ward numerous times with no answer and reached the hospital for visiting time at 3pm my mother did not recognise her own father. His mouth was so dry his tongue was stuck to the roof of his mouth; he struggled to communicate with us, was disorientated and utterly confused. Another contributory factor we found out a few days later was that nurses were mistakenly over-prescribing his epileptic medication, which added to his drowsiness and confusion. When we asked staff about his deterioration in less than a twenty-four hour period spent within the hospital, our concerns were dismissed.

My mother had looked after him for twenty-four years, the last two as his live-in carer. I believe that he was put on a winter pressures ward due to "dementia" being written in his hospital notes, and the fact he was in his nineties; not seen as the precious human being he was to our family but simply as hospital fodder. Placed in incontinence pads and not given the opportunity to be assisted to the toilet, being dirty was something he despised as he was a clean and proud man who when at home woke up each morning at 7.30am to have a cup of tea, a slice of toast and a wash.

There were generalised failings within this ward due to the lack of knowledgeable staff on shift. The locum consultant could rarely be found so junior doctors or registrars were left to make inappropriate and at times dangerous decisions that should have been made by more senior members of staff.

One such case of rude and unpleasant nursing occurred within the first week my grandfather spent on this ward. I buzzed his call bell for him and a health care assistant attended. She said to me, not to my grandfather the patient, in a raised and aggressive tone "*yes what do you want?*" When I highlighted to her that my grandfather wished to use the commode, she said "He will have to wait. I do not have anyone to help me". When I offered to assist she turned her back to me and walked away.

My Grandad Fred was left acutely dehydrated through the poor care of this hospital. Whenever our family went in to visit he would be gasping for a drink but often fluids and his personal items such as glasses, or food our family had taken to the hospital, were left out of reach. I never saw any blood pressure (BP) checks carried out within visiting hours, which were 3pm to 8pm. Furthermore, vital medication would be placed in front of elderly patients but nurses did not actually check to see if patients were taking these drugs. On a number of occasions I would administer the drugs that had been left on my grandfather's table as he was unable to see them due to cataracts. Since receiving my grandfather's medical notes after his death, I now know that he had not been properly hydrated for seven days prior to his death, and food charts had been falsified/lost due to staff not having enough time to monitor patients correctly.

This ward at Whipps Cross failed on basic hygiene; the toilets upon entry to the ward often smelt of human waste. Patients including my grandfather would be left unwashed, lying on their backs to prompt sleep and bedside buzzers left in their cradles on the wall so patients would not bother nursing staff. When my Grandad Frederick George Tolhurst (I like writing his full name because it makes me remember the person he was), was mentioned by any nurses, he was "bed 17", utterly dehumanised, no longer a person with a past and people that loved him. Simply a number, a statistic, void of feelings or emotions.

A couple of nights before my grandfather died, this is one of the memories that I will cherish of him the most. I sat with him for some time and as I helped him, he ate a little bit of an omelette and had a drink. Then he told me this fantastic story about when he was a tailor on Saville Row, measuring people for suits, marking and cutting cloth, making high end garments for the wealthy. I will take that night and feel blessed I shared it with him forever.

The night before he died, due to a breakdown in communication with Social Services, our family was told to expect that my grandad should be discharged the next day as he was free of infection and had recovered fully from his fall. The only thing delaying him going home was that he had become constipated. A young registrar prescribed a laxative called Picolax and when my mother highlighted that my grandad was used to more natural methods of constipation relief, eg prunes or dates, this doctor replied with "*Pfft we have something stronger than that*". Grandad Fred was dead less than sixteen hours later.

When I have asked both clinicians and done my own research about **Picolax**, I have discovered that it is contraindicated for anyone with heart problems (my grandfather had a leaking valve), epilepsy and dehydration. Any fluid lost should be replaced, which did not happen to my grandfather and I remember the ward being especially hot the night before he died, but no bedside fans were available.

On Friday 14th March 2014 at 1.50pm in the afternoon I received a call to say my grandfather had been found unresponsive, he died less than ten minutes later of a cardiac arrest, alone and with no family by his bedside. We later found out that he had been calling my mother's name, Anne, all morning due to the distress of having unbearable sickness and diarrhoea, but no-one had contacted us. He died frightened and alone, in unfamiliar surroundings with people he did not trust.

His death certificate states broncho-pneumonia, carcinoma of the right kidney and heart disease and that he had already lived to a good age of ninety-three. I do not believe this tells the story of what really happened in the days leading up to his death and the ultimate reason why he died.

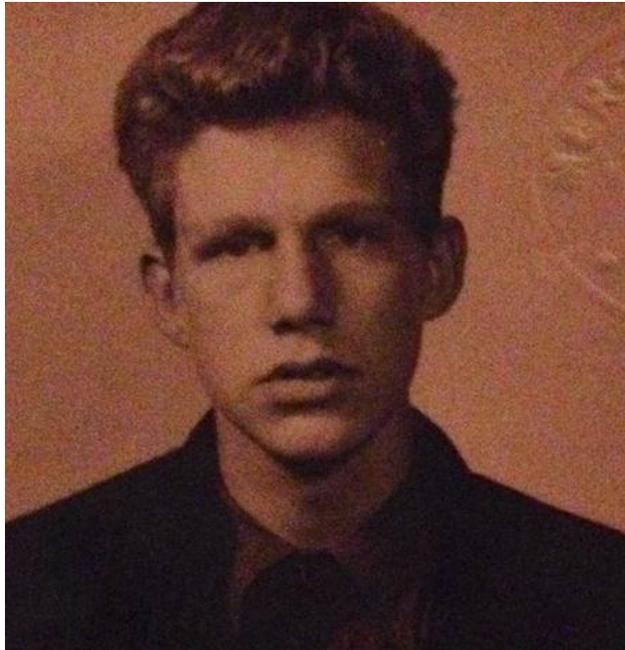
I logged a complaint and a 'Gold Standard' elderly care project is being piloted by the hospital, due to the substandard care my grandfather received, however no formal response to my complaint has ever been received from Emergency Care and Acute Medicine (ECAM) Governance, or Barts Health. Furthermore, it will never take away the feeling that had my grandfather not gone to that ward, I do wonder if he might still be alive and with our family today.

Frederick Tolhurst fought hard for this country and did not deserve the undignified, frightening death he suffered.

I feel drastic changes need to be made within the NHS in their approach to elderly care so my granddad's death is not mirrored by other families. It was hard enough for

us to go through, I would not want someone else to experience this low level of nursing, sometimes only two nurses for nineteen patients, and the first-hand impact that has on a loved one's life.

### **Daniel Wragg- written by his daughter Joanna Wragg**



Daniel Wragg was admitted to Whipps Cross Hospital with choking symptoms after eating a sandwich. It took hospital staff ten days to discover a denture had become lodged at the back of his throat. During nine months within the NHS Daniel has experienced both good and very bad care. He has not yet made a comprehensive enough recovery to return home. His family believes that, had the initial diagnosis been quicker his life would not have been so greatly impacted by this minor event.

My dad was born in London during the Second World War on the 4th June 1939. He has three sisters Iris, Jean,

Joan and I am his only child. He is a widower and has lived alone for almost twenty years. Whenever I think of my dad the words scatty, fun-loving, prankster, independent and a fighter come to mind. He went in the Navy when he was seventeen, followed by National Service in the Military Police and then worked on printing newspapers for a short period of time, but for most of his working career he printed money for The Bank of England. He was a practical joker - he once launched a massive snowball from the roof of the printing building in Debden onto his boss during winter. He was a scallywag who loved a pint of John Smith's, some dad dancing and beating anyone he could at a game of crib. I learned how to play pool from him and make mind-blowing cheese on toast by following his own secret recipe. I owe him a lot - my personality and my will to never give up, but somehow within our journey through the NHS over the last nine months I feel as though I have failed him. Surely getting better after a denture becomes lodged in the throat cannot be this hard?

How do you tell someone's story spanning nearly a year? I do not believe I have the correct words to convey the pain of having so many cannulas piercing skin and puncturing veins. My father's face now contorts before even a doctor or nurse comes near him. I will never completely understand the suffering he has had to go through just to prove to clinicians that he simply wants to live. I will try, but my words will always fall short.

My father Daniel Wragg's story begins on Friday 14th February, 2014 - Valentine's day, but unfortunately there was nothing romantic about this day. I popped in to see my father at home and he looked very distressed, he whispered to me he had been trying to eat a sandwich and afterwards he had not been able to eat, drink or speak

properly. He had been unwell, some vomiting but nothing had relieved the symptoms he was experiencing. Seeing him in distress I rung for his GP who, on seeing my father recommended an ambulance would need to take him to hospital. I knew my father must be feeling poorly at this point as he put up no objections to going into hospital.

My father was admitted to Whipps Cross University Hospital that evening. He was being assessed in their Acute Assessment Unit when I reached the hospital, where he was promised an endoscopy and x-rays to find out the problem with his swallowing difficulties. I was told he would remain in AAU for a couple of days while they evaluated his condition and find answers. This did not happen - he was stabilised and in the middle of the night moved to one of the hospital's respiratory wards, Curie. Some ten days later we found the cause of my father's distress: he had a two teeth denture lodged in his throat.

Once my father reached Curie ward he was told he would have to wait for an endoscopy as there were not any staff available over the weekend to perform this investigation. An x-ray of his throat was never assessed by doctors, only the one of his chest to determine if he had any problems; but the lung area was completely clear. Due to this error in judgment and my father not having the correct medical investigations when he first got to the hospital, his life will never be the same again. After a weekend spent on Curie ward with low level nursing, still being given food which would not go past the blockage in his throat, we were told each day he would have to wait for an endoscopy. I received no answers as to what was wrong with my father, yet I could see his health was deteriorating. His breathing had become shorter, shallower and he appeared to be going hot and cold - the beginnings of infection and a fever. When I highlighted to a young female junior doctor on the ward that I felt my father had only become sicker since arriving at the hospital and requested to know when the endoscopy was booked for, all I received was a reply that my father was fine as he had a Speech and Language assessment earlier that day Monday 17th February. When I pushed for an answer to my question regarding an endoscopy she held her hand up to signal it was not open for discussion and walked away. At that moment I left the ward and looked for an avenue to complain to.

By that evening at around 9.30pm I received a phone call from the hospital to say my father had been found unresponsive and was being assisted with his breathing, he had bilateral pneumonia and was about to be transferred to the hospital's Intensive Care Unit as they had the necessary equipment to look after him. I am thankful that there was an ICU bed available that night because I know how precious they are.

My father spent twenty-three days in ICU, some on an oxygen hood, some sedated completely and on a ventilator, days spent somewhere between reality and coma. Members of my dad's family were shocked by how he looked; tubes, lines going into each arm and his femoral artery but I just saw my dad, our roles reversed, he looked so small and helpless, the opposite of the man I knew growing up. During the second week of being in ICU by sheer luck one day, when a lovely, very experienced nurse in ICU was suctioning my father to take secretions from his throat and chest, along with the phlegm up came his denture, finally dislodged from the place it had called

home for the past ten days. There had been problems inserting a nasogastric (NG) tube due to the lodged dentures, so my father had spent a long period without food.

The days were very hard to take as a relative when my father was in ICU, I was called daily both morning and in the night to say he might die or to repeat the same information I had been told the day before. My father is underweight for his height and I believe he was overdosed on the sedative Propofol whilst in Intensive Care as it took him an extra week to wake up from being in an induced coma, to remember his own breathing patterns and return to the world of the living. I was repeatedly told he would never wake up from sedation, and said the best outcome would be to turn off the life support machines. When I sat by his bed and read his favourite book 'Jonathan Livingstone Seagull' I said to him it was alright if he wished to go and I was proud of him for the fight he had put up in the face of such sickness. However, I told my father if he wanted to live he had to give me a sign to continue to challenge the system, and he opened his eyes briefly and squeezed my hand. I took that as a sign he wanted to survive and I was right, as the next day, slowly but surely he came round from being sedated and having machines breathing for him. I am forever grateful that I disregarded the advice of that Dr to turn off my father's life support machines and gave him the time to recover and a chance at life. The matron on ICU and her team do a fantastic job of working in very tough circumstances. I could not fault the nursing care my dad received whilst on the Whipps Cross Intensive Care ward.

Once my father had become slightly more stable, he was transferred to the ward that specialised in Respiratory. I have to say the care he received here was exceptional and all of the staff that work on this ward are fantastic. I could not have wished for better for my father. I would like to thank them from the bottom of my heart; they looked after my father as if he was their own relative. There were some difficulties; my father had some memory problems after the long anaesthetic, then he had to have a PEG placed and then moved into the duodenum after repeated aspiration pneumonia. But on the 6th June 2014, two days after my father's seventy-fifth birthday, he was transferred to St. Margaret's rehabilitation unit in Epping for what we believed would be more intensive and all-round rehabilitation care. My father and I thought we were on an uphill journey finally towards him regaining full mobility, eating again properly and having a normal life. We were so close to this when discharged from Whipps Cross, but unfortunately that was not the road we were destined to travel down.

I now know that the ward my father was on at St Margaret's rehab unit does not have enough qualified staff to administer PEG-J (that went into his duodenum) feed correctly or safely - often they did not give my father enough fluid via his PEG-J tube and he was left dehydrated. Within ten days of going to the unit, my father's feeding tube was blocked due to a nurse administering medication down the wrong port. It was forcibly aspirated and this tube moved into his stomach, although this was not confirmed until a month and a half later, when my father was admitted to Harlow Hospital as an emergency case.

While we were in St. Margaret's my father's mobility went backwards due to them not having a qualified physiotherapist employed. For the first six weeks that he was in their care he only got out of bed once or twice a week due to the low staffing levels

overall on the ward and lack of compassion or understanding to his individual needs. Comprehensive mouth care was almost non-existent, he was often left for eleven hours in his own waste until I came on ward to highlight issues and help staff to make him comfortable. He was isolated for a lot of his stay in a single person bay. My father often had sickness and diarrhoea which was not addressed by staff. When my father finally left St. Margaret's rehab unit in an ambulance and was admitted to Harlow Hospital it was also found that he had contracted MRSA within St. Margaret's during his stay with them.

Due to the lack of basic personal care, (even though he had a shower within his room he was not washed properly for over a month), my father began to withdraw from the people providing his care and only trusted me who visited daily and his youngest sister Joan, who popped in to see him when she could. I requested to move my father out of St. Margaret's on the grounds I was unhappy with the care they were providing but was told he needed to have a continuing care assessment (which was still being worked on when he was admitted to Princess Alexandra Hospital, Harlow, four weeks after the initial process had begun). My father had a video-fluoroscopy during his time at St. Margaret's to deem if he could commence eating. It came back that he was of high risk for oral intake; he did have a swallow, but some pooling of fluid over the epiglottis, the rehabilitation of my father's swallow never happened. The speech and language therapist only saw my dad four times within three months due to her having such a heavy workload. Due to this my father has never eaten, never seen an ENT consultant or had any real effort made by professionals to regain his swallow fully, other than the daily exercise we did together at this hospital.

On Sunday 31st August I got a phone call in the middle of the night to say my father was vomiting a coffee ground colour and was being sent to Princess Alexandra Hospital, Harlow. I asked for him to be sent back to Whipps Cross as they already knew him and had positioned the PEG-J there, also I was sure he would be well cared for if I could get him back to his previous ward. I suspected the sickness was due to the tube in his stomach and it being blocked some ten weeks previously at Epping rehab unit and I wanted him to be on a ward where they really cared about their patients. My request to the night sister was ignored and my father was sent to Harlow Hospital. Once he was in the hospital, although I mentioned it to consultants and various nurses, I have never managed to get him transferred to another hospital. Due to the MRSA, patient choice was disregarded very early on.

My dad was on a respiratory ward after a short time spent in A&E. It was a twenty-eight bed ward, with only two qualified nurses in attendance most days, assisted by two unqualified nurses. There was a high proportion of dementia patients being cared for on this ward with little support and you could tell the running of the ward was stretched to the maximum. It took me twelve days on this ward for the staff to listen to me and to disregard the incorrect medical notes from St. Margaret's as to where his feeding tube should be placed. Twice x-rays were taken of my father's stomach and, without consulting me or him, the feeding regime was re-commenced because they believed the tube going into his stomach was a simple PEG. Twice he aspirated feed into his lungs and nearly died. I was told by the Head of Nursing and a junior registrar that due to the unknown reason behind his deterioration a Do Not Resuscitate (DNR) was being put on his notes. By chance, after the second time the

ward had commenced the feeding regime and my father vomited, an x-ray was repeated by a young registrar and he told me the tube was coiled in my father's stomach. Thankfully he listened to me when I highlighted that this was the incorrect place for the tube and they were endangering my father's life each time they hooked him up to the feed. His feed was stopped and he vomited a coffee ground colour and a further 1,100 ml of the same colour fluid was aspirated from my father's PEG-J tube. The tube had coiled in his stomach and was irritating his stomach lining and causing it to bleed. One nurse said she had never seen that colour of fluid be pulled from a person's stomach and at that time I began to worry.

We were transferred to a gastroenterology, haematology and oncology ward. Overall my father's time in Princess Alexandra Hospital has not been a success. On this ward they had to have three attempts at replacing the PEG-J tube into the correct position in the duodenum. With each time he lost a little more of his memory as anaesthetics affects him immensely; he can feel the after-effects of these drugs weeks after them being administered due to poor kidney function. He has not had a shower or bath for seventy-four days as his mobility and MRSA are deemed too much of a problem to overcome and make him feel like a human-being again. However, this lack of hygiene impacts on the MRSA, and we are now on the third round of treatment, having never had the all-clear. As it took eight weeks to get his PEG-J tube working again, my father was fed via a cannula with Total Parenteral Nutrition (TPN), which had various risks associated with it. The TPN was given firstly through the veins in his arms and then his feet for almost a month. When those veins began to collapse, the feed was then pushed through a main artery in his neck. During this time I have never had confirmation as to whether or not the arterial line became infected due to poor care management although he did display signs of an infection following the removal of this line.

My father currently has a chest infection but it took them four days to put chest physiotherapy in place. At one point they took away his only means of getting out of bed - a reclining chair - because another patient was deemed to be more deserving of this equipment. It took me fourteen days of fighting staff to get a replacement for him, but he is now classed as bed-bound due to this decision. My father was not bed-bound when he entered the hospital; he simply needed a standing aid to transfer himself between bed, chair or wheelchair with the help of staff or myself. Now we are almost one hundred days into his stay at Princess Alexandra Hospital without proper mobilisation. He has never received any swallow rehab or speech help within his ten weeks spent in this hospital. My father has lost faith in the NHS and he looks frightened a lot of the time. The thing he dislikes the most is the routine, the nurses' ticking off jobs they have to do, medication, bed checks, commencing of PEG-J feeds but no-one really talks to him any more as a human-being with thoughts, opinions and rights. As my father has communication issues and at times you have to make a real effort to hear, understand and build a conversation with him, this is time that nurses and doctors cannot spare in the current hospital climate so my father feels isolated. He has not been allowed outside the bay where he is quarantined since he first came on ward in the middle of September. He is depressed; not able to eat, walk or escape his hospital room; he has lost hope in the system he paid into for all of his working life.

I do not know how my father has endured the care he has. I cannot believe he has never seen the inside of his house or eaten a meal in nine months; all for something as simple as a denture that had become loose and got lodged in his throat. This should have been an easy problem to fix; had the right investigations taken place, he could have been at home after a couple of days, carrying on with life.

I am also amazed that due to my father not ticking a box, he did not have a stroke or a heart attack, a disease like cancer or other medical condition that would place him on a certain care pathway within the NHS, so he has been left to rot within a system that hopes the elderly will die rather than recover from illness.

The thing I find saddest over the past nine months is that due to the various anaesthetics he has had, the isolation and poor care he has suffered, the treatment he has had, these have produced symptoms of vascular dementia that he never had before. No two days will be alike, one day my father will know who I am and smile and joke with me. Then the next day, he looks scared, frightened and unable to understand the simplest of conversations or who he is. He describes it as though someone has turned the switch off to his brain.

I hope at some point in the future someone will restore his faith in the NHS and mine. I hope a physiotherapist takes an interest in him as an individual and he can take a few steps for himself, to have a feeling of achievement and independence. I hope I get to buy him and watch him eat steak, chips, followed by ice cream but the reality is these simple things may never happen, and I have to accept this. I was told last week by a consultant at Princess Alexandra that my father would be bed-bound for the rest of his life, need to be put in a care home and would probably die of a chest infection; a very painful thing to hear but something I will try my best to prevent from happening. I do hope our story does not end this way after all the fighting to stay alive my father has done.

We continue to fight for the right outcome, one day at a time.

## **The Gold Standard Project at Whipps Cross**

The Gold Standard project has been developed jointly with the Patients Association and Joanna Wragg and her family following their poor experience of hospital care for Mr Tolhurst and Mr Wragg.

Initiated by Waltham Forest Clinical Commissioning Group, the Patients Association was approached to set up the project working closely with Joanna Wragg throughout. A plan was jointly developed to identify the components of a Gold Standard Framework for Older People at Whipps Cross Hospital which we hope will be used in other hospitals.

Communication with patients, their relatives and carers, and with staff at Barts Health has been the core component of the project. We have been talking to patients and their families on the wards, making observations and talking to staff to hear their views. The aim has been to use the learning to improve care on a weekly basis.

We have been impressed by the way Whipps Cross staff and especially Mary, B3 and Wavell Wards have been open and willing to learn from the feedback and are making changes to improve care. Following a recruitment drive by the Trust there are now more permanent staff on the winter pressure wards, and we are raising awareness about what is dignity and respect with staff. We are involving the local college to introduce activities on the wards with patients and will be undertaking staff training. Other aspects include ensuring specialist assessments, improving discharge planning and working with adult social care. Jointly with Joanna Wragg we have developed the Gold Standard Charter (see Appendix). Whipps Cross Patients Panel will be taking forward this work at the end of the project to ensure patient views continue to be heard.

## OTHER PATIENT STORIES

- ❖ *John was very upset his father who had an operation was cared for on a trolley in the admissions ward as there was no bed available for him. He was on the trolley from 2pm on Sunday until Tuesday at 4pm. Some of the nurses said how sorry they were that there was no bed available but the night nurse told John that she had to look after patients on trolleys most nights. John's father was very uncomfortable and could not move or turn. John stayed with him for as long as possible. John thinks his father is being treated in an undignified way and wants to know what he can do. John also saw how the nurses were struggling to try and move his father.*
- ❖ *Mary was most concerned to receive a call from the hospital at 9.15 pm to say her mother who had been recovering from a stroke was being discharged from hospital. Mary lives 25 miles away and could not get to her mother's home. She lived on her own. Mary had to contact a neighbour to prepare the house for her mother. Mary pleaded with the Nurse not to send her mother home to an empty house but she was told the hospital needed the bed for an emergency. Mary was very upset and wanted to write to the hospital. She feels there was no communication or compassion.*
- ❖ *Tom's mother had an operation for a varicose ulcer. He believes that the surgeon operating damaged an artery, leading to his mother being readmitted to hospital. Nursing an open wound that needed frequent dressing due to leaking, it was left to Tom or other members of the family to change his mother's clothing as the hospital claimed that "keeping the patient dry is not a priority". The main aim for the hospital was to arrange for Tom's mother to be discharged leaving the family concerned that the full-time nursing care that Tom's mother required may not be available in a respite care setting. This is very distressing for them.*
- ❖ *Vanessa told us that she struggled to get the health and social care professionals to understand she was the main carer for her elderly father and they should communicate with her about his care and treatment due to his severe visual impairment. Each time she tried to use the Choose and Book system to book her father's hospital appointment the message she received was "there are no appointments currently available." When she phoned her Practice to tell them that she could not access an appointment for her father she was told she needed to chase the appointment herself. She eventually found someone at the Practice who was willing and able to help her get the appointment arranged.*

There were also concerns expressed for members beyond immediate family. Some of the callers to the Helpline were making enquiries for a relative who needed support in getting an answer to their query, or who did not know how to go about seeking advice.

- ❖ *Joe was very concerned about his grandfather and some of the other patients on his ward. Many had dementia but were not being adequately cared for. Joe visited his grandfather every day and helped him with his tea. Joe's parents visited at lunch time to feed his grandfather. Joe felt very concerned for some of the elderly people who did not appear to get much food or drink. Some of them were not able to feed themselves and dropped the food. The cleaner took away the trolleys too quickly. Joe was very worried and mentioned this to the nurse in charge who appeared not to be concerned. Joe also left a message for the Patient Advice and Liaison Service but really wanted to do more.*

Often when an individual had experienced poor care whilst in hospital, it was their loved ones who made a call to the helpline about the poor care they had experienced. When experiencing poor care whilst being ill and in hospital, people often did not feel strong enough emotionally to initiate a complaint about their experience and they felt their ongoing care would be compromised. Their loved ones felt committed to taking forward the concern on their behalf and because they did not want other patients to have a similar experience.

### **Care for future users of the health and care system**

There was overwhelming evidence of concern for others by those people who made calls to the Helpline about their experiences of poor care. Often people contacted the Helpline when they had reached the end of a lengthy complaints procedure. They phoned to tell their story to the Patients Association in the hope that they might be able to influence changes that could prevent others having a similar experience. This was a recurrent strong theme throughout most of the categories of complaint. Many of the people we heard from had wanted to raise a complaint or concern whilst they were in hospital, but they ended up feeling forced to make a formal complaint as the only way forward. This was due to three factors: because they were not encouraged to give their feedback; because they did not know who they should speak to; or because their concern was not acknowledged by the health and social care professional - and they had a real fear that their ongoing care would be compromised.

- ❖ *Pauline's 83 year old relative endured a 6 hour wait on a trolley in A&E. Requests for pain relief, assistance with toileting and nursing care were ignored. Pauline wanted to make sure nothing similar happened to others and spoke to the Charge Nurse who responded and said "we will try".*
- ❖ *Daksha's son had suffered poor care in hospital, including being dehydrated on two occasions. She did get an apology from the hospital after she complained but phoned the helpline to report her experience in the hope that she could prevent the situation being repeated for others. She also made some very 'common sense' suggestions to the ward to prevent this happening.*

- ❖ *Misha was very distressed when she was admitted to hospital. She had to have a low fat diet but the staff could not give her anything. She had been admitted as an emergency and she had to wait until her relatives came in the evening to get her some food.*

## 4. THEME 2: INFORMING AND COMMUNICATING

The second key theme '**Informing and communicating**' is about the importance of being kept informed and the way in which information was communicated. People had a need to be kept informed about their care and treatment, and they wanted to know about what was happening to them or what would happen when they accessed services. They also wanted to know when there was no answer to their query. Callers accepted that there would be occasions when health and social care professionals may be unable to provide a clear answer to concerns raised by patients but wanted staff to be honest in explaining that they were unable to respond to certain issues which were raised.

Threading through the themes and subthemes from the analysis were a number of categories and patterns which described the encounters that are currently experienced by people using health and social care services, and the challenges they face in doing so. Analysis of the data in this way permitted in depth exploration of the broad areas of concern that are evident for the people who report their experiences to the Patients Association.

### PATIENT STORY

#### **Sylvia Iris Jarvis - written diary by her daughter, Sue Skerry**



Sue Skerry remains unhappy with the delays in the treatment her mother received at Southampton University Hospital and the poor communication prior to her discharge. Sue kept a diary during the 2 month period where she noted the 6 day delay in operating, the initial 24 hour delay in starting antibiotics, the lack of attention paid to her mother's needs, the poor communication and the uncoordinated way that her mother's discharge was planned.

During her early years, Mum, the youngest child of a publican, wanted to sing and dance. Her first pair of tap shoes were sharpened on a brand new snooker table.

Dancing classes were arranged and before long, Mum was headlining across the Midlands billed as Baby Sylvia. The War years arrived and Mum spent many of her nights tucked up with the family in the pub's cellar. Straws were drawn to see who would have to run upstairs to fill the kettle during bombing raids, and the honour usually fell to Mum.

After Mum and Dad married, Detroit became the family's new home. Wanderlust drove Dad to move the family to many different countries and Mum happily followed, adapting with humour to every society encountered. When Dad died in 2000, Mum was bereft. But her memories sustained her, and eventually her sense of humour (and mischief) returned. It seemed that only the inevitable physical impairments of old age would diminish her - until she was admitted to an NHS hospital with a broken arm!

Sue says "I have a portrait photograph of Mum when she was 18. She looks like a movie star; vivacious, beautifully coiffured and made-up glamorously. A 1940's pin-up. I wanted to take the photo to hospital to show them that *this is the woman you're treating!* She's not a 'bed-blocker', she's not just one insignificant 'geriatric'! Instead, I bit my tongue and every day I made detailed notes of Mum's 'care'. But re-reading my notes upsets me and frightens me, because I'm sure I'm looking at my own future and I wonder who will speak for me?"

Fri 22.08.14, Mum admitted by ambulance to Accident & Emergency at approx 11.00 am because she had fallen at home. X-ray x 2, plaster x 2. Admitted to the acute medical unit (AMU). Seen by 2 Doctors and told it would be best to have an operation for a plate and 2 pins, that afternoon. Mum signed consent form. Visited Mum later in the day. No op, but transferred to the ward that evening. Op will be tomorrow.

Sat 23.08.14 and Sun 24.08.14. Visited. Mum doing ok, waiting for op so nil by mouth. Both days on theatre list but not operated on. Both days told it would be "tomorrow". Emergencies and Bank Holiday cited for delay. From home I rang Sister who advised I ring again after 8.00am to see if Mum's on theatre list for Mon 25.08.14. I asked if, because of Mum's age, she is being 'bumped'. I told her I'm worried about Mum's confidence etc. She told me that Mum is as much a priority as anyone else.

Mon 25.08.14. Visited. Mum okay, but rather disorientated. Sister said she has slight urinary tract infection (UTI) but will receive antibiotics. Nil by mouth earlier but told not operated on probably because appropriate specialist would need to be consulted. (Now they say this??!) Told op will be tomorrow 26.08.14. Mum ate good lunch with my help. Again I'm getting the Bank Holiday chant.

Tues 26.08.14. Visited. Checked first to find if Mum was on the list but - delayed again. Guess what? Bank Holiday. Anyway, assured she will be on the list for tomorrow, pm. Mum said she had eaten something, and she looked quite good, just

smaller somehow and is definitely confused. Spoke to Sister who said UTI, antibiotics would be given. Why not given yesterday?! Later rang Sister again, as concerned. She said Mum has had one dose of antibiotics, doesn't expect improvement before tomorrow morning. I said that I hoped this would not delay Mum's op, she said she doubted it.

I keep telling people that every day in hospital for a lady of my Mother's age is a step backwards. In 4 days there is a clear deterioration and I'm frantic with worry. I've explained, ad nauseam, that Mum is no doubt 'weak', but she is **not** feeble. It cuts little ice. I am worried that the NHS will take a hitherto 'able' old lady who is as sharp as a tack, and discharge a woman who is beyond my care!

7.10pm, Registrar rang me. He asked me if my Mother has dementia!!! I said she most certainly does not. I explained about the UTI and added that it isn't surprising she's still confused as it's taken them 24 hours to administer antibiotics. Dear God. Seems he's worried about the consent form - more concerned with forms than injuries! I gave consent to go ahead tomorrow afternoon. I reiterated my concerns at their delay in administering antibiotics and the delay in treatment. I got; "I understand." Poor Mum.

Wed 27.08.14. Rang the ward at 8.30am. Mum's antibiotics are working and she's okay. She is on the list for today – trying not to get excited here. Rang again at noon, spoke to Sister. Mum is 3<sup>rd</sup> on list; the person who was 2<sup>nd</sup> has just gone down. I said I'd ring before visiting this evening.

Meantime I had 2 calls this morning. One from SUHT pharmacist to confirm Mum's medication, and another from SUHT Occupational Therapist, who ran through Mum's abilities, amenities at home, etc.

2.14 pm rang the ward. Told that Mum hasn't gone down but they are a Trauma Unit and that other cases may take priority. I feel sick. I said that as Mum has been waiting SIX DAYS, as well as admitted through A&E surely she's a priority too! I rang off rather than sounding off. Poor poor Mum.

7.00pm, back from visiting. Mum is, as usual, nil by mouth and on a drip for hydration pre-op, almost back to her normal self mentally. She is worried that as she is 89, they won't bother with her. She got tearful. I spoke at length with the sister. Went through 'saga', SIX DAYS wait, delay of 24-hours in administering antibiotics, unnecessary periods of being nil by mouth. I said if she can't walk, she can't come home, I can't cope. Groundhog Day. She said she'd ring me when Mum goes down, it will probably happen, as they operate until around 9.00pm. Mum was crying because she'd thought she was being punished, but the Nurse told us both that she's still on the list, nothing's changed.

7.40pm. Just had a call from the Surgeon who tells me op is delayed **again** until hopefully tomorrow. I queried numbers of surgeons, theatres, why was Mum

bumped again and again? He said 2hr job became 4hr job on patient 2<sup>nd</sup> on list. I asked why Mum wasn't 1<sup>st</sup> on list! No reply to that. He then said he knows exactly how I feel because he would feel the same if it was his Mum. I said "No you wouldn't. If it was your Mum, you'd have operated before now!" The call ended. Over and out for tonight. Exhausted.

Thurs 28.08.14. 10.45am Switchboard (ever helpful,) put me through to the PALs (Patient Advice and Liaison) Team. I gave her a run-down to date, concerns etc. She said she would investigate and ring back, which she did an hour later. Very nice lady. Said Mum had eaten a little cereal and is all ready to go down; she is 2<sup>nd</sup> on the list. I thanked her very much but said I won't hold my breath as this is exactly what I've been told for the last SIX DAYS. I concluded the call by saying that I will be making a formal complaint irrespective.

4.00pm. Rang the ward and was told Mum had gone down for surgery. PALs rang at 4.09pm to say the same.

Fri 29.08.14. Series of calls to the ward last night, up to 11.00pm. Mum is still in recovery. My last call was taken by another nurse who 'didn't know' anything. I asked her to find out!

Sat 30.08.14. 11.29am I spoke to Sister who said Mum doing quite well, pain as expected, etc. All gone well, not complex.

12.15pm. Visited to find Mum looking quite well considering, but in pain. Lady opposite told me staff had been trying to ring me since 10.00am because Mum has been crying so much but could not reach me. Thought I'd left her there 'forever'. But no one had attempted to phone either my home or mobile number. (I checked). My numbers are on my mother's notes, and they are also on a piece of paper, prominently displayed for mum. So attempts to contact me a fabrication. Shambles. Poor mum.

Spoke with Sister and asked that Mum be encouraged to use her legs, not be left to sit or lie all day. I explained that Mum can't come home unless she can 'walk'. Brownhill was discussed or a step-down at Princess Anne Hospital.

I feel I've done all I can in respect of liaising with staff, but I can see that Mum is going to suffer far more than she should have done because of the ghastly delay, and the delay in treating UTI.

Sun 31.08.14. 1200 noon. Visited Mum who was in a chair and looking pretty good. Brownhill was discussed again particularly in respect of Mum's confidence which, after such a long time, has begun to fail. Thought that had already been dealt with. The Doc saw Mum this morning and said he would like to have spoken with me. I said that both my numbers are available to him, I'm surprised he couldn't be bothered to phone me!

Mon 01.09.14. Visited at noon. Lady opposite told me Mum had been confused since early morning. Sister confirmed it's another UTI and antibiotics are being given. Again, no one had rung me and she's been very distressed. I could have come sooner. Mum was in a hospital gown and very unhappy about it. Clean nighties are in her bag, all the staff know this. I later rang the ward, spoke to Sister who assured me Mum has been washed, and is in a clean nightie. She said she's beginning to respond to antibiotics.

Tues 02.09.14. Visited at 11.50am and took Mum outside in her chair. She's still confused.

Wed 03.09.14. Visited at noon. Pleased to hear staff had had Mum up and 'walking', though she's still confused. Dr and I had a catch-up and Mum is back on antibiotics.

Mum Discharged to Brownhill on Sat 06.09.14.

Wed 10.09.14 Visited Mum at Brownhill as usual to find that she has a great deal of pain in her back still. I queried with staff to check that she's having all her meds. She isn't! Why did SUHT bother to contact me re Mum's drugs if they don't take any notice? Anyway, she's getting them this afternoon. I'll check tomorrow to be sure of everything else. Someone has to. Over and out.

Thurs 11.09.14 Just received letter from RSH, addressed to Mum at home, with appointment for her to attend Trauma & Orthopaedic Dept on 16<sup>th</sup> Sept 2014. I rang to ask why they would do this when Mum is in Brownhill House. They said I had to notify Brownhill. I asked them to check the discharge summary from SUHT. It made no mention whatsoever that Mum had been discharged to Brownhill House. Further it said 'removal of plaster'. Mum isn't in plaster!

So, my complaint is now founded on FOUR points:-

- 1) **Six day delay** on operating on Mum (and all the harrowing things the delay included)
- 2) UTI not treated for 24-hours
- 3) Incorrect information on the Discharge Summary from SUHT
- 4) Discharged to Brownhill without Mum's appropriate medication.

Tues 16.09.14 Mum arrived back at Brownhill from her outpatient's appointment at RSH - 5.5 hours after she was picked up by 'transport'. She was disorientated again, and in plaster! No one called me or said I could go with her. All that time without a drink or food or the toilet. Outrageous.

Weds 17.09.14 Mum transferred to Brambles at RSH. She was still disorientated and yet I was unable to persuade staff that this is Not NORMAL for Mum. I bit my tongue for 10<sup>th</sup> time.

Monday 22. 09.14 attended with Mum to see consultants at RSH Outpatients. Physiotherapist and Nurse kindly accompanied. They advised letting the arm mend even though plate etc has shifted. They made Mum feel more at ease, and I think they care about her. Left it there.

Tues 23.09.14 - Consultant rang me. He wants Mum to have a revision Op first thing in the morning at SUHT. He explained in detail, I agreed, as did Mum, and he said she'd be 'priority' tomorrow morning. I'm so grateful because I think he wants to do everything he can, and he actually phoned me!!!

Wed 24.09.14 - @ SUHT. Despite me finding Mum dumped alone in Reception at the Day Unit (she cried when she saw me – just another old lady, after all) but staff got her nicely settled in. The Op seemed to be much better than the first Op as she was in far less pain and much less swelling, as the consultant predicted. Mum went to Recovery and I was allowed 2 mins with her (7pm). Then she went up to a different ward.

Care on this ward seemed middling (even though they lost mum's things and gave her a sandwich when she didn't even have her teeth), Mum seemed okay in herself. Voila! Mum's stuff arrived – 3 people said "her things should have followed her". 'Should have' seems to be the phrase du jour – every jour!

On one visit I found a member of Housekeeping, sitting with Mum and just chatting etc. She'd been there some time and I thought that was extremely kind, let alone 'above and beyond'. She said she often stays on and talks to patients, she finds people like Mum interesting and she likes to see them happy. Why are people like this so under-valued?

Mon 29.09.14 had a lengthy talk with Physio Team, at their 'station'. To date no one has sought me out to discuss Mum's physio. Oh dear! Sister and Nurses have passed on bits. Physio told me Mum has not walked as yet and she is not happy to release her home anytime soon. (Nurse later told me Mum had walked quite well, with support. She seemed surprised by what Physio had said). Physio and her colleagues, went on at length about how much at risk Mum was if she comes home, they can do more for her there etc. I said that if they are so concerned, where were they on Saturday and Sunday? No answer! I said I could do more for mum, she would only get worse if she stays. It ended on an amicable note, if a strained one. An 'acute' hospital shuts on weekends.

Tues 30.09.14 Saw the Link person for Home Care @ SUHT at 2.30pm on F2. She's getting the care sorted for Mum at home etc. She will finalise tomorrow, and see Mum again at 2.30pm with me.

Wednesday 01.10.14 spoke to Sister at 11.08am who confirms Mum home today!

11.26am Call from Social Services, they have papers, are happy re discharge. However @ 12.01pm, had a call to say Home Team can't do today, but I said I'm happy to 'bridge' if necessary, I'll see her at 2.30pm today on the ward.

Monday 06.10.14 - I was assured by the Hospital at Home Team that Mum's care would be on-going in respect of Physio and wound. But as of today there's been no word from the hospital regarding physio or wound care!

11.24am - Rang number given by the ward this morning and a very helpful lady promised to ring me back within the hour, said she would do all the chasing to save me from phoning the world. I told her how I appreciated this. However I said I would be ringing to speak to the CEO because there is no trace of my mother having been referred to the Health at Home / Recovery at Home / Hospital at Home Team (there is apparently some uncertainty regarding titles here) despite speaking to the Link person for Home Care who 'organised' Mum's aftercare!! She said Mum's GP would have been notified by the ward. She asked me to delay my call to CEO at SUHT to give her time to sort. I agreed. Meantime, called GP Surgery to ensure they know about Mum's wound needing attention at some time. Receptionist searched, but the Surgery has not been notified.

12.10 pm, helpful lady rang back. The Link person for Home Care told her that she has no recollection of Mum's care arrangements, so many patients, and didn't have her notes with her, and is sure physio is being carried out by Social Services (although no one turned up yesterday morning). As for the wound, the lady has no information, but she has asked the Link person for Home Care to be sure to call me within the hour to discuss all - she said she would.

4.45pm, the Link person for Home Care rang me (that was one long hour). She flatly denied the conversation of 30<sup>th</sup> Sept took place, said I was told there would have to be assessment. I reiterated she told me that she would "start faxing and get the ball rolling for tomorrow." She even said she had handed over to Social Services entirely. I said I recalled her telling me a lady from Social Services would meet me Wednesday, on the ward, that there was no longer any need for her (the Link person for Home Care) to meet me. She intimated I was willing for Mum to be discharged without assessment. I flatly denied this and was told on 1<sup>st</sup> Oct Mum was ready to go! Seems not enough time to get her story straight, after all!

5.00pm, Lady from Health and social care at Home phoned me – she's not sure what they call the 'service' either!!! But she clarified that Social Services carers don't do physio. I'm too worn out to go into it all over again, so I just said "get mum physio, I don't care how, please just do it."

Tuesday 07.10.14 Mum doing well, but am worried in case her wound isn't right. Had a chat with Surgery Receptionist (ever-helpful and resourceful) who suggested I ring the District Nurse direct, don't wait. Did so and gave brief details – she didn't know about Mum either! Within the hour, the DN arrived and took blood and is coming tomorrow to check the wound. Seems the bigger you get, the worse you operate. Needs a DN to run SUHT then.

Wednesday 08.10.14 District Nurse arrived at 10am and is wonderful. Same DN as after Mum's knee op a few years ago. She sorted mum out after that debacle too. Examined Mum's wound and it is infected; she asked what had been said to me about removing staples. I said nothing's been said! She ordered a prescription from Surgery and it will be delivered today. I'm so grateful. Staples will need to come out, she'll do that on Friday.

Seems this will be another complaint to SUHT. I can't understand why they are so utterly unable to communicate. Why isn't there an 'at a glance' computer record of each patient which clinicians can easily access? A computer at the foot of each bed, with records accessible by GP's and consultants, to ensure care pathways are being followed? Why are paper folders still being used instead of authorized personal numerical log-ins? There should be a true (legible) record, which could not be denied by someone because they forgot, or say they're too busy, or just can't be bothered. How can my mother's care have become such a rats-nest of misinformation and miscommunication?

None of these administrators or clinicians seem to realize that one day, sooner than they think, they might be in exactly the same position as my Mum. If they stop to acknowledge this fact, they need to sort the mess out now – just in case they won't have anyone to fight their corner for them.

Thursday 09.10.14...and still no call from Health at Home.

Friday 10.10.14 - 5.30am - Mum shouts for me. Her arm's extremely painful, she's lying on it. Calmed her, tried to make her more comfy. 6.00am gave her tablets, she's drifted off. 7.45am she called me, needs toilet but in pain. I said to wait for Social Services (SS) lady who came 8.00am, told her all. She sorted Mum, told me to ring GP. I don't want Mum in hospital again. SS lady said they'll probably x-ray/plaster and send her home. GP coming after morning surgery – Receptionist now confirmed received Discharge Summary from F2. Only took 9 days!

11.15am, DN came, told her latest, she removed dressing and staples to maybe help pain, wound's very sore-looking, dressing clean. DN thinks will be back on Tuesday.

1.45 pm-ish GP arrived and assessed. Her view is Mum should be re-admitted for the orthopaedic team to assess and x-ray. If only they'd taken proper care of her, it wouldn't have gotten this far. Doctor tried calling to arrange transport but failed – seems no one's got the edge.

Surgery rang at 3.31pm to say ambulance will arrive within next 2 hours.

Ambulance arrived at 4.45pm, exceptional care from both gentlemen, thorough assessment before travel. Admitted straight through A&E to another ward. Handover to Sister completed. Discussed visiting hours; Mum has no bits and bobs with her. I said I'd call the ward in the morning as I'd like to visit earlier than 3pm, so I'd check to see its okay. Sister agreed to call me regarding any decisions made about care, deterioration, etc and gave me the ward number. She's a bit 'chilly'. I left after seeing Mum safely ensconced.

Rang the ward at 9.25pm, spoke to a Nurse who said Mum's x-ray will be tomorrow. I don't want to have to do any more pushing, but... Mum is at least settled in. I said I'd call tomorrow morning.

Saturday 11<sup>th</sup> 10.14 – spent from 8.00am until noon phoning the ward. Constantly busy. Sister not chuffed to see me at noon, but did discuss Mum's current state (I said I'd been trying to get through all morning but 'busy'. She said they don't answer the phone as they're concerned with patient care. I said I appreciate that BUT as with previous experience, no one ever calls me if something changes, how am I supposed to find out what's going on?) There's going to be a 'multi-disciplinary' meeting about treatment as x-ray has shown Mum's broken bone. Sister showed me a plastic brace, morphine for pain etc. I told her Mum seems vulnerable to UTIs etc. Hope they'll let me know whatever's happening.

2.03pm I rang via switchboard to speak to Duty Clinical Manager on bleep (as I thought, Patient Support Services are shut for the weekend!) Manager came on and I asked if she would kindly ensure that I would be contacted by someone if there are any changes in Mum's condition or if a decision is made regarding her treatment. She wasn't too keen on doing this and asked why I want it. I told her that I have an issue with communication and have made a complaint. I made no apology, was nice but definite, but I'm not feeling all that confident.

Sunday 12<sup>th</sup> Oct 2014 10.39am - Rang and Nurse went to find out Mum's current state. Doctor came on and said Mum's stable, a bit confused, wants to see me, they're checking for UTI. Decision re treatment is still being made.

1.25pm - my daughter visited. Mum distressed and waiting for Doctor to fit brace. Why not yesterday?

Monday 13<sup>th</sup> October 2014 11.12 am, tried ringing to ask how Mum is, but not connected. Totally wound up already. District Nurse rang me to see how mum's doing. I talked to her about Mum being confused, she said the wound was bad enough to make her bad, it could still be that. SO, 3 days gone by and Mum not getting better?

Visited at 12.30pm to find Mum in a chair, looking good! She seemed orientated and said how kind staff are - nice surprise. Nurse came direct from handover and said no

decision yet made re Mum's treatment, but consultant would 'hopefully' see Mum today. As long as she seems to be doing so well, I'm cooling my heels. Arm still painful but the brace is on and she's putting up with as much as she can, taking painkillers. Best news is she's walking to and from the toilet, with a nurse!

Tuesday 14th October 2014 12.30pm visited Mum. Physio with her so overheard some. She looks great and was chuffed to see me. Chatted while waiting for lunch and ward sister came to see me and explained consultant decided to let bone heal, with support. Sister also said they'd start the discharge process, probably to step-down at Princess Anne. I'm relieved. So nice, all the nurses. The Housekeeper is especially fussy over Mum.

Don't see any need to continue these notes now. At last things seem to be going as well as possible for Mum and I'm sure discharge will go to plan this time.

### ***Wanting to know***

This theme reflects the importance to patients of knowing what was happening with their care. Due to the complexity of the system, the manner of some staff and the continuous changes taking place, people find it difficult to navigate the health and social care system even when they are well informed. People who gave us their stories and experiences described feeling left not knowing:

- how to access care;
- what was available to them;
- their rights;
- what was happening to them, or supposed to be happening to them.

There was evidence to suggest that sometimes when health and social care professionals were asked about certain aspects of a patient's care, they either:

- did not know how to communicate their response;
- did not want to give a response;
- did not know the appropriate response, and crucially were not willing to find out.

The issue of health and social care professionals not being willing to find out answers has been raised with us on numerous occasions.

- ❖ *Jean's husband had his colostomy reversal operation "suddenly cancelled for unknown reasons" and has heard nothing since, despite trying to contact the hospital and the consultant on several occasions.*
- ❖ *Amelia's mother had a biopsy and when she asked the doctor if everything was OK – he said he would go away and look at the notes. He did not return. Amelia's mother was discharged the next day and still not told the outcome of her biopsy.*

Patients were confident that they wanted to be involved where possible and wanted to know what was happening to them or their relative so that they could understand and accept the situation. It appeared that health and social care professionals might not want to impart information to patients because it might mean that the patients would hear stressful news that was difficult for them to accept. This suggests that some health and social care professionals might not be confident in communicating with patients, especially around sensitive issues.

- ❖ *Eileen didn't understand the information about her MRI scan. She said she sometimes walks away from consultations with the doctor in the clinic without really understanding what is happening due to lack of appropriate communication. The doctor always gives the least amount of information which concerns Eileen.*

Patients who called the Helpline were often coping with interpreting new information they had been given, which was either poorly communicated or incomplete. The Helpline provides signposting and support services for such situations but this evidence suggests that the health and social care organisation providing care might not always provide a complete picture for people who need to manage large amounts of information about their condition, or that of their relative. This process could be improved for patients if meaningful information was provided for them in a timely manner.

### **Openness about not knowing and acceptance of not knowing**

The NHS Constitution states that NHS organisations commit to openness in their statement, **“We are honest and open about our point of view and what we can and cannot do”** (NHS Constitution 2013, P5).<sup>i</sup>

The acceptance of not knowing was a strong theme throughout a lot of the data sources that were used. Integral to the training of health and social care workers is the acceptance of ambiguity in relation to many areas of clinical practice and this is part of their learning. Not always having an answer is a way of working for many health and social care professionals a lot of the time. If health and social care professionals were honest with patients when there was no clear answer to their situation, and that this is an acceptable part of clinical practice, it might help patients to understand the system better. Likewise, patients too should be encouraged to express their lack of understanding about an aspect of their care without being made to feel as if they are ignorant compared to health and social care professionals.

Patients often expressed their fears of the unknown when talking about their condition to the Helpline and this was often not managed well by the health professionals. Patients felt fear but did not express this in their encounters with health and social care professionals. If patients were given the opportunity and time to have discussions about how they felt about the information they were given, it

might help them to better understand their situation, reduce anxiety and unnecessary health and social care appointments.

- ❖ *Sandra's 98 year old mother was prescribed Penicillin even though she was allergic to it and this was noted on her records. She was also denied a home visit. After a hospital admission and subsequent discharge home Sandra pleaded with the GP for advice about caring for her elderly mother at home but the GP felt he couldn't help – the hospital had not kept him up to date.*
- ❖ *Paul asked his GP if he could be referred to a particular hospital but he refused and told him that he would need to go to another hospital which was further for him to travel and did not have the specialised physiotherapy service he needed. Even though he had previously been to this particular hospital for other treatment he was not allowed to go back there for physiotherapy. Paul was told that the GP's decision was final and even though another doctor he saw disagreed with the decision, he could not overturn it. Paul felt that was not involved in the planning his care or why specific options were only available to him.*

Sandra and Paul's experiences reflect poorly on the statement made in the NHS Constitution, 'We speak up when things go wrong' (NHS Constitution 2013, P5).

### **Summary of findings**

The findings from the analysis of data from the Helpline and data collected directly from patients and their families and carers has shown that there are common themes recurring throughout the patient journey. The experiences described in contacts with the Patients Association suggested:

- Patients want to be treated humanely and with compassion. Far too often that is not people's experience.
- People want to be included in any decisions made about their care.
- People are anxious about raising concerns or making a complaint about their health and social care experience because of fear of recriminations.
- What motivates people to raise concerns is seeking to ensure that others do not share their negative experiences.
- People want to be kept informed about events affecting their health and social care but are often not kept adequately informed.
- People accept that health and social care staff may not be able to answer concerns that they raise directly for a variety of reasons. However it is important that health and social care staff cover such matters directly with the patients and/or their family to avoid ambiguity.

## 5. PATIENT STORIES OF FAILINGS REGARDING THE NHS CONSTITUTION

In this section of the [report](#) we have compared the experiences of people who contacted the helpline with the principles enshrined in the NHS Constitution. The latest version of the NHS Constitution was published by the Department of Health in 2013 and is intended to act as a single document covering the principles and values of the NHS, as well the rights and responsibilities of patients and staff within the NHS. The NHS Constitution does not include social care.

The way that health and social care professionals should conduct themselves and the way that patients would like to experience their care are core to the NHS Constitution. Indeed, the NHS Constitution makes the following claim about the commitment of NHS organisations to their patients: **“We do not wait to be asked, because we care”** (NHS Constitution 2013, P5).

However, from our analysis, the experiences of many patients differ from many of the principles and values that are outlined in the NHS Constitution.

Amongst other topics the NHS Constitution advocates the rights of patients regarding:

- Information about services in the local area;
- Access to treatments available in the NHS;
- The quality of care received;
- Confidentiality;
- Access to personal records;
- The right to complain if things go wrong.

These rights are aimed at enabling and helping patients and their relatives when they use services provided by the NHS.

This section illustrates examples where patients and their relatives and carers have been let down by the NHS through organisations failing to adopt the principles and values of the NHS Constitution.

### ***Right of access to services***

The Patients Association helpline receives a huge number of calls with regard to access to services and many patients report feeling they are passed from pillar to post. Similarly, many calls come in regarding pain and pain management such as the following example.

- ❖ *Suzanne is taking painkillers and recently had a new injection from her GP, which led to an adverse reaction and even greater pain. She phoned an out of hours doctor who told her she had to come in, (even though she explained that it would cost her a taxi fare of £18, and she had a wheel chair). When she arrived they suggested that she put a cold compress on it and told her there was nothing they could do because she had a cortisone flair/reaction to the pain killer. Suzanne believes the out of hours doctor was rude, and that the original GP failed to advise her of the risk. She is in pain which she is worried might possibly become permanent pain.*

Many patients are unable to access the services that they have a right to access, and communication processes about this are inadequate. The following cases give examples of patients whose experiences conflict with the NHS Constitution which states, **“You have the right to access NHS services. You will not be refused access on unreasonable grounds” (NHS Constitution 2013, P6).**

- ❖ *Jake asked his GP to refer him to the hospital where he had originally been treated for his condition (which was not the local hospital) where he had received excellent care. Despite the GP including Jake’s availability for treatment, Jake advised us that “the hospital telephoned me during precisely that period without leaving a message and, getting no reply, they took me off their list. I subsequently contacted them and was restored to the list but I was told they could not say when I would get an appointment. This remains the position despite further telephone calls from me and a further communication by my GP.” Jake has now been waiting 24 weeks for his appointment whereas the NHS target timescale for referral to treatment is 18 weeks.*
- ❖ *Ann phoned to tell us about her experience when trying to get an appointment for her elderly mother who was unwell and she did not want her to go to hospital. Ann called the surgery for 5 days morning and afternoon but could not get an appointment. On the sixth day she had to ask for an urgent home visit. Her mother had a urinary infection.*
- ❖ *Jonathan has moved to live with his sister for four months. He has been unable to find a GP practice that will register him as a temporary resident; they all refuse.*
- ❖ *Gary complained to NHS England about his GP Practice as he tried repeatedly for four days to get an emergency appointment for his daughter and was told that she could not be seen. His daughter required injections for anaemia which had previously been diagnosed by the practice - she was very unwell and very weak and needed to be seen urgently. Gary received a letter from his practice striking him off due to breakdown in relationships and giving him no opportunity to discuss their decision.*

Providing timely access to services is very important to patients. The following examples show some of the issues arising with regard to the length of wait.

- ❖ *My late wife had a rare type of cancer which presents early with a blocked bile duct and thus has a 50% chance of 5 year survival. It took the doctors 94 days to get to perform the lifesaving operation. This is 32 days longer than the 62 day maximum target for all cancers. I went through local complaint procedures which were unsatisfactory because the consultant surgeon was allowed to be judge and jury.*
- ❖ *Susan says she has been waiting for 32 weeks for surgery. She was told she was on the waiting list. She has a letter from a consultant surgeon saying that he would personally do the surgery and would hope that she would be admitted quickly. She is still waiting.*
- ❖ *Kathleen contacted us regarding waiting times; after seeing her GP she required an x-ray and had to wait seven weeks for an appointment. After the X-ray was taken, she was advised that the results would be with her GP within 7 - 10 days. She then booked an appointment to see her GP in 10 days to discuss the results but they had not come through when she attended the appointment so the GP phoned and found she required further investigations and surgery.*

Confusion about and dissatisfaction with dental charges is a recurring theme:

- ❖ *Georgina had been told that she needs root canal treatment and that she will have to have this done privately as the NHS can only offer extraction. The treatment would cost £700 and Georgina asked whether she has no option but to either have the tooth extracted or find the £700. Georgina does not want others to find themselves in the same situation.*
- ❖ *Richard was initially told by the dentist the cost of treatment for a dental plate would be £300. He paid for his treatment in advance. However as the course of treatment was finishing the dentist approached Richard and said it could not be classed as one course of treatment as it had gone on too long and charged a further £214 which he had to pay.*

Similarly the Helpline had some enquiries regards charging for GP services. For example:

- ❖ *Madeleine wishes to view her medical records. Her GP surgery have advised her that they do not have the facility for her to view them and they will have to have copies made at a charge of £50. Madeleine called us to find out if it is right that surgeries can charge for paper copies.*
- ❖ *Daniel called to say his GP has said he will charge £50 for a letter clarifying the name of an illness.*

Choose and Book is an electronic appointment system described as “a national electronic referral service which gives patients a choice of place, date and time for their first outpatient appointment in a hospital or clinic”

([www.chooseandbook.nhs.uk](http://www.chooseandbook.nhs.uk)). Some patients have reported difficulties in getting their appointments booked using this system.

## Transfer of care between services

The NHS Constitution pledges “**to make the transition as smooth as possible when you are referred between services, and to put you, your family and carers at the centre of decisions that affect you or them**” (NHS Constitution 2013, P7).

Certainly, when a patient is referred between care providers or between services or from primary to secondary care, it is even more important that they can expect the quality of their care to be consistent.

Similarly, when patients are moved between wards within the same hospital setting they should be able to expect a degree of consistency and quality of care.

- ❖ *Sue’s mother was transferred to a rehabilitation unit for the elderly. She was unwell with stomach pain which was so bad that her friend who was visiting her that day had to tell staff to call a doctor urgently. This they did and it ended up with her mum being taken back to the hospital. They found out that she had gall stones which they planned to crush to avoid an operation. After the procedure, she was transferred back for more rehabilitation and physiotherapy. Due to the pain in both her stomach and leg, she was too unwell for physio. However, the physiotherapist wrote in her notes that she was not trying and was refusing their help. Sue said “I am certain that this had an effect on the care that was deemed necessary for my mum when she was to be discharged.*
  
- ❖ *When David called the Helpline he was suffering from pain caused by an impacted wisdom tooth which had repeatedly become infected. He attended a Dental Services Access Centre and had been given several courses of antibiotics. He had been referred to see a hospital specialist two months previously. He had checked with the hospital and was informed that the hospital had not received any referral form from the dentist. His referral letter had gone missing. Upon returning to the Dental Services Access Centre he was told they would generate another referral but they did not examine him or offer any treatment. He was in a lot of pain and in urgent need of treatment. He had not been able to eat properly for 8 weeks and had lost a considerable amount of weight over that time. He called the Helpline to ask for advice about what he should do next to get his appointment with the hospital specialist.*

Fatima’s story below also shows that there is sometimes a failure in people’s continuity of care.

- ❖ *Fatima called the Helpline on behalf of a friend. After attending A&E on the advice of the 111 service following chest pains, the patient felt that she was being told that she should not have attended the emergency services, and that she should see her own GP. When she visited her GP surgery she was seen by a locum doctor who advised her that her heart rate was too high and that her usual GP would get back to her. The patient's usual GP failed to contact her after she had received such alarming news from the locum GP, and she was distressed with the news and wanted to know what to do.*

### **Treating people with dignity**

The NHS Constitution outlines that **“You have the right to be treated with dignity and respect, in accordance with your human rights” (NHS Constitution 2013, P8)**. The following examples show that this commitment is not applied consistently.

- ❖ *“My mum received little care in terms of being left food which had gone cold and sometimes she didn't receive the help she needed to eat. There were also occasions when my mum had to wait over 2 hours to be changed because it requires two nurses. The worst occasion was when she was left to be changed while the nurses took their breaks.”*
- ❖ *Caroline told us about when she went to visit her mother in hospital the day after her surgery to find her sitting in a chair crying in pain. She had not been given pain relief, had not been washed and had not had her ulcerated legs treated.*

Just as some transfers between hospital settings have not been carried out as the patient would like, some discharges are made without the appropriate medicines or medical care package being in place:

- ❖ *Joanna had a hip replacement and after surgery waited for seven hours for pain relief. She left hospital without any pain relief or proper discharge and was not shown how to give herself the necessary injections that she needed to take. The discharge nurse at the hospital suggested that Joanna could return the next day in a taxi to collect her medication.*
- ❖ *Mrs. Phillips has informed us that although a surgical procedure her 16 year old daughter requires can be done at the children's hospital of her choice and where she has always attended the consultant refuses to discuss it with her and said she has to go to another hospital on the adult ward. The operation can also be done by 4 other surgeons at the children's hospital. The consultant in charge of her care will not agree to this and has stated that it can only be done by him at the hospital of his choice. The only other option is for Mrs. Phillips to go to either Oxford or Exeter which have closed their waiting list. Mrs. Phillips has involved her MP, the CEO of both trusts but to no avail, the Consultant will not add Mrs. Phillips' daughter to his list at the Children's Hospital or allow another surgeon to carry it out at the children's hospital.*

## PATIENT STORY

### **Mona Eileen Craig- written by her daughter, Pauline Scott**



Pauline's mother was admitted to the Great Western Hospital where she was diagnosed with pneumonia. A few days later, she was moved to an isolation ward as she had contracted MRSA. Pauline describes the poor care provided to her mother and in particular, the appalling state she found her mother in on the morning of her death.

Pauline tells of a lack of dignity, care and compassion and believes the hospital failed her and her mother miserably.

Two days before our holiday in June, paramedics were called to the residential care home my mother stayed in to assess an unwitnessed fall she had had earlier. She had complained about her hip but after checking out her mobility, this was not deemed to be a problem. However, the paramedics were concerned about her heart and took her to Great Western A and E department.

I was informed of this on Saturday 14th June and went to the hospital. To me, my mother's condition seemed similar to when she had had an infection at Christmas for which she was given antibiotics and morphine patches. At that time, she had to be treated for several weeks, a situation made more challenging because of her dementia. She had been agitated then and now she was agitated too.

A lovely doctor saw her and suggested that she should be returned to a place that she knew to calm her down and so a decision was made to take her back to the care home that evening. As we waited for the ambulance, her condition worsened. She turned grey and her fingernails changed colour too. Her lower legs were cold. The A and E lady doctor was called and confirmed that she was deteriorating and should spend another night in hospital.

The following day, a calm and sensitive doctor diagnosed pneumonia in the right lung and suggested mum be given antibiotics. He said he understood that she should not be resuscitated in an emergency and that palliative care might be the only option.

On the Monday when I went to see her she was in a separate side ward waiting to be assessed. She was very agitated, writhing around, shouting and grabbing hold of

people and not letting them go, not knowing what she was doing. Normally, she was a calm, quiet person but bladder or chest infections changed her.

When the third doctor came to see my mother, she had just dozed off. He came in loudly and in a loud voice asked me who I was. I pointed out that this was the first time that mum had had any sleep but this did not seem to concern him and he was only interested in getting a diagnosis. To me he appeared arrogant with no bedside manner, either with myself and mother or the lady doctor and two nurses who were in the room too. He wanted mum to have a brain scan because she had had a fall the previous week and he was concerned there might be a bleed. There was an icy atmosphere when he left the room and I asked the lady doctor whether it was necessary to have a brain scan and what would they do if they found it in an elderly lady. She explained that it would be possible to drill a hole and drain the bleed in a younger person, but in a 92 year old it would be more of a problem. I shrugged my shoulders and wondered whether there was any point. How could they do a brain scan with all the agitation and movement?

They went ahead nonetheless and I accompanied them to hold mum down. The X-ray people decided that she was too agitated to have a brain scan. It had been a wasted journey. She was not seen by any other doctors that day.

The following day mum was moved to a ward with three other ladies. She was being given antibiotics intravenously, fluids and paracetamol and they were thinking about morphine patches to calm her down. She slept a bit and managed to eat and drink a little.

The two younger ladies kept an eye on her. This appeared to be the pattern. They looked after each other. This meant that she got some nourishment and drink and they also notified the nurses when her bed was soiled. Throughout all this mum was still very agitated and noisy.

After two or three days, she was moved again and ended up in an isolation ward. She had been diagnosed with MRSA on top of the infection that she already had.

It was here that things started to deteriorate. It was very difficult to get anyone's attention with nurse stations badly positioned in relation to some wards. Frequently there was no one there and when there was, the nurse would be glued to the computer, not wanting to look up to attend to my query or request. It was all very frustrating. Another difficulty was working out who was who because of the many different types of uniform. There were no names, not even NHS insignia. It was difficult to know whom to approach.

It all seemed very chaotic with people running around with bits of paper not wanting to look at you. I found it really daunting in this environment, isolated with mum who seemed to be getting worse.

I usually tried to get there mid/late morning so that I could help her with food and drink over lunchtime. She could not have done this on her own. Trolleys with drink were being left too far for her to reach and of course there were the attachments of the machines getting in the way. I found it distressing thinking about what was happening to her after I left to go home. It was really upsetting thinking of her in a soiled bed with canulas coming out of her arm. Sometimes the canulas had not been positioned correctly and the fluid was getting into surrounding tissue, swelling her forearm to two/three times its normal size. This, I understand, can be very uncomfortable.

On one occasion I called someone for help on discovering this scenario and whilst the canula was removed, it took an hour and a half for someone to change the soaked bed on that particular day. One and a half hours of an elderly patient with pneumonia lying in a wet bed. It was always a case of "We'll be with you in a minute".

The bed had to be changed with mum still in it and it required two nurses to do this. On the occasions when I was there I would hold mum's head since she had an arthritic neck – frequent in elderly people. The nurses seemed to be unaware of her head as pillows would be whipped away and her head would jar painfully. They would just say "Sorry Mona" and hurry on. There was not enough care and attention being paid to mum who found it uncomfortable being rolled, moved or lifted.

I had hoped that I could feel assured of mum's safety given she was in hospital. However, one morning I came in to discover that she had fallen out of bed during the night. There was no damage since the bed was low and there was a crash mat on the floor. However, the staff should have known to keep a cursory eye on her because habitually she used to writhe and wriggle to the bottom of the bed which took some time to do. Yet she had had time to fall out, with canulas attached, distressed and with a bed soaked again. It was a very disturbing thought.

At her home, Mum would have had a pressure pad on her bed mattress and another on top of the crash mat on the floor, both fitted with alarms which would have been activated once she left the bed or hit the floor.

I was not sleeping myself, thinking about my mum, probably at the end of her life, still pumped full of antibiotics and paracetamol and morphine patches, but in a great deal of discomfort which I could tell by the way she was rubbing her tummy.

At one point, three doctors took me to the Visitors' Room and asked about our medical family history. I told them about the womb and bowel cancers and Crohn's disease, hoping this would help them.

On the third weekend there, mother took a nosedive. I arrived on the Sunday morning to find blood being sucked out of her bleeding mouth. A physiotherapist was called to help her with her breathing after which she settled down. As I was leaving I

noticed that she was also bleeding from her back passage. This had increased by the next day and mum was not eating or drinking, but the doctors were still coming in and prescribing antibiotics. At one point I asked a young doctor "When is it decided to stop all this and let her go?" He replied that the doctor would make that decision. Here was my mum, covered in bruises, having bled from her mouth and back passage, not eating or drinking still being fed antibiotics.

At one point, a young lady doctor came in to take more blood, not wearing a gown or gloves, which even I was required to do given mum had MRSA. I watched as she got blood all over her hands. It really was not very sensible. I could not understand it.

On the Monday night, I received a 'phone call informing me that mum had had another bleeding session and that they were thinking of stopping the antibiotics.

I arrived on the Tuesday to find mum in a despicable state. She was lying half way down the bed, no pillow under her head, slewed sideways, naked apart from a soiled pad and with no sheets covering her. Her eyes were glazed over, but I could tell she was aware of what was going on. I did not know what to do, given I could not go out since I was already wearing an apron and gloves. It needed more than one person to sort mum out and so I would call to passing nurses, only to be told constantly "Yes, in a minute". I was becoming very agitated. Eventually, I caught the eye of the young, male nurse who seemed to be in charge of the area.

I could not accept that my mother, nearing the end of her life had been neglected like this and left in that state, possibly from 7.00/8.00am. I had arrived at 10.55am and this was now 12.00 noon.

The male nurse was taking COPD [chronic obstructive pulmonary disease] patients for X-rays and telling me about this, something I did not need to know and was not interested in whilst my mother was in this state. I could not believe how little compassion he showed.

Eventually, I got a sheet and bed jacket to cover her, at which point I noticed that her left leg was dangling in a pool of blood on the floor. Distraught and furious, I called out to the nurse on several occasions and he started to say "I've just got to..." "This is the end of her life and you have left her in this despicable state. I want her seen to!" I shouted.

I think that finally he saw my fear and anger and how distraught I was for within a few minutes, there were three nurses to attend to the floor, and mother on the bed. Mum shouted out when she felt the cold antiseptic spray on her back. She was still aware and obviously very uncomfortable. It had taken one hour from my arrival to deal with her, and then half an hour to clean her up.

Afterwards, I had a word with the doctor in the Visitors' room and it was decided that apart from the morphine, she would get no other medication and the priority was just to keep her comfortable. Why had this not happened two days earlier? Why was she

given antibiotics until the previous night? Finally, she was peaceful and I was told that her dying would probably take hours rather than days.

I was exhausted after two weeks of coming to hospital every day to care for my mother and so I decided to pop home for a rest. After a two hour break, I got into the car to return to the hospital. 15 minutes after my departure, my husband received a call to say that my mother had passed away. I had not said to anyone that I didn't want to be there at the end, so I thought it would have been decent and kind to have contacted me so I could have been there.

When I got to the hospital I was told that two nurses had sat with my mum at the end, holding her hand for which I was very grateful. However, I was distressed to see that my mum still had her mouth open.

The ward sister gave me mum's jewellery straight away and I braced myself to say something to her since on the journey back I had been seething with anger. I told her how mum had been neglected and her dignity compromised. She had not been looked after in a compassionate way. She had been given antibiotics for too long in my opinion, and her situation had deteriorated too much for her to be taken to a hospice for the palliative care that I had hoped for. The ward sister had been unaware of this awful experience and suggested that we talk about this later. True to her word, she 'phoned the following day and was extremely nice and apologetic. It was decided that I would have a meeting with the departing ward manager and ward sister as well as the young male nurse that I had had issues with. I had calmed down a bit by the time I had the meeting in which I went through my complaints, but wondered if this would just be another statistic. I hope not.

We do not expect our relatives to be treated badly at the end of their lives. My mother and father-in-law and my father had been treated with more dignity and care and compassion in a workhouse hospital than my mother had received in this state of the art one.

Care and compassion – two words that I hoped the young man would heed in what was his supposedly caring profession. I had not seen enough of either in the last two days of my mother's life. I lost confidence in the care and I felt very let down. This is not acceptable.

## 6. THEME 3: CONFIDENTIALITY OF PERSONAL INFORMATION

A number of callers raised concerns about breaches of confidentiality in respect of medical records despite the commitment in the NHS Constitution that **“You have the right to privacy and confidentiality and to expect the NHS to keep your confidential information safe and secure” (NHS Constitution 2013, P8)**. For example:

- ❖ *Kim called to advise the helpline that she had received a letter addressed to her containing someone else’s details (name and medical condition – end stage cancer) and medication.*
- ❖ *Susan was shocked to hear an insensitive message left on her answerphone by the Patient Advice and Liaison Services (PALS). The message gave an update on the condition of an extremely sick relative and Susan was concerned that this message could have been picked up by anybody in her office.*

There were also very many calls to the Helpline from people reporting an excessive time lag for their medical records to be transferred to their new practice, with examples of six and nine months given. In some cases the records seemed to have been lost. This is also something we are hearing frequently when people make complaints and request their records. Many times crucial clinical entries are missing.

### ***Involvement in decisions***

The NHS Constitution sets out that patients have **“the right to be given information about the test and treatment options available to them, what they involve and their risks and benefits” (NHS Constitution 2013, P8)**. Patients also have the **“right to be involved in decisions” (NHS Constitution 2013, p.9)** about their care and treatment. However, a number of callers to the Helpline described their concerns about not being involved in decisions about their care. Likewise the relatives of some patients in hospital called to report that they had not been invited to be involved in decisions about their family member’s care.

- ❖ *Martha’s mother is in hospital and has apparently given consent for an operation. Martha believes that this was not informed consent because the procedure was not fully explained and her mother was pressured into it by hospital staff. She tried to discuss this with the Patient Advice and Liaison Service who said that they could accept the complaint but not act on it as the caller was not the patient. Martha cannot get her mother to speak privately about what she wants, partly because she is too frail and partly because her mother feels intimidated while in hospital and fears that her care will be affected if she complains.*
- ❖ *Brian called about ongoing problems regarding three different organisations that have cared for his mother. Firstly she was admitted to hospital with pneumonia, was moved to different wards and then got hospital acquired*

*pneumonia. Brian discovered his mother had a Do Not Attempt Resuscitation put on her, which was discovered by accident when Brian was having a friendly chat with a member of the staff at the hospital. The DNAR was later removed. Brian's mother's health deteriorated and she was getting constant infections at an Intermediate Care establishment. After being transferred to a care home for just two nights, the staff did not answer Brian's mother's alarm call – she tried to get up and had a fall, she lay on the floor for an hour with a hairline fracture to her spine and lacerations to her head. Brian says his mother begged him to get her out of the home. She is unhappy with the lack of care.*

The organisations treating these patients do not seem to recognise the rights of patients, their families and carers in relation to their involvement in discussions and complaints.

Another caller described the lack of engagement with the family around end of life care for their mother:

- ❖ *Joe described how "A moral crime for me was committed when, against my protests and threat of legal action, the hospital refused to give my mother a chance of survival by refusing to give her any nutrition and by withdrawing antibiotics. My mother was conscious on entering the hospital but in a confused state. She could communicate and after a few days did recognise her family and spoke to them. At one point she did succeed in eating some food. How can a diagnosis leading to the decision to starve my mother to death be made within a day or so of her entering the hospital? Why was only one member of my family kept informed of the fact that a decision had already been made to place my mother on what I can only call a 'death path.'? Why was the whole family not involved in this decision?"*

Another example of failure to adopt the NHS Constitution around end of life care was given by another caller:

- ❖ *The staff kept putting pressure on us to put our mother on the Liverpool care pathway, but we have refused. At that time our mother made a recovery and was discharged home. Our mother is in hospital again and we feel we are being pressured to agree to a Do Not Attempt Resuscitation (DNAR) order for her, but we are not convinced that she should be put on a DNAR notice because no-one has explained anything to us.*

### **Access to records and copies of records for patients**

Callers to the Helpline have reported examples of being refused access to their records or to be allowed to have a copy of their records:

- ❖ *Andrew's 5 year old daughter was seen by a specialist in the local hospital and the report was sent to the GP. Andrew's wife rang to ask the GP to see the report but the practice manager said "we can't show you; it's not addressed to you." Andrew phoned the Helpline to ask about their rights of access to their child's medical record.*

NHS organisations should routinely offer copies of letters or relevant parts of medical records to patients or parents of patients under the age of 18 as outlined in the NHS Constitution, **“The NHS commits to involve you in discussions about planning your care and to offer you a written record of what is agreed if you want one (pledge)”** (NHS Constitution 2013, P9).

### ***Making a complaint***

Complaints and raising concerns continue to be a common issue for callers to our Helpline. The NHS Constitution makes a commitment **“to ensure that when mistakes happen or you are harmed while receiving health care you receive an appropriate explanation and apology, delivered with sensitivity and recognition of the trauma you have experienced, and know that lessons will be learned to help avoid a similar incident occurring again”** (NHS Constitution 2013, P10).

From the Helpline data, there is a mix of positive and negative experiences for patients engaging with the complaints process, including some people sharing distressing events related to hospital admissions, poor care, and staff attitudes. The most frequently cited areas for complaints from the enquiries to our Helpline are poor communication, discharge processes, appointments, admission to hospital, diagnosis, care and surgical complications. Poor patient experience was consistently identified as the most common theme for complaints to hospital Trusts.

Specific issues with the complaints process included delays in responses to complaints, staff attitude, lack of personal contact, lengthy letters which lacked compassion, concerns not being dealt with openly and a lack of satisfactory explanations. Very few complaints at Trusts were being risk assessed.

Callers also reported that the availability of information regarding how individuals can raise concerns or complain about the services offered within a Trust is inconsistent and frequently woefully inadequate. Many patients, their families and carers do not know how to complain despite having been in hospital for some time. Many say that they are nervous and anxious to complain whilst still in hospital, in case it has a detrimental effect on their care and they suffer staff reprisals.

- ❖ *Suzanne continued to suffer pain following hip replacement surgery and investigations indicated that revision surgery was now required. The surgeon told her that there would possibly be consequences such as higher risk of infection, higher risk of bleeding and there may not be an improvement in the situation. She would like to complain but is very worried that there will be a black mark against her as a result.*

Suzanne’s initial treatment had not been successful and she suppressed her desire to complain for fear of this influencing her future care.

Many people make their call to the Patients Association Helpline after they have already made a complaint about their care to their local Trust or to NHS England and have been dissatisfied with the response they have received.

- ❖ *Rita and Eric complained about the care management of their recently deceased father, including many issues centered around his care, insensitivity, failure to pass on information to the family and failure to consult with the family regarding a DNAR order (which is disputed by the hospital's Patient Advice and Liaison service.) The family feels that there may have been a misdiagnosis, with confusion between a heart attack and a stroke and consequent use of inappropriate clot busting medication, after an 8 hour delay. The family believes that their complaint has then been badly managed, with the 30 day deadline being missed, responsibility for responding passing from one person to another (10 people in all) and an investigation being handled by 3 people, 2 of whom were subjects of the complaint.*

The family did not have their rights acknowledged by the NHS organisation that treated their father especially around the right to make a complaint, **“You have the right to make any complaint you make about NHS services acknowledged within three working days and to have it properly investigated” (NHS Constitution 2013, P9).**

One caller described their experiences of using the complaints process in the following way:

- ❖ *The complaints process has "traumatised my life," "put my life on hold" and put me in "a horrible place." It took a year to get a response. The process kept being put off and I am now concerned that it will over-run the three year time limit.*

Compassion in care, humanity and kindness are not always evident in health and social care environments. Another example of poor care was described by Helen whose husband suffered very poor care before dying in hospital.

- ❖ *One time when she visited he had "blood left in his hair." Helen's husband was diabetic and sometimes received very little food at meal times because he was "forgotten at the end of the meal run." His bed was in a separate room. When relatives visited on this occasion they found him falling out of the bed. It was a weekend and there was no senior member of medical staff to undertake a full assessment on him. He had a heart attack and died two days later. Helen has made a complaint to the hospital during a very difficult time when she is grieving for her husband. She was only able to do this with the help of her family.*

Helen's experience illustrates a lack of adherence to the commitment of the organisation which provided her care in relation to the NHS Constitution which states, **“We ensure that compassion is central to the care we provide and respond with humanity and kindness to each person's pain, distress, anxiety or need” (NHS Constitution 2013, P5).**

It is not always patients who call the Helpline with their concerns. Staff wishing to raise concerns sometimes call the Helpline. During this period we have received

calls from several staff reporting a culture of fear about raising concerns in their Trust describing issues which included bullying and harassment in the hospital.

Patients reported experiences of not being given enough information about their treatment and care and for that of their family members.

Family members are worried and stressed during such difficult times for patients, and health and social care professionals need to bear this in mind.

Information received by the Patients Association suggests that awareness of the NHS Constitution is piecemeal within the NHS. One individual reported that he had contacted the Department of Health with regard to trying to find out more about the NHS Constitution and if NHS bodies are bound to adhere to the terms set out in the Constitution, but concluded that the staff he spoke to at the Department of Health appeared to be unaware of the NHS Constitution and its Terms.

There is often a lack of support for patients who make requests to see a particular GP in a practice which conflicts with their rights outlined in the NHS Constitution.

- ❖ *Andy was very keen to ensure that he received continuity of his care. He phoned his practice to ensure that his appointment was with the same doctor he had seen previously. The Practice Manager was very intrusive in his questioning and asked inappropriate, very unreasonable and personal questions. Andy called the Helpline to ask how to go about raising a concern about his attitude and manner.*

In contrast, the NHS Constitution states **“You have the right to express a preference for using a particular doctor within your GP practice, and for the practice to try to comply” (NHS Constitution 2013, P9).**

Despite a commitment to welcome feedback from patients, many are afraid to do so in case it should influence the way their future care is delivered – by the same provider they have complained about.

- ❖ *Nicky felt victimised for not booking her annual follow up appointment with her GP. Even though the practice does not offer the option of booking ahead for follow up appointments she was criticised for not making her own follow up appointment. She told us she was afraid to complain to the practice, “as all the complaints go to the Practice Manager, and that was the person who I originally complained about.”*
- ❖ *Another caller was afraid of complaining to the care home where her mother was being looked after for fear of being intimidated by the manager. She had seen other complainants treated disrespectfully by the manager in front of others, she reported that the staff did not like their manager and residents were ignored when they called for help.*

Another caller had her case mismanaged when she did enter into the complaints process.

- ❖ *Tricia made a complaint after undergoing a procedure which ended with complications. After complaining to the Trust she was eventually invited to a meeting which she attended with a friend who was going to take notes. The consultant told her the meeting would be recorded and she would be sent a copy of the recording, so her friend did not take notes. However she was later told that the tape did not work. She was very disappointed and angry. She also discovered at the meeting that a trainee doctor had performed her procedure, to which she had not agreed. When she asked to see her consent form she was told it was missing from her notes. Tricia phoned the Helpline to seek advice as she was not satisfied with the way her concerns were being handled. After a long process the consultant agreed to give evidence that the procedure had been done incorrectly.*

The health service providers in these examples are probably not doing enough to support their patients in providing feedback if they fear giving feedback for the reasons given above. Such organisations are not committed to the principles and values of the NHS Constitution which states: **“The NHS commits to encourage and welcome feedback on your health and care experiences and use this to improve services” (NHS Constitution 2013, P9).**

## 7. PATIENT STORIES OF GOOD CARE

It is important for us to highlight some examples of good practice that we have heard about through our work with patients and through the Helpline. Whilst most of the calls to the Helpline are from patients who have concerns about their care, our interviews, listening events and focus groups have revealed examples of compassionate and excellent care, and patients who are very satisfied with their experience of the health service.

- ❖ *Sally talked about her complicated medication regime for her several long term conditions; Chronic Obstructive Pulmonary Disease (COPD), angina, arthritis, black outs and was full of praise for her practice after they arranged for her medication to be delivered to her home once a month.*
- ❖ *Val told us about her district nurse who checks that Val knows what each of her tablets is for by holding up each one and asking her what it is for. In this way she feels reassured and safe that she will not take an incorrect dose of anything and she knows what medication she is supposed to be taking.*
- ❖ *Mary couldn't speak highly enough of the doctors at her practice saying they were all "brilliant."*
- ❖ *Janet was very happy with the ease with which she received her prescription. She phoned the practice one day to order her medication and she received the prescription when she returned the next day.*
- ❖ *"My mum spent another five months in hospital and thankfully received outstanding care"*
- ❖ *"Ambulance arrived at 4.45pm, exceptional care from both gentlemen, thorough assessment before travel."*
- ❖ *Once my father had become slightly more stable, he was transferred to the ward that specialised in respiratory. I have to say the care he received here was exceptional and all of the staff that work on this ward are fantastic".*

In addition to these examples we also have been told stories by people who have complained about their care on one occasion and who have also had a very positive experience of care on a different occasion.

## 8. CONCLUSIONS

Most patients value their health and social care services and receive good quality care. However where care falls short, it is usually due to overly bureaucratic systems and unacceptable staff behaviours. When patients or their relatives wish to raise concerns or complain, the complex processes adopted by many sections of the health service often get in the way, leaving them confused and frustrated.

With increases in medical advances people are living longer, albeit with many long term conditions and more frequent need for intervention from care professionals. Greater numbers of older people are finding themselves needing care from their GPs and hospitals. Maintaining dignity is vital for all patients including the elderly, which means not being treated in a derogatory manner. Patients want to be involved in their care, receive information to make informed choices and finally receiving care that meets their needs. Many of our callers are relatives of older people who want the best for their loved ones.

Evidence from our Helpline indicates that our callers are finding that the systems and processes that are meant to work for them, are getting in the way of the patients receiving person-centred care. Instead they are often being subject to undignified, fragmented and varied treatment, which is detrimental to their health and wellbeing. They often feel unable to navigate the systems, including the complaints process. Many callers are afraid to complain, as they do not have faith in the system and are worried about their care in the future. They believe that staff attitudes and behaviours are key in making their experience a positive one, but can feel powerless to raise a concern when they or their loved one is subjected to poor care. There is an urgent need for ensuring a joined up approach at all stages of their care process. This must involve the patient and their relatives, and must protect patients who are vulnerable due to their age or condition.

The NHS is under considerable strain due to increasing demands and constant reorganisations. Unfortunately, this frequently contributes to the needs of patients being overlooked. The evidence from this report suggests that more needs to be done to listen to patients and understand their needs and expectations. Systems and processes will not do this alone. Initiatives such as duty of candour and the robust regulatory processes may help, but good health care is also about good communication. Fundamentally, this is about true engagement between patients and health and social care professionals. An important starting point is services acknowledging when something has gone wrong and apologising to patients. This would remove much of the anger experienced by patients and their families, which leads them to believe that complaints processes are more focussed on protecting the organisation, rather than providing a clear explanation of what has gone wrong. Unless we all treat each other with humanity, poor and undignified care will continue

in the NHS and callers will continue to contact our Helpline in absolute despair. In the last year the number of enquiries and complaints specifically regarding end of life care and *do not resuscitate*, has shown a very worrying increase. Additionally there is an increase in the number of complex calls and requests for support regarding failings in the provision of safe mental health services. As a nation, we are failing those who are most vulnerable and in need of compassionate, care and support.

As we have previously highlighted, the failings of NHS Trusts and GP practices to resolve concerns at a local level and the PHSO's clear failings at the higher level, has led to the cycle of complaints going round and round in circles. Complaints are like gold dust and they should be welcomed as a warning that something is not right. It is a sad indictment of our NHS today, that rather than signposting the majority of our callers as we historically have done, we are helping them to navigate a treacherous complaints system. There is a need for all complaints to be treated as critical incidents due to the distress and harm it causes to those raising the concerns and their families. The Hippocratic Oath, "**First do no harm,**" appears to have been lost when it comes to the handling of complaints and concerns in a so called caring and compassionate NHS.

## 9. COMMON THEMES/ FINDINGS

### **General practice**

1. GPs are not always promoting an attitude of trust between staff and patients, by fostering a supportive, welcoming and non-threatening environment. Many older patients are vulnerable and may find complex systems of registering, making appointments, accessing records or understanding their diagnosis intimidating.
2. GPs are not always engaging, involving and or encouraging of patients by improving the communication process which enable the patient to make informed choices or by providing the patients with meaningful information. This includes providing multiple options for feedback, to ensure that patients are able to express their views and have them taken seriously.
3. Patients should be supported to speak freely about concerns regarding their care and should be allowed to change their GP without difficulty, if they wish so to do.
4. Clear information is not always made available for patients from the GP service to understand how this service works, both within primary care and its relationship with secondary care.

### **Communication with patients and relatives**

5. Communication about treatment options should be open and transparent, clearly explaining the treatment, its risks and side effects, so patients and their relatives can make informed decisions.
6. Health and social care professionals do not consistently involve patients and their carers in decisions regarding care and treatment.
7. Clear reasons for delays in operations or cancellations are frequently not communicated, along with the expectation of the rescheduled date.
8. Health and social care professionals do not always explain diagnosis in a simple and easy to understand manner in order to reduce the anxiety and stress for patients.
9. Many patients do not have a named health and social care professional as the contact point in case of clarification or concerns need to be raised.

## **End of life care**

10. Professionals do not always proactively discuss with patients their preferred place of death. The patient's choice must be respected by the health and social care professionals.
11. No patient should be put on 'Do Not Attempt Resuscitation' (DNAR) notice until proper consent has been sought, whether directly from the patient or through the Advanced Directive.
12. If a patient is being put on the end of life care pathway or under a 'Do Not Attempt Resuscitation' notice, relatives must always be involved and consulted where possible. This is not happening routinely across the NHS and Social care system.
13. Families experience difficulty accessing provision for emotional support to help them to make difficult decisions and go through the bereavement process.
14. There must be additional resources in palliative care services. Inadequate care continues for too many. This is part of a national trend of poor end of life care in acute hospitals, identified by Care of the Dying Audit 2014.

## **Access to Mental Health Services**

15. Mental Health deaths are not being investigated properly.
16. Access to Mental Health services is poor in many areas.

## **Care and humanity**

17. Staff are not appropriately trained and supported in caring for the person in their charge. All care providers should invest in training their staff to ensure that they are providing a high quality service.
18. Clear guidance and accountability from senior management, that poor care is unacceptable is not always issued.
19. A culture of openness and transparency, where staff feel free to speak up if they see unacceptable staff attitudes and behaviours, is not embedded across the NHS.

## **Complaints processes**

20. NHS trusts must be more open about their complaints process and provide clear, easily accessible, guidance on how to make a complaint.

21. Every department should publish the number of complaints they have received and the action taken as evidence of on-going learning.
22. The Care Quality Commission (CQC) should encourage all Trusts to participate in the pre-inspection Patients Association complaints survey, to ensure any issues can be identified and addressed.
23. Trusts are not always adopting good standards for complaints handling, such as the Patients Association Good Practice Standards for Complaint Handling. These standards provide an excellent framework for improvement.
24. Complaint investigation processes and structures should be comprehensive and transparent. This should include the development of investigation templates, structured interview documents and support on the use of clinical guidelines and Trust policies and protocols. Every complaint or concern should be risk assessed and a level of priority assigned.
25. A Complaints Review process should be developed and implemented which includes the identification of a Decision Maker or panel, **independent** of the investigator to establish if a complaint is upheld, partially upheld or not upheld. The review process may be led by a Non-Executive Director, to encourage impartiality. Internal review outcomes should be included in regular Divisional and Board reports.
26. Complaints handling training programmes are not routinely mandated and established for all staff. This should commence at induction with ongoing training on a regular basis.
27. Formal Investigation Officer training for all those responsible for investigations of complaints should be implemented. This training should include an evaluation of competence, to ensure due diligence and transparency of the investigations.
28. Learning from complaints is not transparent and should be published openly on all Trust websites.
29. All NHS trusts and GP practices should be obliged to regularly publish all their complaints and summaries of outcomes.
30. The current PHSO process for investigating complaints is significantly failing patients and their families. The PHSO role in handling complaints needs to be totally overhauled, open to public scrutiny and external audit.

## 10. 2013 STORY UPDATES “ONE YEAR ON”

### 1. Olive Burns; by her daughter, Gillian O’Hearns

My beloved mother Olive Burns died on 30<sup>th</sup> May 2013 after 5 horrific weeks in Tameside Hospital. Following the inquest in to her death on January 13<sup>th</sup> 2014, I received a letter from the Interim Chief Executive of Tameside Hospital NHS Foundation Trust, dated 27<sup>th</sup> January 2014.

The letter stated that “the trust recognised that the care afforded to your mother on occasions fell short of the standard expected. As a result of this the Head of Nursing requested that the original action plan put in place to support the complaint response accurately reflects the omission by nursing staff in the care delivery afforded to your mother.”

The Interim Chief Executive also stated that she would like to assure me that the relevant staff involved in my mother’s care have been managed through the appropriate trust policy, the outcome of which could be no action, recorded counselling, disciplinary procedures or dismissal.

She said that another key focus of the trust is to ensure that staff employed by the trust are committed to quality and safe patient care, and the trust has introduced a values base test into the recruitment process for nursing roles.

She also stated the trust has accepted all the recommendations made by the Keogh report in July 2013 and will implement each and every recommendation in full.

I have had no further contact with the trust since this letter and can only hope the many areas of concern highlighted by my family have been implemented to ensure no other patients or their family suffer like mine did.

In July 2014 (12 months after the hospital was put into special measures by Sir Bruce Keogh) England’s Chief Inspector of hospitals announced that although there have been some improvements at Tameside hospital, significant issues remain over patient care and the hospital will remain in special measures for a further 6 months after being rated ‘inadequate’.

### 2. Averil Hart; by her father Nic Hart

Averil Hart our wonderful daughter, sister and friend died of a treatable illness at the age of just 19, whilst at the University of East Anglia studying Creative Writing a subject that she loved.

***Averil died from a treatable illness simply because of the lack of care provided by the specialist community ED team (NCEDS) and the GP surgery at the UEA Medical centre, compounded by the numerous failures of Norfolk & Norwich and Addenbrooke's hospitals.***

***If they had done their job properly then Averil would still be alive today.***

***Averil's death was entirely preventable by proper care and early intervention and this is well known by many of those involved.***

***Even Averil's cleaner at University did more to save Averil's life than the NCEDS team who couldn't even attend Averil in the hours after she was rushed to hospital by ambulance.***

For her family and her friends, life without Averil has been difficult over the past year. Coming to terms with Averil's loss has been virtually impossible, while some of the NHS organisations involved in her care still pretend that nothing went wrong.

Even Averil's cleaner at University, Carol, who called for medical help on two separate occasions, did more to save Averil's life than the lead consultants who were responsible for Averil's care. Yet they still suggest that the care they provided was "satisfactory".

The fact is that the only person from the specialist community service to see Averil was newly qualified trainee, had no experience of her condition and went on holiday in the last days of Averil's life without proper cover arrangements.

The pain of losing Averil in such tragic circumstances has left us bereft and unable to move forward in a life that now seems so empty and so often reverts to Averil's tragedy.

The process of dealing with the NHS has been extremely difficult. The NHS managers appear to have set tactics for dealing with serious complaints involving death or injury. To put it simply, they seem to deny that anything went wrong and try to bury bad news along with the death of your loved one.

At the outset as a grieving relative, you are given condolences, you are told that "no stone will be left unturned", but as time goes by, you begin to realise that these words mean nothing and that the longer you are left in limbo, the safer the NHS organisations feel. There is no accountability and a vast machine that will keep you in limbo without answers and without change.

In Averil's case it took over 18 months just to obtain copies of Averil's complete medical records, as the lead clinician involved in her care was able to censor the

records at the outset and keep them under wraps in order to help cover up the negligence that occurred.

Slowly it began to dawn on us, that the only thing that concerned these NHS organisations is the thought that Averil's case would become more public and damage their reputations, that more people would hear how our wonderful daughter was left to die alone at University without medical help and hear how these organisations had been negligent.

We set up a web site to honour Averil's life at [www.averilhart.com](http://www.averilhart.com) and we also published information on Averil's care together with a regular blog of how her case was being dealt with by the NHS complaints system. This proved to be a turning point in many ways, it was a place for tributes and thoughts about Averil and pictures of Averil taken by her family and friends. The web site also turned the spotlight of public awareness on UEA Medical Centre and Cambridge and Peterborough Foundation trust (CPFT), which supplied the NCEDS service.

The web site and the regular blog has been therapeutic in the long struggle in dealing with the NHS machine, it allows time for reflection on progress and also keeps all of Averil's friends and those wishing to help up to date with progress.



With many thousands of page views on Averil's web to date, there is a growing confidence amongst Averil's family and friends that the truth will be made public and that those responsible will be made accountable at last.

*So where are we now in terms of the complaints process surrounding the lack of care that Averil received?*

Without the help of the Patients Association in guiding our family through the complexities of dealing with NHS England and four NHS trusts and clinical

commissioning group, we would be struggling to make headway - the Patients Association have "held our hand", attended meetings with us and made every effort to show us the way to tackle the bureaucracy and cover up that we have faced.

### *Averil's Primary Care*

The UEA medical centre have been in denial since Averil's death. Despite having been requested to carry out weekly medical checks for Averil, the UEAMC GPs failed to carry out the prescribed tests. Averil's appointments ceased in early November without any blood tests having been done. Had the appointments continued and the requested checks been carried out, concerns about her condition could have been raised, and Averil would still be with us today.

Since our complaint the UEAMC have failed to answer our letters and provide answers to even basic questions. They have run to their defence union and to this day remain "in the bunker, with their heads in the sand".

### *Secondary Care in the Community*

North Norfolk CCG commenced commissioning of mental health services in Norfolk from April 2013. They took the lead role in our complaint about Averil's community care.

Initially NNCCG appeared helpful, however, it soon became clear that they had their own agenda and used their legal (corporate affairs) department as the main interface with Averil's family and appeared to be colluding with CPFT to ensure that we didn't find out the truth. They did not record the minutes of our meetings properly and only responded vaguely to direct questions.

When we asked detailed questions about the supervision and role of the NCEDS trainee who failed to provide adequate care for Averil, we got nowhere. When these questions were asked directly to the Chief executive of CPFT to establish what happened, the final response was "we will not be answering any more of your emails or letters".

We have been left with the distinct impression that there has been a substantial and ongoing cover up at CPFT with a number of clinicians and managers involved right up to and including the chief executive.

### *Averil's Care at Norfolk and Norwich Hospital*

Averil was taken to Norwich hospital by ambulance after a 999 call by her cleaner, who had found her unconscious, and who had been concerned about her wellbeing for a number of weeks.

The Norfolk and Norwich hospital wrote to us following our complaint about Averil's care and said that the care that Averil received was "satisfactory", this despite the fact that NNUH failed on numerous counts to look after Averil in the acute ward,

including allowing her to fall and sustain a head injury when she should have received close monitoring. They also failed to sustain her nutrition during the period and as a result her condition worsened and became critical.

After receiving this "denial" we persisted with a call to Anna Dugdale, the chief executive at NNUH, she finally agreed that Averil's care had "not actually been satisfactory" and agreed to an external inquiry into Averil's care at the hospital. This external inquiry has shown the numerous errors that the hospital made and highlighted the need for change to protect other AN sufferers admitted to the acute ward.

Our work continues with NNUH to ensure that changes are made.

### *Averil's Care at Addenbrooke's Hospital*

Averil was taken by emergency ambulance to Addenbrooke's hospital after her condition worsened at NNUH. Here there were unacceptable delays in her treatment and within hours of her arrival she became hypoglycaemic and fell into a coma as her condition had been left without adequate or proper treatment.

Averil died after several days at Addenbrooke's hospital on the 15th December 2012 with her family and boyfriend always by her side.

Addenbrooke's response to our complaint, was that of typical NHS denial. Our FOI requests indicate that the internally Addenbrooke's are well aware that there were serious omissions in Averil's care. We have finally, after eighteen months, been "granted" time with Keith McNeil the chief executive with the prospect of an external inquiry into the failings at Addenbrooke's to commence shortly.

### *What next?*

Nothing will bring back our beloved Averil, but we are determined to ensure that this tragedy does not happen again. No young person should be left in the community or at University with a treatable illness but without the proper NHS care that they need.

We have spent over eighteen months, trying to find the truth and being hampered by those that should be there to help patients and families and those that have a duty to improve services. We have now gathered several hundred pages of information and submitted these to the PHSO (Parliamentary and Health Service Ombudsman) and as of October 2014, they have commenced an investigation into Averil's death and into the cover up that has ensued. **We are relying on the PHSO to get it right, bringing justice for Averil, change in the NHS and peace of mind for her family.**

We would like Averil's story to show others that persistence is what generates progress when making a complaint to the NHS. Grieving families do not have to be satisfied with a response that says that nothing went wrong, when it is so clear that something has gone terribly wrong.

So to those members of NCEDS and UEA medical centre, the hospitals involved and those involved in the cover up that has followed, I would just simply like to say...

*"I hope you never have to lie at the bedside of your son or daughter, as they die a long and terrible death due to the lack of care of a medical team."*

*"I hope that you never have to live with the truth that a medical team were so disorganised, underfunded and poorly run that your son or daughter died a tragic and terrible death as a consequence of a catalogue of NHS failings."*

*"I hope that you never have to put your faith and trust into a medical organisation to look after a loved one, only to be let down by a complete lack of care, compassion and ability to provide appropriate medical care which results in their death."*

*"I hope that you never have to try find the truth from an NHS organisation that is so ingrained in trying to protect itself that it will go to any lengths to hide the truth of what happened."*

Averil's web site remains a focus for us, providing a place for tributes, photographs and videos of her life and a way inform others about Averil's tragedy and the lack of care she received.

*"God rest your soul my darling Averil, please forgive me for not protecting you from those that did not and do not care, but yet call themselves "medical professionals".*

### **3. Annie Carroll, by her granddaughter, Sarah Carroll**

After details of my nana's care at Aintree University hospital were published by The Patients Association, we heard from the hospital on 22nd November 2013 apologising for the delay and promising an imminent reply. The Ombudsman also contacted us, they chased the hospital for an update and they talked us through our escalation options. Unlike we had originally thought, we could not escalate our complaints to the Ombudsman straight away if Aintree did not respond in compliance with complaints deadlines, nor could we escalate it if we were unhappy with their response when we did receive it. We had to give Aintree hospital however much time they needed to respond, and then if we remained unhappy either because we didn't think they addressed our concerns or new questions were raised, we had to write back to the hospital to tell them we were unhappy and why, to give them a final right of reply.

The Ombudsman also advised they normally only investigate incidents which have happened within the previous 12 months. While they do have discretion, there is no guarantee they will investigate. And in order to escalate to them you have to fill in

another form outlining your complaint. So more forms to fill in and hoops to jump through.

Finally on 14th December 2013 we received a written response from the hospital but it was to our first two complaints only. When I chased a reply to our third complaint in January 2014, (6 months after it was submitted), they hadn't even started investigating. They claimed to be unaware of it. Once I provided their initial reference they found it, stating it had been misfiled and finally began investigating.

I then wrote to the hospital on 4th February 2014 advising why I was unhappy with their reply to our first two complaints. They phoned us on the 10<sup>th</sup> February, offering a meeting. The ombudsman had already told us we had the right to opt for a written reply, which we did, as if they spent 15 months putting together an initial reply and didn't succeed in responding to our concerns, then how would they respond in a meeting? And if they did have all the answers to our questions, we wanted a written copy.

Despite being informed on 5th July 2014 that a final reply was imminent, as I write this I am still awaiting a final reply to complaints 1 and 2 and an initial reply to complaint 3, so all 3 are still pending.

As our first complaint was submitted in September 2012, it has been pending for 26 months as we waited 15 months for an initial reply, and have now waited 11 months for a final one.

As our second complaint was submitted in January 2013, we waited 11 months for an initial reply, and have now spent another 11 months waiting for a final reply, so a 22 month wait.

As our third complaint was submitted in July 2013, they have had 16 months to investigate and have still not sent an initial reply. Aintree Hospital has not adhered to the NHS constitution at all in the handling of our complaints, nor their own complaints procedure.

We have also seen first-hand that they have not sought to learn from their mistakes as my Nan has again been an inpatient and the same problems continue to arise.

Making a complaint against the NHS is totally futile, it is a waste of time. They simply don't care and they don't want to listen. The complaints process is not a serious process it is just a game to them. So while more mistakes have been made on subsequent admissions it is not worth the time or the effort to complain again when complaints fall on deaf ears. There will never be improvements in patient safety while hospitals cannot be held to account, and while the CQC, (as they have again recently said), cannot investigate individual concerns raised by patients.

I wonder how many more scandals will arise, how many more patients will continue to needlessly suffer and how many more tragedies will unnecessarily occur in

families before someone finally listens and takes responsibility and there is accountability introduced into the NHS complaints system.

#### **4. Stan Norman; by his daughter, Janet Kite (Dec 2014)**

Since the Patients Association published my story in 2013 about the poor care provided to my father, I have been engaged in a continuous battle to get answers from Chase Farm hospital. I have kept a chronological list of emails and contact with various people at the hospital since November 2013 – this extends to 38 pages and is still ongoing. I had to wait nearly six months for the initial response from Chase Farm which, when it eventually came, was woefully inadequate. After a second response I requested a meeting to ensure the context was understood and all the evidence was considered. Very poor notes were made at the end of the two and a half hour meeting and Chase Farm refused to provide a transcript. They then sent a third response which again had not used the meeting information to address the complaint-and the responses were actually even more shocking than earlier letters. It demonstrated once more that no one bothered to look at the evidence I supplied.

During this time, my father sadly died, but my family and I will pursue this complaint until it is resolved. As a family, we now need to be able to move forward but that can't happen until we can draw a line under dad's unfortunate experiences and we are being completely hampered with this by Chase Farm.

In my view, the managers at the hospital have repeatedly failed to provide any timely responses to my requests for feedback. There have been conflicting responses, delays upon delays in responding to me; it seems to me that the hospital has simply tried to time out this complaint. Indeed, just a few weeks ago, 12 months after this started, I received a message from Head of Complaints & PALS saying "*Whilst we regret that you remain unhappy with the treatment provided to (your father) and the responses provided to date, given the responses provided to date and the time that has elapsed since some of the events concerned, we do not feel that further correspondence from us is going to be beneficial at this time*"...." *should you wish to pursue this matter further, we would suggest that you ask the Parliamentary & Health Service Ombudsman to review your case*". I will indeed be contacting the Ombudsman and am also in the process of agreeing a date for yet another meeting to revisit all areas of the complaint with Chase Farm, with the support of the Patients Association.

There appears to have been no thorough consideration of evidence that I have provided or of dad's records, nor at times, even the will to consider it, and there seems to be no concern for ensuring such experiences are not repeated. I am still waiting for reassurance that these failings have been addressed across the hospital and that there has been consideration of the impact that these failings had on the rest of my dad's life. This whole experience has been, and continues to be,

exhausting, heart breaking, and constantly threatens my sanity. I will continue fighting to try and get answers to my complaints because I believe that vulnerable patients are at risk, that systems need to be improved to ensure that vital information is in place and recorded in an accessible way and that patients' families are viewed as a valuable source of information. We need to stand up and say this is not right. This isn't just about my dad anymore. It's actually about processes in a hospital where no one wants to take responsibility.

#### **5. Patient B, by her brother (Tim Rees – NB original story was anonymous)**

I confirm that my brother, (the designated next of kin), my sister and I met with one of the consultants, Matron and the Services Manager for the Emergency Assessment Unit, and a member of the Hospital Complaints department of Colchester General Hospital on 14<sup>th</sup> October 2013. We had a long and frank discussion after which we received an apology from the consultant and were told that an Action Plan (including some vital telephone numbers) would be set up for any future admission.

It is true to say that we were satisfied with the outcome of the meeting.

However, I was very disappointed that I did not receive a copy of the promised action plan until 2<sup>nd</sup> December. Moreover, it came to me via the Patients Association, who weren't even represented at the meeting, and only after a series of chasers from me and persistent work by a member of the Patients Association.

It was a *Learning from Experience Action Plan* and it included the promised telephone numbers. There was also a written record of the meeting (rather than an exact minute) and a letter from the hospital's liaison officer for patients with learning difficulties to the Matron.

The hospital's liaison officer undertook *to contact the patient's brother in the week of 25<sup>th</sup> [November]*. I have no knowledge of him having spoken to my brother and he didn't call me.

We also have a slight concern (which we didn't pursue) about patient passports, because the care home told us that they have been tried before but didn't work very well.

Apart from that, it would be difficult for us to assess the hospital's improvements and promises. My sister hasn't been readmitted this year thus we have had no further dealings with Colchester General Hospital. That in itself raises some potential concerns as, should my sister need to be readmitted in the future, would the hospital be able to guarantee that the named consultant or named matron and their telephone numbers would be updated as and when there are staff changes within

the hospital. I like to think, however naïve it may be, that they have been true to their word and implemented the improvements.

## **6. John Moore; by his daughter, Caroline Donald**

It has been a difficult year, particularly as the neurosurgeon that we complained about has left the hospital where he worked and has been in the press. He has written a book about his career and is also giving quotes on unrelated matters. This is the man who gave a terminal prognosis to my father, on an open ward, with no warning. He also got the time frame dreadfully wrong (he told us 1-2 years when he later admitted he should have told us 3-6 months) which affected how Daddy dealt with his treatment plan, personal planning and his own death. We know that he was "reprimanded" by the hospital and he did apologise to us in writing. While we had no wish to see him stopped from working entirely, we find it difficult to read so much about his opinions in the press.

It is also very difficult to read in the press about the recent proton beam debate involving a young child, as it brings back all the bad memories of wondering about whether we were being told the truth. We were told categorically that Daddy was unsuitable for proton beam therapy. At worst were we lied to or even were the doctors lazy in their dismissal of this treatment - or was it an issue of funding especially as Daddy was over the magic age of 70? Were our doctor's right when they gave that advice? It has been like a constant torture of not knowing.

We are now also of the opinion that the radiotherapy was almost certainly not the right treatment - several of us have wondered whether we ought to have embarked upon radiotherapy at all when the real prognosis was so short. It felt like they just put us on the conveyor belt and went into autopilot. We feel that the radiotherapy was unsuitable as it made him so exhausted that his quality of life collapsed. And he only survived for 4.5 months from diagnosis. Was it really the right way to go? Had the operating surgeon done his job properly and the right communication been had between hospitals, would the doctors still have advised this treatment?

We would urge all UK neurosurgery or other units to agree a protocol for how, where and on what technical basis they give a timeframe when delivering terminal prognosis (NHS Executive told us that there was a protocol in place already which addressed our concerns, which teams should follow, and they would send out a reminder - not of huge comfort) Wouldn't it be sensible for some basic small practical steps to be enforced locally at each hospital e.g. at least two senior doctors taking responsibility for what view is given? Individual doctors should not be having life and death conversations unless more than one person has provided a check and a balance and can justify the view they are taking.

We would also like a specific protocol for patients with prognoses of less than 6 months (very different from longer prognoses) such that their teams only recommend conventional radiotherapy if they believe that it more likely than not will increase quality of life. Of course some patients will still want it and good for them - but please let's be honest with patients and their families.

It has been a year of hell but we are calmer since the anniversary and we have received great support from the Phyllis Tuckwell Hospice in Surrey and many others. I went back to work and my mother is coping admirably and stoically. The pain of bereavement does not go away it just gets incorporated into your life, and when you have been let down into the bargain, nothing is ever as shiny and new again. The added distress surrounding the advice we received has been a burden which we do not want any other family to have to go through. Please please can the NHS put some measures in place - for once it won't even cost any money - it is just leading people towards common sense and decency.

#### **7. Herbert & Irene Boswell; by their daughter, Doreen Hadfield**

Mrs Hadfield has not heard anything from Tameside since her story was published last year. She would like reassurance that the improvements referred to in the hospital's statement have been made.

## **11. TRUST RESPONSES TO OUR 2014 STORIES**

### **Peter Woolliscroft**

*"Thank you for sharing this patient story with us.*

*The patient did share a brief verbal summary of his care during a meeting with our Chief Executive who acknowledged this in writing on 2 December 2014. The patient did not ask for any further response or action from this. Although we have not had sight of this document previously, the Trust would welcome the opportunity to take a closer look at some of the aspects of this statement.*

*If it would be helpful for the patient to speak to us again about his experiences, we would be more than happy to do this"*

Kettering General Hospital NHS Foundation Trust

### **Daniel Wragg**

**Trevor Smith, Deputy Chief Executive at The Princess Alexandra Hospital NHS Trust, said:** *"We can confirm that Mr Wragg was admitted on 31 August and that his daughter made contact on 5 September raising concerns. Immediate action was taken by the senior medical and nursing teams to try to address these and to reassure Ms Wragg that her father was receiving good care and treatment.*

*“A full investigation is underway looking into all Ms Wragg’s concerns in detail, and we will ensure we learn any lessons from this. In the meantime, we can offer assurance that staffing levels on both wards where her father has spent time are reviewed throughout the day and night to ensure they are adequate and meet the needs of our patients. As well as daily contact with the senior medical team, Mr Wragg’s care has included visits from the start by a dietician and speech and language therapist, as well as daily checks by a senior matron to oversee his treatment and to satisfy ourselves that everything is as it should be.*

*“While we have worked very hard to collaborate with Ms Wragg throughout her father’s time with us, we accept that there have been times when we have failed to communicate effectively with her and for this we sincerely apologise. We take our Duty of Candour – being open and honest with our patients and their families at all times – very seriously and our senior medical and nursing teams make every effort to involve patients and their families in all decisions affecting their treatment. The most important priority for us now is to continue to provide the very best care to Mr Wragg, as well as to support his daughter in whatever way we can”.*

The Princess Alexandra Hospital NHS Trust

### **Daniel Wragg and Frederick Tolhurst**

*‘We are truly sorry for the experiences of Mr Wragg and Mr Tolhurst, and the distress it has caused their family. We are committed to doing all we can to ensure that these mistakes do not happen again. All our patients deserve to feel safe and well cared for, and their families need to know that they are in the best hands possible.*

*‘We know that we need to listen to the experiences of our patients, the good as well as things that can be improved upon, in order to get things right each and every time. To help us achieve this, we very much appreciate the ongoing support and dedication of Ms Wragg, alongside the Patients Association and Waltham Forest Clinical Commissioning Group, who are working with us on wards and hosting drop-in sessions at Whipps Cross Hospital to aid us in listening to any concerns patients may have. This innovative approach is helping us to quickly respond to the needs of our patients and their families and is improving their care.*

*‘In addition, we are now offering all inpatients over 75 years of age a comprehensive assessment that takes account of possible health needs that often come with getting older but that they may not be aware of, such as problems with hearing or balance, and are offering the chance to spend time with a hair dresser or chiropodist to make people feel comfortable and improve their hospital experience. All staff who work with older people have also been trained in caring for people with dementia, as well as undergone an intensive, week-long programme to ensure compassionate care and the patient experience is at the centre of all that we do.*

*'We believe this work will improve the quality of care we provide to older people across Barts Health and help in our commitment to achieving the Patients Association Gold Standard.'*

Barts Health NHS Trust

## REFERENCES

All references to the NHS Constitution are derived from: Department of Health (2013), *The NHS Constitution*, available at <http://www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Pages/Overview.aspx>

## APPENDIX



listening to patients,  
speaking up for change

# The Gold Standard Charter



- ✓ To always be cared for with compassion, dignity and respect.
- ✓ Listen to me and involve me and my family/carer in any decisions about my care and treatment or plans for leaving hospital.
- ✓ That staff get to know me as a person and treat me as an individual who matters.
- ✓ Do not harm me and keep me safe from risk of infection, injury or further illness.
- ✓ To know that the staff team is co-ordinating my care and treatment and to be told what is happening next.
- ✓ To have easy reach of food and drinks and help with this if I need it.
- ✓ To be able to tell a member of staff if I am in pain, worried or nervous about anything.
- ✓ To be able to receive pain relief if I need it.
- ✓ To have assistance to go to the toilet when I need it.
- ✓ To always have my personal items such as spectacles, dentures, hearing and walking aids near me.
- ✓ I must be able to listen to the radio, watch TV, read or do some other activity if I want this.
- ✓ Ensure I can see a specialist in a timely way such as geriatrician, occupational therapist, social worker, physiotherapist or others if I need this.
- ✓ To know how to give comments, raise concerns or make a complaint without fear of my care or treatment being affected.
- ✓ To always have easy reach of the call-bell.