My Mother’s Voice
My late mum had dual sensory impairments coexisting with complex comorbidities. Mum wanted me to continue to be her voice and tell of her experiences of NHS Scotland in order to acknowledge the great good, but also to highlight the problems that she endured, for the sake of others in the future.

Health &Sport Committee Q: ARE SERVICES SAFE EFFECTIVE AND EVIDENCE BASED?
Some are of a very high standard. Unfortunately, some are unsafe, ineffective and do not appear to consider the “evidence”, i.e. the voices of the elderly and their carer/s to the detriment of the individual and finite NHS Scotland resources.

Legal Omission - Adults With Incapacity (Scotland) Act 2000 - NHS Scotland Allows Consultations During Which Hearing Aids Are Not Actually Required to be in Patients’ Ears in CONSULTATIONS – “Mechanical Aids”
I have been clearly advised by a solicitor (email 04/2016), that whilst the Incapacity Act 2000, Principle 3 1.6.4 makes reference to a “mechanical aid” it makes no stipulation that, if like mum, an individual actually has been prescribed hearing aids by an NHS Scotland audiologist, the “mechanical aids” must actually be worn in their ears in consultation i.e. to enable them to facilitate their hearing.
This lack of legislation ensures that as long as it is not mandatory it is not implemented by all NHS Scotland staff. I liken this to saying that it is okay to watch TV with the sound silently off.

Equality Act 2010 - Making Reasonable Adjustments
Various staff did not seem to comprehend the functional effect and outcome of mum’s individual hearing impairment (sibilants/high frequency loss) and did not, therefore, make appropriate “reasonable adjustments” e.g. write down key information in large print (due to her visual impairment).
On various occasions mum misheard e.g. she once thought a doctor was attacking her with a hammer as she hadn’t heard them say about using the reflex hammer, on another she thought the doctor said that she would be having chemicals inserted (camera) and on another occasion when doctors tried to discuss “do not resuscitate” (DNR) she told me, when I entered her room, that doctors were “trying to put her to sleep”. If only I’d been included in that ward round to help reassure mum.

“What Matters to You” Board: some staff obviously demonstrated a lack of understanding of her hearing impairment in their medical practice, even though I wrote about it on the board.
Due to mum mishearing, she was put at risk as a result of giving the wrong answer, or put another way, the “right answer” to the wrong(ly heard) questions. Some NHS staff seemed to think that if they spoke loudly and clearly mum could interpret correctly as if because it was said in the manner they thought okay, ergo it would be
heard. Often a doctor would “reassure me” that mum had heard what they said, but when I asked mum to repeat back to me she expressed a different interpretation altogether.

**Action on Hearing Loss Scotland: Advice About Equality Act 2010 “reasonable adjustments”**

Mum and I are indebted to Action on Hearing Loss [https://www.actiononhearingloss.org.uk/about-us/scotland.aspx](https://www.actiononhearingloss.org.uk/about-us/scotland.aspx) for their invaluable advice. I bought a write on/wipe off board for mum (large print).

**Detrimental Consequences of Ignoring Individual and Carer: Incapacity Act 2000: Principle 4**

Ignoring mum and I, a “relevant other”, put mum at risk and was ineffective e.g. doctors ignored mum thus discharging mum home in pain with Cameron lesions, and despite a 999 admission to “A and E” mum was again sent mum home, despite my pleading with the doctors, which further put mum at risk.

**Labelling “Elderly” Could Lead to Exclusion of Diagnosis Options**

In our experience mum was labelled “elderly” and treated as if it was frailty, as if she did not have serious health problems, e.g. Cameron lesions yet taken off stomach medicines->becoming very sick.

**Swallowing Difficulties – Speech and Language Therapists (S&LTs)**

Despite my telling doctors that mum had swallowing difficulties I was ignored until mum got a lung infection due to aspiration, hospitalised, had a video fluoroscopy and was immediately put onto stage 1 thickened drinks, pureed diet with all medicines needing to be crushed or in syrup form if available.

**Nursing Service- staff levels are potentially unsafe**

There are simply not enough nurses in Care of the Elderly. I wonder if the complexity of individual need is understood by service planners. If they sit in a ward for a day, then they will understand…

I have spent many an hour by mum’s bedside and observed dedicated, hard-working nurses e.g. doing the drug round whilst simultaneously trying to ask for help from other extremely busy nurses as a patient tried again and again to mobilise independently when requiring assistance, at risk of falls or individuals simultaneously needed assistance to go to the toilet. Drug rounds were also delayed…

**Health and Sport Committee Q: ARE PATIENT AND SERVICE USERS’ PERSPECTIVES TAKEN INTO ACCOUNT IN THE PLANNING AND DELIVERY OF SERVICES?**

**PANEL Principles**

One of the PANEL principles is participation in their care planning by the individual. From our perspective this may have been evident in writing, but rarely in practice.

**Carer’s/Power of Attorney’s Voice Ignored Contrary to “Incapacity Scotland Act 2000”**

As a carer it was a distressing struggle to have my voice heard, to advocate. I was so excluded that I sat in an NHS Greater Glasgow and Clyde car park in despair last December, and contacted Carers Link [http://carerslink.org.uk/](http://carerslink.org.uk/) It transpired that
doctors were considering cancer but didn’t tell us, weren’t ever going to treat mum. Mum was subsequently trapped in hospital for 41/2 needless months and became infected with influenza Type A with which she was very ill. We would not/did not have agreed/agree to an effectively futile test, without any hope of treatment. Mum was denied her last ever Christmas at home, for no reason whatsoever. No written/verbal consent for CAT scan.

Carers Link
I can never thank Carers Link enough for their invaluable support/calls on that day and all other days!

Neither Mum’s Consent or My (Power of Attorney) Consent Was Sought or Given
Mum was given a CAT scan and no consent was sought or given. We were later told that no matter what it showed conclusive or not, no treatment would be given to mum so why not let mum go home? As mum said correctly “They’re not doing anything for me, anyway”, except that she got a hospital acquired infection. The non-existent palliative care pathway which caused so much suffering…

Lack of Informed Choice Regarding Tests for Potential Non-Treatable Cancer
Mum didn’t even have her hearing aids in her ears when doctors/a senior nurse excluded me during visiting on 23/12/2016, shutting both mum and I out of participative, informed choice i.e.no choice

Power(less) of Attorney: Carer Not Told Mum Getting Cancer Tests-Phoned Results Xmas Eve!
I was appointed Power of Attorney by mum and I tried to advocate with mum, on her behalf. I said to ward staff, “please make no key decisions about mum, without mum or without me”. The power of Attorney would have been more use being a doormat at the entrance to the Care of the Elderly unit.

No Continuity of Communication e.g. Information Board Naming “Go to” Staff Beneficial
It is also extremely difficult to actually communicate information to/from ward staff as there is such changeover of unidentified (name/role/time on ward) for continuity trainee doctors, no day to day “project manager” no continuity. This practice excluded and isolated individuals and carers.

Non-Inclusive Multidisciplinary Discussion
Generally it was the experience of mum and I that our perspectives were only taken into account if they concurred with the decision already made by the ward team. Mum said, days before she died that hospital “doctors didn’t listen to my wishes”. Decisions were made at MDT (multidisciplinary team) meetings and ward rounds which excluded the individual and carer unfortunately.

Ignoring Carers’ Perspectives
On one occasion, in 2015, I was very concerned at a doctor trying to discharge my sick mum saying that mum just “doesn’t like hospital food”. He said to me “I’m the doctor” and I said “I’m the daughter”. One change of consultant later and mum was correctly diagnosed with gastroparesis.
This is just one of many examples of the detrimental struggle for our voices to be heard.

**Decision Making by Some Doctors - Patronisation of Mum: Decisions about Mum without Mum**

On another example a CAT scan was inconclusive (suspected liver lesions) and I asked several times for mum to have an MRI scan. We were refused, doctors patronisingly /deciding on mum’s behalf, that it would be “too much for your mum”, although they did not even ask mum who had had previously had two MRIs and told me she would willing to have another one. *Months later* mum was given another CAT scan and it showed a growth on her bowel which we were told had been present at the first scan in December 2016, but that which had metastasised to her liver. Months wasted in hospital!

> **DO SERVICES TREAT PEOPLE WITH DIGNITY AND RESPECT?**

Many NHS staff did treat mum with dignity and respect and kindness in day to day interactions, but some presumably thought that they were doing so but did not, in reality, as follows

**Inaccessible Communication**

By excluding mum from the decision making process either by meeting in a different room or not “making reasonable adjustments” to enable her to receptively communicate, by not including mum or I in the decision making process the team did not, in truth, always treat her with respect or dignity.

#hellomynameis: Mum Was Not a “Resusci Anne”;

**Accessible Communication**

Identifying introductions should be instilled into every member of staff. Nurses wear large name badges with accessible large print but many temporary staff e.g. trainee doctors failed to either introduce themselves or even wear a badge. A lanyard with tiny writing often turned inwards and the name badge becomes inaccessible to visually impaired individuals et al.

**Ward Mission Statement**

The Mission statement on the ward wall sounded wonderful about communication with patients and carers alike. It looked great, read great – but theory was often as far as it went.

> **Health and Sport Committee Q: ARE STAFF and the PUBLIC CONFIDENT ABOUT the SAFETY and QUALITY of NHS SERVICES?**

Mum and I experienced a great deal of kindness but we lacked confidence about safety and quality due to the lack of knowledge caused by lack of continuity and poor staff communication pathways.

> **Health and Sport Committee Q: DO QUALITY of CARE, EFFECTIVENESS and EFFICIENCY DRIVE DECISION MAKING in the NHS?**

Quality of care, effectiveness and efficiency can, on paper appear to drive decision making, but not necessarily in practice. It vital to say that mum and I encountered
many individual NHS Scotland staff giving world class quality of care, effectively and efficiently achieving beneficial outcomes for mum.
I believe, however, the lead decision makers, policy makers in offices do not always, as evidenced by detrimental outcomes, relate to 3-d practice of day to day demands in the NHS today.
As mum’s carer, I never ever tried to diagnose mum but I could bring knowledge of observed changes in mum, to doctors and nurses, when mum was unable to communicate effectively.
Whilst some doctors were the epitome of human rights, some treated me as if I had no right to speak as I didn’t have an honours degree in “being a daughter”.
Unfortunately, my reported changes in mum, ignored initially, proved to be accurate observations, and mum suffered needlessly by my being ignored. I cannot even imagine the accumulative cost of repeatedly delayed treatment resulting in frequent extended admissions.

**Food Waste and Lack of Appropriate Food Groups: Not One Egg Dish: No Variation of Choices**
I observed considerable food waste. Mum would get given huge portions in hospital which due her large hiatus hernia she could not eat. At home we ordered in “petite puree “dishes with similar nutrition condensed into smaller portions so that maximum nutrition for mum equalled minimum waste. I gave staff the Appetito/ Wiltshire Farm Foods leaflet but for nearly 5 months mum had the same unvarying limited selection in hospital. Despite the many benefits of eggs mum was not given even one egg dish in her 4 1/2 month stay in hospital...

**Pharmacists: Medicine Waste**
There needs to be more intervention with pharmacists. I asked to meet one, due to mum’s swallowing/meds issues. Also, every time mum’s medication was changed all the unopened i.e. sealed bottles had to be thrown out! A quite terrible waste of precious and expensive resources.

> **Health and Sport Committee Q:** ARE the CORRECT SYSTEMS in PLACE to DETECT UNACCEPTABLE QUALITY of CARE and ACT APPROPRIATELY WHEN THINGS GO WRONG
>> No. The Complaints system is not fit for purpose. It should be independently, externally organised.

**Default of Complaints Manager Was to Support NHS Staff – Never Once Spoke With Mum**
No matter how serious the complaint, complaints automatically supported NHS staff as if mum and I wrote fictional complaints! It is and should be a matter of very serious concern that Complaints never once came to talk to mum, in person, when any medical complaints arose (notwithstanding kind non-management individuals).Patients should be given equal protection to staff and consumer goods! Mum and I spent weeks in hospital asking for her to be issued an electric bed. I had previously injured my shoulder assisting mum to sit up. Refused a bed before discharge, she couldn’t sit up when she returned home, spilt coffee and the Social Work Homecare Manager immediately had the nous to facilitate mum’s
independence by issuing mum an invaluable electric bed, and saving us from injuries.

**Complaint of Bullying in 2015: took 7 ½ (seven and a half) weeks for a formal written response to be sent to mum; Elderly Person Ignored i.e. Further Bullying, Isolated from Help**

In 2015 mum complained to me that she had been bullied by a doctor, who avoided our arranged meeting, so I immediately phoned Complaints at Greater Glasgow and Clyde and was told that it had to be put in writing.

My very ill 89 year old mum was left frightened and alone in her room and not one single person from Complaints/NHS Scotland manager walked onto that ward to talk with her, to listen to her as she voiced her concerns. This evidenced that they did not act, they were effectively *in-act-ive*, inert.

**Request for Independent Quick Access Team/ Independent Complaints Team**

There should be an independent, intermediate “quick access at bedside” team to come to people’s bedsides. Mum and I would have preferred to “explain” and try to seek resolution before “complain”.

**More Active Legal Rights Evidenced for Inanimate Objects – Consumer Rights Pathways**

If I have issues with objects there are various clear Consumer Rights pathways such as Citizens Advice and Trading Standards to quickly follow and get results timeously. The Human Rights enshrined in legislation *look* inspiring. Until awareness is raised that the words need to actually leave their pages, must be enacted upon, and are made mandatory, we have more protection for objects than human beings, in mum’s experience.

**Nursing Has a Clear Ward Hierarchical Pathway if Issues Arise**

I asked a Senior Consultant if it could be made clear either on a wall chart/leaflet etc. who people could approach if issues arose. Even in a supermarket there is a clearly identifiable “go to” destination i.e. Customer Services. Nurses wear identifiable uniforms and it is clearly marked on the ward entrance who were the Senior Charge nurses that day.

I have to say that, previously, when I have persevered to find a person in charge, I have found Clinical Service Managers an excellent support. They are not, however, doctors’ line managers.

**Mum’s Voice**

Mum’s comment about those NHS staff who ignored her (2015) “*It is as if they have already buried me 6 foot under*”...a damning indictment of the fact that when “unacceptable quality of care” was brought to the attention of NHS Scotland staff, they did not “act” to protect my mum, a vulnerable 89 year old, as she lay helpless and isolated in her bed. Letter to (then) Chief Executive of Greater Glasgow and Clyde Health Board) 2nd December 2015 “*My mum, has come to the inevitable conclusion that no senior member of NHS staff is going to talk with her*”. I suggested that there be a formation of a Rapid Response Team. In what other situation in life is a complaint about bullying ignored for weeks on end?
I have found that, in practice it is far easier to have resolution over inanimate objects which have, in practice, have far more consumer rights that my elderly mum had the Right as a Human to participate in her health care decisions or to have her daughter included, as was her wish and right so to do, allegedly through Power of Attorney.

Default Response by Complaints Manager
The Complaints’ Manager’s response was to simply fail to uphold our complaints whether lack of electric bed, bullying or lack of support about obtaining a MAR sheet (medical assessment record). The Complaints’ Manager’s response was so far removed from the accurate reality of mum’s predicaments that it was as if the manager was responding about a different mum in a different ward in a different hospital in a different city – understandable considering that she never once met mum.