

John's Campaign: Voices

12th October 2016

The Voices of John's Campaign

The ten people who will speak at our conference on October 12th and whose scripts are included here (pp 7-16) represent the thousands who have expressed their support via letters, emails and articles, on social media, at meetings and through their actions.

John's Campaign is particularly indebted to the *Observer* Newspaper. It published the initial article written by Nicci Gerrard after her father's death (re-printed here pp 3-6), and her subsequent articles. The *Observer* has covered our achievements in their news pages and has provided a regular space on its webpages for supporters of John's Campaign to contribute their own insights into the ways in which the experience of dementia patients in hospital can be improved. These good practice examples are listed on pp 17-27 and can be read in full both on the *Observer / Guardian* website and at johnscampaign.org.uk. The *Observer* has also hosted the growing list of hospitals and other institutions that have pledged to work in partnership with carers (theguardian.com/society/2015/jul/25/johns-campaign-listing-hospitals-that-welcome-carers). Here are some voices of ward sisters, patient experience managers or dementia lead nurses as they choose their own 50 words to express their welcome.

Ward 12 is focused on the carer. Carers are the most important person in the patient's life and know the patient better than anyone so why should we deny ourselves this knowledge? We have no special facilities for overnight stays but will do our best. Please speak to our staff to make arrangements. (Wishaw General Hospital, Lanarkshire)

Our staff see you as partners in the care of your loved ones and as such we want you to spend as much time with them as you wish, be that day or night. Using "Carers Cards", you are invited to participate in care, activities and decisions for their treatment. (Warrington & Halton Hospitals, Cheshire)

St Julian's welcomes carers day and night. This enables tenants to have family visits at any time. Families often stay if tenants are unwell, when families visit tenants can make them tea, and continue crucial family contact and independence for tenants. (St Julian's House, County Tyrone)

D4W welcomes carers. We will never willingly place any human being in a situation where they feel stranded or fretful in a strange ward environment. We will always seek the advice and support of a familiar person, family member or carer to assist us to care and bring comfort and orientation. (Royal Gwent Hospital, Newport)

James Munro

In today's busy healthcare services, listening to patients and carers often seems to be seen as an optional extra, or even a distraction from the important business of "real" healthcare. But the truth is that listening is the essential ingredient without which healthcare can't work at all.

And, to be clear, by "listening" I mean something interpersonal, relational. I don't mean listening in the GCHQ sense of "we've got your data and we know what you think".

At Patient Opinion we've read and published thousands of stories from patient and carers over the past decade. And being listened to – or not – is at the heart of people's experience of care.

Recently, we explored this issue in the accounts people share with us. We found that when people are listened to, they feel valued and cared for. They gain confidence in the service and in their own ability to recover or cope. They gain motivation, resilience, and feel more able to be actively involved in their care. They feel, well... healthier.

Conversely, when people feel ignored, excluded or treated without respect, they experience distress, lose trust in professionals, may stop treatments or use services in unproductive ways. Overall health and quality of life suffers.

In listening we learn, connect, empathise – and both speaker and listener are changed. In essence, that's our mission at Patient Opinion, a web site where people share their experiences of care – good or bad – and staff listen, learn, respond and say what's changed. And because the stories people share are public and online, the listening and learning can spread widely, to students, commissioners, researchers and policymakers. A single story can resonate with hundreds or thousands of listeners.

In short, I believe that listening is the beating heart of healthcare. It matters whether we have interventions that work or we have none. It matters at the start of life and at the end. It matters in the midst of joy and at times of deepest sorrow. It matters when there is nothing else to do but just to sit and listen. That is when it matters most of all.



James Munro is Patient Opinion's chief executive and chief technology officer.



Nicci Gerrard

*My father entered hospital articulate and able.
He came out a broken man*

My father would often say in the years before his death how lucky he was: lucky in his family, his friends, his life. Even when he barely had any words left to him, he would repeat the phrase. Not everyone would say that he was always so fortunate.

My father was a doctor and then a businessman. He was very clever and also enormously competent; he could make things, fix things, solve problems, name trees and plants and insects and birds, grow vegetables, sing in tune, do cryptic crosswords, read maps, sail boats, tie knots, paint and draw, play chess. I always knew that with him I was in safe hands; nothing could go wrong. He was also modest, courteous, reticent, mild-mannered, mischievous, stubborn and sweet. For decades, my mother – who has a disablingly bad back, suffered multiple strokes and cancer – has been an invalid and my father was her devoted carer, shopper, chauffeur and ardent admirer. Looking after other people was part of his identity. As a friend said when he died, he was one of the good guys.

About 10 years ago, he was diagnosed with dementia. It was a slow but steady decline, with accelerations when he was ill or upset – he was particularly distressed when he was no longer allowed to drive. But he remained largely cheerful (or at least he hid his fear, only rarely speaking of going into the darkness).

And he could still have a happy life, although it was increasingly limited. He went for slow walks, helped round the house (he was especially fond of washing up and mending broken china), saw friends, worked in his beloved garden, potted in the greenhouse, ate with gusto, told stories about his past, put food out for the plain brown birds he so loved.

Last year he went on holiday with us to Sweden, where he had a sauna and swam in the lake and looked for mushrooms in the forest. He went to Turkey with my brother and sister and there are pictures of him sitting with his sketch pad among the wildflowers, very contented. He celebrated Christmas with us and sang carols and ate goose and pulled crackers and wore a torn orange crown on his soft white hair and teased the grandchildren and the dog. He celebrated new year with his close friends. I sometimes thought of him as a great city whose lights were going out one by one, but slowly, so that you hardly noticed.

Then in February he went into hospital with leg ulcers that weren't responding to antibiotics. He was there for five whole weeks, and for as long as I live I will regret that we didn't understand sooner what this prolonged stay would mean. The ulcers were slow to heal. There was an outbreak of norovirus in the hospital, which meant that he wasn't allowed visitors – although all of us did manage to sneak in every so often, it was only for a few minutes at a time. When his infection was healed, the hospital wanted him released to a rehabilitation ward because he had lost so much of his mobility, but no beds were spare and so his stay was prolonged further, until we insisted he leave.

Five weeks. He went in strong, mobile, healthy, continent, reasonably articulate, cheerful and able to lead a fulfilled daily life with my mother. He came out skeletal, incontinent, immobile, incoherent, bewildered, quite lost. There was nothing he could do for himself and this man, so dependable and so competent, was now utterly vulnerable. He could not sit up. He could not turn over. He could not put one foot in front of the other. He could not lift a fork or a glass to his mouth. He could not string words into a sentence – indeed, he could barely make a word (except to say hello, to say thank you, to say that he was lucky). He did not know where he was, who most of his friends were, sometimes perhaps he no longer knew who he himself was.

He came home to my mother, his wife of 61 years, but had to have 24-hour care, and even that wasn't enough: we hired people to come in during the day to lift him into a wheelchair and take him into the garden, or help with the routines. He was washed, had food and drink put into his mouth; he lay in his bed day after day and night after night and his family and friends spent as much time with him as possible, but sometimes it was impossible to tell if he even knew we were there, still loving him. He remained indelibly himself, sweet-natured and courteous, but he did not know himself. He was alive, but he did not have a life.

Of course, my father had dementia: perhaps this is what he would have come to in the end. But not so soon, not with such terrifying swiftness, a sudden and heart-wrenching obliteration. I am certain that if he had not lain in hospital for five weeks, with no one who loved him to take care of him, he would not have descended into such a state of incapacity.

It wasn't really the fault of the doctors and the nurses. They healed his infection, they put food and drink beside him, almost all of them treated him with respect and genuine kindness. But they left him to himself and couldn't spend hours making sure he ate and drank. They couldn't brush his teeth and shave him and comb his hair and read poetry to him, do crosswords, play chess, talk to him, hold his hand, tell him he was safe, keep him anchored to the world he loved.

It was as if all the ropes that tied him were cut over those weeks and slowly he drifted from us. We thought that when we got him home we could draw him closer to the shore. But he was too far out. Three weeks ago he slipped from us at last, over the crumbling line that separated him from death.

I write this now not because it's a unique story, but because it's not. Hospitals are full of demented people who are ill, bewildered, frightened and alone. During the month that my father was in hospital, my mother was also there for a week, just down the corridor. Both were in general medical wards, but there were only old people there. Almost every patient was demented. Some were quiet like my father, lying passively in their beds, others were in a state of terrible distress. There was a man who shouted and shouted for help. There was a woman who cried out that she had to get home, had to get home. They moaned, wept, begged, whimpered. It was like a scene from hell. How did we ever get to this state?

It is unimaginable now that children used to be left in hospital without their parents; that battle was won long ago, and NHS advice to parents of children in hospital is clear:

“Stay with your child as much as you can. Hospital staff have found that children often adapt better to a hospital if their parents stay with them for as long as possible. Reassure your child that you will be staying by their side, and let them know that the hospital is a safe place to be.” (This is from the “Children in Hospital” section of the NHS website.)

It’s unbearable to think of a child alone and uncomfortable, and I cannot see that the needs of patients with dementia are any different. They are as vulnerable as a child, and can be as scared, distressed and disoriented as a child would be. The effect on their future mental health can be catastrophic, as it was for my father. Carers should be allowed to stay with those suffering from dementia. It should not be a duty but an inalienable right, a matter of moral decency and simple human kindness.

There is so much that needs to be done in our care of old people: a whole change of culture. This is one small thing, but it’s achievable and seems important. And, along with friends who fear the same for their own parents, this will be my campaign, because it’s the only way I can think of turning what was so sad into something hopeful. What happened to my father, what is happening to thousands of others, must not be allowed to continue.

I think of him as he was in hospital: so thin and confused, with his white hair in tufts and his sweet smile. My father looked after people all his life. He was a good man who believed in the goodness of others. He was a man of dignity and integrity and optimism. Yet – with the best of intentions – we had to abandon him to a system that could not care for him in the way that he required. At his hour of need, we didn’t rescue him; we let him go. It needn’t be like that; it mustn’t.

Observer, 29/11/2014

Nicci Gerrard co-founded John’s Campaign with Julia Jones.



John’s Campaign

for the right of carers of
people with dementia to
accompany them in hospital

Tommy Dunne

Going into hospital is a very worrying time for anyone, but for a person with dementia it can be a nightmare. Can you imagine waking up everyday in a ward, a strange place surrounded by strangers you do not know, and people who do not understand how a person with dementia feels or their special needs?

A strange woman comes and puts this thing round your arm and says "I'm taking your blood pressure" and suddenly something tight starts squeezing your arm and it hurts, they then stick something glass in your mouth, "just taking your temperature". Okay they say and walk away.

A meal menu is put in front of you for you to tick which meal you would like, but you may not understand it, you may not have reading glasses on or you may be dyslexic - but none of this is taken into account as they collect the menus and then realise you have not ticked any so they say to you "would you like the chicken pie?" and because you don't answer they assume you are deaf and shout "would you like the chicken pie?" This makes you jump and nod with fright so they assume you said yes.

They then come round with the tea trolley and a stranger is standing at the bottom of your bed saying, "would you like a nice cup of tea?" You are startled: who is this person at the bottom of my bed?

"I'll leave you a nice cup of tea." They then come back later and take away the tea you could not drink and assume you did not want it. They notice that your water jug is full and assume you are not thirsty. They also notice that your chicken pie dinner has not been touched and assume you are not hungry, so they take it away without any note being made that you have not eaten or drunk.

The same scenario is played out over the next few days, so you start to become dehydrated and delirium sets in. This is bad enough for any person, but for a person with dementia it is twice as bad.

They put your worsening condition down to your dementia and the nightmare cycle of waking up in a strange place continues.

You become agitated so they give you medication to calm you down and so the quick decline in your health begins. Yet no-one knows or understands why.



Lyn Juffernholz

As a boy, my partner Alan had a traumatic experience in hospital when he was separated for a long period from his parents. Later, in the 1950s, he was able to stay with his own daughter in hospital when she had TB. But at the end of his life, confused and scared, he was once more denied the constant support of those who loved him.

In early 2012 Alan was living well with dementia – he was sociable and articulate, still walking a lot, enjoyed his food! And he generally carried on loving life – with restrictions – as he'd always done.

Then one evening in June he was sent to A&E with suspected pneumonia. I was not prepared for what happened next. After a night and a day there, he was finally moved, first to a ward where the staff accepted I would stay, then to another where I was told that staying the night was against the rules. I protested: Alan became anxious and upset about being separated from me – he was scared, he had had no time to get to know the staff, he was used to me being with him at night. I knew he would feel abandoned if I had to leave him.

When I returned the next morning, Alan looked terrible. He was weak and could barely stand up as he had been up trying to leave the ward all night. I calmed him down and settled him on the bed and he immediately fell asleep, exhausted. But still I was told forcefully that it wasn't visiting time and that I should leave until it was! I've since tried to explain to anyone who will listen that carers of dementia patients aren't visitors – they are like food and medication, essential to their well being. We were encouraging Alan to eat and drink, to find the toilet; we helped him carry on with familiar things such as walking and reading. I knew his personal and medical history. I was his voice and his memory.

Alan spent every night on that ward in extreme distress; each morning he was exhausted and distraught. He started refusing food and even water. By Saturday, he had become dehydrated and delirious and was deteriorating fast although it took until Sunday before he was put on a drip.

When Alan did finally come home he needed special dietary supplements, district nurse visits, a rehabilitation team for six weeks and a wheelchair as he was no longer able to walk far. One year later, after months of trauma, he died at home.

My enduring sadness is that Alan went through these traumatic experiences at both ends of his life, when he was powerless. He was a kind, compassionate man and now it falls to me to do what he can't: work with those who have been through similar experiences to improve the lives of those with dementia when they enter hospital, and to make it standard practice that carers are welcome to stay with those they love at their time of greatest need.



Catherine Edwards

Hello and my name's Catherine Edwards. I have worked in social care for twenty-seven years, and I am a senior social worker in the south of England. But I am proud to say that I started as a carer, working shifts, emptying bed pans, on low pay. So I know how it is. Ninety per cent of my clients have dementia

I read about John's Campaign in the *Observer* and contacted Nicci Gerrard last August to say what a great campaign it was. My only criticism was that the valued input of social workers was not mentioned. She changed this so that social workers were mentioned in subsequent articles.

My father died in January. He had been diagnosed with dementia for nearly six years, during which time I watched an intelligent and able man become a dependent individual whose personality also changed. I helped arrange care and respite and I reduced my working days to Tuesday to Friday so that I could support Mum as much as possible.

Dad also suffered from physical health issues like chronic heart failure. By fluke I was nearby on the Friday night he became acutely unwell and was admitted by urgent ambulance to A&E. The admission went well on the Saturday and I visited Sunday. However, when I went to visit him on the Monday, I found the ward (a general ward) was locked until the afternoon. The ward clerk begrudgingly gave me and my mother 10 minutes with my dad.

I live 100 miles from that hospital. Visiting in the afternoon only would mean on the Monday getting home at 9pm, with work to do before the next morning. I asked staff if I could visit on the Monday morning, but received very mixed responses. Some nurses were openly unhelpful and I felt lacked

compassion. Despite negotiating an agreement to go on Monday mornings, I was made to feel unwelcome, and yet it was clear that staff needed me there. When I met the occupational therapist and the consultant, both were grateful I was there as Dad could not answer questions.

The hospital told me that Dad wasn't that unwell. I knew he was dying, although if I had known how close he was to death I would have taken the time off and stayed with him. On the final Monday of his life, January 25, I once again had to battle to see him. Thank goodness I got my way, because he died three days later. I had a call to come when he was already gone. He died alone.

When battling to see my dad I felt stronger by having John's Campaign behind me. The ward at the time knew nothing about it, but quoting it helped me. Only one nurse seemed to know that visiting hours should be more flexible in dementia cases. The professionals needed my input, and my dad needed me. I hope that things will change at that hospital as a result of the campaign: the whole experience was profoundly distressing and sad.

The end of his life should have been better.

Catherine Edwards

Teresa Canale-Parola



Teresa Canale-Parola

Hello. My name is Teresa. I was John's partner and now I'm his widow. I've been a supporter of John's Campaign right from the start because it gave a voice to my feelings of anger and distress and showed me I was not alone.

John was diagnosed with dementia in 2009, aged 55. I was his carer, but by 2013 John had become extremely violent and I could no longer cope. He was in two hospitals during the last months of his life, and was placed under a mental health order.

The first hospital was nearby and I visited him every night and twice a day on my days off. Our daughters visited every evening and at weekends, while his sisters came up from Glasgow on the bus twice a week. The family gathered round to support him. With medication he became much calmer but basic care and falls prevention were lacking and he was often scared and confused.

When John was transferred to a second hospital, it was no longer possible to visit him daily, monitor his care and comfort him. It was 18 miles away, through country roads, and the bus only went once a day, if that. The visiting hours were very strict, and of course I had a job. Days would go by when I couldn't see him.

Anyone who understands Alzheimer's knows that change and disconnection from loved ones is not good for those with the illness. I knew that isolation would be bad for to John's health and for his well-being and it was: he walked into that second hospital, but very soon he could no longer walk at all. Although he was no longer violent he was placed under restraint. When he had a sore throat they paid no attention, even though it meant that he stopped eating. If we had been

present, none of this would have happened.

I took my concerns about John's care to a tribunal. Here, the doctor said that the strict visiting hours would make no difference to John because his hospital stay was just a stepping stone before going into a nursing home. The tribunal went with "medical evidence", not with the family's knowledge of their husband, father, brother.

After 10 days John had deteriorated very badly. I hadn't been able to visit for eight days because of my work rota and at no point on my twice-daily phone calls was I informed of the deterioration in his health. When I finally went to visit him after being taken to look at a care home with his care manager I found John restrained in a chair, dying.

I contacted our daughters and told them to come. We refused to leave. On Sunday 16th March, 2014 John died, 35 days after being transferred. He was sixty years old. He had been restrained 24 hours a day, and neglected by nurses and doctors. The death certificate cited Alzheimer's as cause of death. But we believe that John died of dehydration and starvation. No attempt to reverse his symptoms was made.

Because of how he died, we have not been able to grieve for John properly. I can never express the anguish, anger and hopelessness we felt and still feel.

I came across John's Campaign when it had just started and it has helped so much to know others feel the same as we do and are prepared like us to stand up and fight for present and future sufferers. If we can make a difference the untimely and lonely deaths of those we love will not have been completely in vain.

Liz Charalambous

I remember how I felt when my parents were seriously ill in hospital (they both subsequently died). I had small children at the time and, juggling work, I used to drive up to Yorkshire from Nottingham and sit and wait outside the ward until visiting times. I always remember the kindness of the cleaners who would ask me if I wanted a cup of tea.

Fast forward 10 years and finding myself doing a masters degree I decided to research visiting times as a change-management project for the leadership module.

I couldn't find any evidence to support restricted visiting but was very interested in the culture of ward teams and how some resisted and others supported change. I found more and more evidence to support the idea, such as how it supports people with dementia, can prevent delirium and does not negatively affect infection rates.

I never thought it would take so long. I found funding to do a PhD so needed to work with others to accelerate the process. I talked with patients, carers, ward based staff, management, Nottingham Hospitals Charity (who paid for the carers passport cards to be printed), and John's Campaign (Nicci and Julia).

I spread the word via Twitter, Facebook, national media (TV, radio, local and national newspapers) to raise awareness. I published a paper in the *Nursing Times* on how to manage change to implement open visiting so others can follow.

When we presented the project to the executive board and the carers' group, I was so happy to hear the positive comments from one particular gentleman who said he and his wife cared for each other. He said the card

would give him confidence to "get through the door" without any confrontation, an important point when you may be feeling low and lacking the courage to confront an authority figure. I certainly remember how I felt when visited my parents all those years ago, and I bitterly regret not being more assertive. But even though I can't turn the clock back, I can make sure others don't feel the same, when they often may not have many more hours left together.

He slipped one of the carers' passports into his jacket top pocket and said he would show his wife when he got home. The rest of the board were similarly happy with the project, some shared their stories of how they felt when trying to visit family outside "visiting times" and could see it would be a great help to families.

Thank you for all your support and positivity throughout this, I am very happy it has reached this stage and hope that one day we will look back in astonishment that we had restricted visiting at all.



Rafi Rogans-Watson

My name is Dr Rafi Rogans-Watson; John Gerrard was my step-dad's father, my grandfather, and Nicci is my aunt. I'm a 2nd year registrar in geriatrics (or care of the elderly medicine) and I'm in my 7th year working in the NHS.

Almost two years ago Nicci wrote her piece in the *Observer* about John's stay in hospital, arguing that he wouldn't have deteriorated so dramatically had his family been allowed open visiting access. She emailed me soon after about her ideas for John's Campaign, asking what I thought doctors' responses might be. My initial reaction was that it made perfect sense, but wearing my junior doctor's hat I also had some reservations:

- Would it put pressure on families rather than ward staff to care for patients in hospital?
- Would patients without caring families be indirectly neglected?
- And, most importantly, because I'd learnt that an unhappy boss meant an unhappy junior doctor, would it disturb the flow of the ward-round and upset my consultants?!

Thankfully, I needn't have worried – Nicci and Julia pressed on regardless, and we've heard some examples of the impact of their efforts today. The Campaign has been embraced by all the hospitals I've worked in around London, particularly by consultants in elderly care medicine and by nursing staff.

It's been an exciting time to enter the field of geriatrics and dementia care, because I've witnessed and been part of a cultural change in which John's Campaign has been central. A greater emphasis is being placed on creating a caring environment for those most in need. On my ward for example, I've got patients

who I'm sure are being given a better chance of recovery because they have family around them every day; talking to them, engaging with them, helping to nourish them. These are things we all wish we had time to do more of ourselves; I know our nurses and healthcare assistants feel this way, but most patients respond better to familiar faces anyway.

The old stereotype of the ward run by the stern matron and the strict consultant is gone (well, almost). The way we care for our patients with dementia is changing, and hospitals are slowly becoming more accessible. But there is still much to be done, and by the time I'm a consultant I hope it will look very different. Creating change in an organisation as large as the NHS is no easy task, and so I'd like to acknowledge everyone who has led or backed the Campaign, whether you work in hospital, in allied charities, or in the media, because you've done an incredible job and it's truly been a catalyst for progress.

John Gerrard was such a family man. He was so much fun to be around, and his relationships with his family and close friends were so important to him, and to us. Knowing that this is part of his legacy, keeping families together and creating a more caring environment for people in hospital, brings me and my family so much joy, so thank you.



Alice Thorogood

I come from a traditional close-knit family in rural South Wales. My grandparents were an extension of my own parents. The older members of my family care for the younger and when the time comes, the younger care for the older. Care and respect for the elderly at the end of their life is nothing special, it's just what you do...isn't it?

But when my both my paternal nanna Agnes, who had Alzheimer's, and my maternal grandfather David, who had vascular dementia, had long stints in hospital, it's what we couldn't do. I think the staff were doing the best they could with limited resources. However, our love for our relatives, our knowledge of them, the reassurance they felt when we were close by was so confined and rationed by visiting hours and hospital protocol that it stripped them of their humanity and dignity. How different would Nanna's stay have been if one of us could have sat with her at dusk, her most fretful time of the day? Or helped feed Gramps once he had lost the ability to hold a spoon?

My last visit with my Gramps is etched in my mind. He was in a corner bed of a dementia ward. It was noisy and stuffy. There was no record of him eating that day, so I asked a nurse. "Oh yes, Dave, you've eaten loads today. You loved that yoghurt, didn't you love?" I asked if someone had fed him: they hadn't. Gramps hadn't been able to hold a spoon for months. I can't think that he had "loved" his yoghurt.

When a nurse insisted on getting Gramps out of bed for a physio assessment, I explained he hadn't stood by himself in over 18 months. My Gramps was dying; walking was not high on his list of priorities. But he was lifted out, placed in a chair. "Sorry Love,

visiting's over now." I protested that Gramps couldn't be left just sitting there. He was frail and weak; I was scared he would fall forward. I can see his beautiful blue eyes looking at me now, those same bright eyes that looked so proudly at me when he showed me how to change a tyre, watched me in school plays and terrible violin recitals, the same blue eyes that looked so disappointed when I got that third ear-piercing. Those eyes were now begging me to stay with him. But you see, I had no RIGHT to stay with Gramps, to be his voice, his person, his granddaughter giving him the care and dignity he has always given me. Imagine if that hospital had adopted John's Campaign, if my mum had given me the "carers' pass" for the afternoon. The overstretched nurses would have recognised me as the person responsible for Gramps, have listened when I said no to getting him out of bed, have let me explain, in familiar, family language what was happening and why, have let me stay.

That same hospital was phenomenal when it came to the last stages of Grampa's life. His death, in a private room, surrounded by family, filled with love and at times laughter was in stark contrast to those months before. John's Campaign is a simple answer to a simple problem. I wish it had been there for me and my Gramps.



Theresa Clarke

In 2010, I was diagnosed with dementia. Since then, I have wanted to communicate as widely as possible that while we certainly do not like it, and would not choose it, we can live well with dementia. We can still contribute to society, our family and the world beyond. But for this to happen, we need to be part of the conversation about dementia: not just spoken about, like an object, but talked with and to.

It has been my very painful personal experience that even a short hospital stay can radically damage our self-confidence.

Watching the relative who accompanied us into hospital leaving is deadly – like being in deep space, not sure which way is up. Those of us with dementia look normal and if we speak sensibly we appear to be normal and “with it”. At times, health staff may bombard us with information at the same rate as they do for everyone else, which suggests that their knowledge of the thought-processing power and the memory difficulties of persons with dementia is poor.

A comparison could be made between the way staff communicate with people after a moderate or severe stroke and the way they communicate with people with dementia at points along the dementia road. With stroke survivors, there are often obvious disabilities and observant staff make suitable adjustments. But people with dementia, especially at the start, may not give obvious clues or indicators. The result of any consultation must be written down clearly: together, the spoken and the written diagnosis make life a great deal more understandable for us.

As an ex-health professional, I know what the stresses are for staff. Dealing with people

with dementia requires extra time and the patience and kindness of even the most well-meaning staff can easily be dissipated by these difficult times, when there are busy periods with not much let up.

When I worked in the health service, we tried to find the time to tell anxious patients and their relatives what was going on. Nowadays, it can sometimes seem that informing and reassuring lonely and fearful patients with dementia is not always a priority in our busy, overstretched health and healing services.

Times have certainly changed and are changing still. Those of us with dementia need to generously share our lived experiences with all staff, so that they can understand what it is like to be us and can help us to live well and to contribute to our world.



Rebecca Myers

My story started 17 years ago as a new mother trying to juggle home-life and my career in the NHS, which was made possible by my own mother. But when my second child was born, my mum became increasingly anxious, disorientated and forgetful. My dad made light of it (his way of hiding what was happening from us and himself) but I finally persuaded them a GP visit was needed.

Things have improved significantly since then, but ours was a 2-year drawn out process of trying to get assessed and diagnosed. And so at 58 she was finally officially diagnosed with Alzheimer's. Suddenly I was exposed to a part of the "system" in which, even for someone who had worked within it both clinically and managerially, I struggled to get heard and get access to services for my mum and support for my dad.

During my mum's illness and two episodes of hospital admission, conversations were avoided, explanations not given and attitudes observed which reflected a lack of understanding or empathy. But looking back now, I feel we as a family also let her down; we tried to reassure and take control rather than accept and encourage – even if it came from a place of fear and love. It's hard...

In 2013, after a very difficult year battling with the continuing health care processes, my mother died.

All experiences, good and bad, give us an opportunity for learning. I wrote about our experience and many families commented on how it reflected their own. Several people in the system criticised me, saying it was disloyal to write publicly about the care we received. I didn't agree then and don't agree now. I believe it is only by talking about what isn't working (as well as what is) that we can

truly improve things. That's why I am a fan of John's Campaign. It not only seeks to highlight what is wrong, but also offers an opportunity for improvement. In the words of Arnie Beisser "change occurs when we become who we are, not who we want to be".

We, as a system, need to look at what is happening and not be defensive or dismiss poor experience as isolated incidents, but question whether the problem is more systemic. Lots of excellent work is being done, which needs to be promoted, encouraged, and, something that doesn't happen enough, congratulated. AND at the same time, when things aren't so good we need to acknowledge it and support people to change.

For me now, having returned to clinical practice in the community, my work is about having pragmatic empathy. Working in the community, the power dynamic changes; it is often professionals that are in an unfamiliar environment and you can be on your own and feel vulnerable. I believe for all of us, it is the quality of the relationship that lies at the core: the relationship between the person with dementia and their family and/or carer, between the person with dementia and the professional, and between the professional and the professional. Actually it is about so much more than that; it is about one human being connecting to another, in the moment, in the environment, for a shared purpose - to take care, of and with, each other.



Kate Kellaway

My father died three months ago at the Whittington Hospital in Archway, London – he'd had a fall, broken a hip, had an operation, recovered and been discharged. Then he had another fall and had to be readmitted and it turned out he'd had a silent heart-attack. He was 90. He had for some time suffered from chronic kidney disease. So – a medley of misfortunes, including, towards the end, dementia. He had an intermittent belief he was back in the war and that there was a soldier in the bed next to him – he was determined to know the soldier's name. I helplessly selected "Jim" which seemed to pacify Dad. But, of course there was no bed and no soldier other than Dad himself, gallantly fighting on. For when it was clear he was dying, the Whittington found him a room to himself. And that was just the first of the blessings of being in that hospital during Dad's final three weeks.

The care was, in every way, exemplary. The staff were happy to waive visiting hours without question. We were able to come and go as we pleased and sit up all night with Dad if that was what we wanted to do. The number of visitors at any one time was left to our discretion. My sister and I were bowled over by one nurse in particular and the compassionate intelligence with which she grasped the emotional picture. Sam Hunt talked to Dad with warmth, respect and gentle humour. She tried to find out how he was feeling. At one point, he admitted he was frightened and she listened, smiled and reassured. And she reassured us too – she made us believe in the goodness of which people are capable. The doctor – Dr Mitchell – was outstanding too – a model of intelligence, sympathy and tact. She was exceptionally clear in her information – impressive, in particular, in telling us what

she was not sure of as well as informing us about whatever she knew. Towards the end of his life, Dad had given us instructions about not prolonging his life unnecessarily – we had power of attorney. The staff listened to us but as Dad became less and less able to speak, Dr Mitchell never neglected to address him first: "Mr Kellaway, I'm just talking to your daughters about how we can try to make you more comfortable...." The palliative care team was first-rate: educating us in the art – or science – of dying comfortably. And when Dad gently breathed his last – it seemed to me that it resembled what a friend of mine once described as pushing your boat out – I was with him and when he was gone, it was the nurse and doctor I embraced. They had retained the necessary professional distance and yet had allowed us to feel, if only for a moment, that they were – almost – family.



Series of Observer Articles

Liz Charalambous



How loved ones can help prevent patients developing delirium in hospital

1/8/2015 “Delirium is a state of acute mental confusion where a person may see or hear things that are not there and become very agitated, sleepy or a mixture of both.”

In the first of a series by health professionals on the importance of family and volunteers helping with a condition in hospital, we hear from a nurse at Nottingham University Hospital Ward B48.

Dr Sophie Edwards



Passport to making life better for people living with dementia

15/8/2015 “Going into hospital is stressful at the best of times. Being admitted to hospital if you have dementia is much harder.”

Carers are more than visitors: they are part of the team that support a patient with dementia and frailty. Many of the hospitals that welcome carers issue them with passports to identify them and give them a tangible sense of their authority and recognition. These passports were the idea of Dr Sophie Edwards, consultant geriatrician at the North Middlesex Trust, who explains here why she felt them to be crucial.

Karen Wilson



It's great to formalise the right for families and carers to be with their loved ones

30/8/2015 "Imagine you wake up only to realise that you are in an unfamiliar place and it certainly isn't your own bed. You hear lots of noises and realise that you are not alone and suddenly these strangers are entering your room. Scary sounding, isn't it?"

Why our campaign is important even in those wards where carers are already welcomed. Karen Wilson, ward sister from Wishaw hospital in North Lanarkshire, explains why she feels so enthusiastic about the campaign.

Mary Dunsford



"I dreamt I saw an angel today"

19/9/2015 "When I enter the hospital ward, I keep the ethos of 'expect nothing' firmly in my mind as I start to move my fingers across the strings of my small harp. I work as a musician in healthcare, a role that sees me engaging musically with patients, family and staff across the wards of Furness general hospital."

Harpist Mary Dunsford brings music into the wards, humanising a clinical space.

Jo James



Detecting when a person with dementia is suffering from pain is so important

30/9/2015 “My mother had advanced dementia when she sustained facial injuries after a fall. I rushed to the emergency department to see her but walked straight past the cubicle she was in: I did not recognise the person lying on the trolley.”

Jo James, dementia lead at the Imperial College Healthcare Trust, tells a story about her own mother’s unidentified pain in hospital and advocates a tool that would prevent the unnecessary suffering of patients with dementia.

Anita Ruckledge



Family rooms make a space for care and closeness

30/10/2015 “If being in hospital is an anxious and often lonely time for patients and their relatives, imagine if the patient has cognitive impairment or is at a palliative-care stage of their life. “

Anita Ruckledge, dementia lead nurse at the Mid-Yorkshire Hospitals NHS Trust, describes how the new family support rooms at Pinderfields hospital enable families to stay together at times of greatest need.

Natasha Lord



*Support for the carers
is important too*

23/10/2015 “Carers have an intimate knowledge of the patient and can support and comfort them. But these carers also need support, comfort and recognition. We want to care for the carer.”

Natasha Lord is a clinical psychologist for the Worcestershire Health and Care Trust. She works in a mental health setting and recognises that carers as well as patients need to be valued and supported.

Pam Kehoe



*Specialist nurses
are here to help you*

10/11/2015 “Admiral Nurses are to people with dementia what Macmillan Nurses are to those with cancer, and at times of great need and vulnerability they offer specialist, tailored, practical and psychological support.”

Going into hospital is scary and often very hazardous for a person with dementia – but Admiral Nurses can make it less so. Admiral Nurse Pam Kehoe explains why Tameside Hospital appointed one of the first Acute Hospital Admiral Nurses in the country.

Ruth Evans



People with dementia and their carers had input into a useful new guide

20/11/2015 "Entitled *What can I expect from good quality services if I have dementia?* a new guide, written by the Improving Quality of Care group, is for people with dementia and their carers."

Ruth Evans introduces the new guidance recently launched by the London dementia strategic clinical network.

Catherine Shyjka



Relatives and carers are allowed to be with loved ones immediately before and after surgery

4/12/2015 "Every year, our inspirational director of nursing Duncan Burton holds a nursing conference and at this year's I heard about how the trust is focusing more on how we care for our patients with dementia. It struck me that we didn't do anything for these vulnerable patients when they go to surgery. "

Catherine Shyjka, matron for theatres at Kingston Hospital NHS Foundation Trust, explains how a welcome to carers does not have to stop at the door of the operating theatre.

Sophia Stanworth



*Dementia patients are people,
not a medical condition.
Communication and co-
operation are key to their care*

19/12/2015 “When I first came across John’s Campaign I remember thinking: ‘Why is this needed?’ But the more I read, the more I realised that my own experience, 10 years earlier, had many similarities.”

Sophia Stanworth has personal experience of the importance of carers in hospital. Now, as a lead volunteer with the Alzheimer’s Society and a dementia friends champion, she works to raise awareness of the condition.

Tracy Dodd and Jacqueline Young



*First emergency admissions
department joins campaign*

9/1/2016 “The importance of the support of relatives and carers for people with dementia was vividly brought home to us recently.”

The emergency admissions department at Wishaw General Hospital is the first to have signed up to John’s Campaign. This department is often the gateway to a stay in hospital. Tracy Dodd, the senior charge nurse, and Jacqueline Young, nurse team leader, describe why they decided to welcome carers.

Julia Jones



“The patient will be at the heart of everything the NHS does”

13/2/2016 “‘The NHS belongs to us all.’ These are the first words of the NHS Constitution, a recently revised document which we should all read.”

Julia Jones, writer and co-founder of John’s Campaign, reads the recently revised NHS Constitution and urges us all to do the same so that we are confident of our right to accompany our loved ones in hospital.

Delyth Fôn Thomas



Carers are a crucial part of the ward-based team

18/3/2016 “Involving carers provides an enriched care-planning approach. With their help and their intimate experience, we can explore the quality of ‘life at the moment’ for the person with cognitive impairment.”

Ymgyrch John has arrived! Following its introduction in a single ward, Glaslyn ward, Betsi Cadwaladr has become the first health board in Wales to sign up to the campaign. The woman who started the whole process, the acute dementia nurse Delyth Fôn Thomas explains why she feels John’s Campaign matters so much.

Janine Valentine



*Come into the garden for
a real sense of wellbeing*

29/3/2016 “Imagine an elderly man with dementia being admitted to hospital and being able to spend time in a garden with the sun shining, the smell of lavender, the clink of china tea cups and the gentle buzz of conversation.”

Janine Valentine, nurse consultant for dementia at Yeovil Hospital, knows first-hand the value of a beautiful and tranquil garden for patients with dementia. Away from the press of busy hospital wards, they can plant seeds, sit in the sunshine, spend time with family and friends – and find peace.

Theresa Clarke



*Those like me with dementia
can live well with it, but people
need to know how best to
communicate with us*

9/4/2016 “In 2010, I was diagnosed with dementia. Since then, I have wanted to communicate as widely as possible that while we certainly do not like it, and would not choose it, we can live well with dementia.”

Theresa Clarke has worked as a nurse and a midwife in many different countries. Six years ago, she was diagnosed with dementia and since then she has been involved in sharing her experience and spreading the message that people with dementia can live well and can contribute to society.

Debra Carberry



*A ward refurbished
with dementia at the
heart of the design*

15/4/2016 "We are proud to have achieved a care setting that, whilst still delivering the care expected of an acute hospital ward, provides a less clinical, more homely, more welcoming, altogether warmer environment."

Debra Carberry, nurse specialist for older people at Warrington and Halton NHS Foundation Trust, has seen how imaginative changes in the hospital environment can cheer, calm and console patients with dementia.

Kelly Lockyer



*Twiddlemitts – improving
life for patients*

7/5/2016 "If you enter our wards at the Royal Bournemouth Hospital, even on a warm and sunny day, you will find many patients holding what look like thick and brightly-knitted hand warmers, in stripes, checks and zig-zags."

Sometimes, the simplest tools are the most useful. Kelly Lockyer, dementia specialist nurse at Royal Bournemouth Hospital, explains why the homely twiddlemitt is improving the lives of people with dementia.

Eilish Morris



Where families make a real difference to health and wellbeing

3/6/2016 “One of the tenants we care for is movingly happy whenever her daughter visits, and so proud. She tells everyone: ‘This is my daughter!’ It is a crucial part of her identity.”

St Julian’s in Northern Ireland is the first supported housing association in the UK to sign up to John’s Campaign. Here, Eilish Morris describes how welcoming and involving families makes such a valuable difference to their tenants.

Catherine Edwards



“When battling to see my father I felt stronger by having John’s Campaign behind me”

8/7/2016 “On the final Monday of his life, 25 January, I once again had to battle to see him. Thank goodness I got my way, because he died three days later.”

Catherine Edwards has worked in social care for 27 years, but when her own father, who had dementia, went into hospital she was unprepared for the lack of compassion and understanding that she encountered and had to fight for the right to be with him.

Donna Cummings



The importance of making carers feel welcome at hospital

26/8/2016 “As a senior sister in critical care, I know that welcoming carers is the right thing to do for everyone.”

Donna Cummings, senior sister in adult critical care at Manchester Royal Infirmary, describes how she not only welcomes carers but enables them to be involved in the critical care of their loved ones if this is what they want.

Maggie Woodhouse and Julie Fountain



The Forget-Me-Not Walk where patients stroll among their memories

9/9/2016 “West Suffolk hospital chose dementia as its annual fundraising campaign in 2014.”

What do you do with a long, bare hospital corridor? You turn it into a memory walk for the patients with dementia. Maggie Woodhouse and Julie Fountain explain why vivid images of the past plaster the walls of West Suffolk Hospital.



June Jones

To Home it may concern
 My name is JUNE S. JONES
~~I~~ I am 90 YEARS OLD,
 I suffer from ALZHEIMERS

~~Am I going to be~~
 If I have to stay in HOSPITAL
 for something like a BROKEN
~~WATER~~ BONE HOW COULD I MANAGE?
 WHO WOULD HELP ME??
 WITH MY LACK OF MEMORY and
 MY LACK OF UNDERSTANDING
 How ~~do~~ WOULD I KNOW HOW TO
 CALL A NURSE OR EXPLAIN
 MY TROUBLE? FOR MY FIRST TIME
 IN HOSPITAL I WOULD BE VERY
 FRUSTRATED PLEASE
 PLEASE MY DAUGHTER
 STAY WITH ME

Nicci Gerrard

In telling their life stories, we seek to restore dignity to society's "ghosts"

When people are in the last stages of dementia, we who love them (we whom they have loved) may bend over them, trying to find in the sounds they are making some words, sentences, a form of communication and a kind of meaning. Even a syllable is precious now. It is a bit like a parent straining to hear language emerging from their baby's babble of sound – but with a baby this emergent language marks the beginning of the great formation of the self, and is full of hope and possibility.

With the person who lives – and who dies – with dementia, the language that connects us to others is disappearing, the self is being broken up. An entire world is being un-made. We come to darkness, silence, the radical slowing of death: dementia's long goodbye.

The honourable, often courageous, tradition of journalists to uncover what is hidden is celebrated by the Orwell prize. In the new category for which I was shortlisted, "Exposing Britain's Social Evils", there were wonderful stories that investigated hidden worlds (banks, hospitals, detention centres...) to find out the stark truth of what went on there, behind barred doors.

I wrote about dementia and the arts in an attempt to find a language for what has become wordless. Today, art is freshly and imaginatively illuminating the experience of self-loss in a way that no external, factual account, however vivid, can do. Art may take us to the very edge of darkness.

But dementia is not hidden – or if it is, it is hidden in plain sight. More than a million

people in the UK have dementia. One in three hospital beds are occupied by them. They are everywhere; among us, in the streets we walk along, the shops we go into; even in our homes. We see them, and we don't see them. We know them, and we don't know them. They are our society's ghosts, and we should be haunted.

Instead, we often talk about them as objects: they are (cruellest phrase) "bed-blockers". They are burdens. They are problems to be solved. They are terrifying statistics. They are bureaucratic impediments. Because they are incomprehensible to us, they scare us; and because they are old and their body decaying, they even disgust us, for they remind us of life's unbearable truth: we all must die. They are not hidden – but we are often hiding from them and their shattered meanings, and so hiding from ourselves, from the old person we will, if we are lucky, one day become.

The piece that I wrote about dementia and the arts was one of many articles I've written in the *Observer* about the care of people with dementia, and was born out of a campaign that I have been running with my friend and co-campaigner, Julia Jones. John's Campaign fights for more compassionate and person-centred care in the medicalised and often intimidating space of the hospital.

Over the past 18 months, I have met and worked with fabulous, kind and heroic carers, nurses and doctors, and I have also seen the terrifying cost of dementia to all those whose lives are touched by it. There is so much loneliness and so much loss.

But humanity must not be lost. On corkboards above the beds where dementia patients lie, confused and often scared, there are often photographs of them when they were younger. So somewhere inside that old woman lying slack and corpse-like is also her younger self: radiant, beautiful, just setting out on her journey. That man, crying out for help on a tormented loop, is also the father holding his new baby in his arms. Art encourages us to see them as precious and as human. As one of us.

If the Orwell prize recognises journalists who uncover what is hidden, it also honours those who give a voice to the voiceless, to those who cannot speak for themselves or tell their own story. This is political journalism in its deepest sense (and it is why the Joseph Rowntree foundation, which works with the marginalised and the dispossessed, is such an appropriate sponsor of the “Exposing Britain’s Social Evils” category).

Telling stories is part of what makes us human. With stories, we make sense of the world and impose a kind of order on to chaos. We continually edit our own lives into a narrative that will give it a coherent meaning: without this, we’re lost.

And people with advanced dementia become lost: lost to us and lost themselves. They can no longer speak themselves and without memory to bind the pieces of their life together, they are trapped in an endless present. Since my father’s illness and his sad, long dying, I have been trying to tell their stories.

After I won the prize and was walking around the hall grinning like a pumpkin and two glasses in, person after person came up to me to say: me too. I have a story to tell about my mother, my father, my loved one. Sometimes the stories are good ones: last Thursday, one woman told me how she had repaired her relationship with her mother during her

illness, and how being her carer had been a painful gift. A man described his father driving his car through the fog and unable to find his way home. (Of course, home here also means the home of the self.)

We are all Ancient Mariners, carrying the stories that we are compelled to tell, to share and pass on. The stories that journalists write can help us imagine what it is like to be other people, to empathise with experiences that are very different from our own, and to forge bonds with different cultures and histories.

But while we can identify backward, because we know what it is to be young, it is hard to identify forward. Until we arrive there, old age is a foreign country.

The question of how we care for those with dementia is also a question of how we live and how we die. It is about what it means to be human. We are all human. We all have stories.


Observer, 29/5/2016

Nicci Gerrard’s article Words Fail Us: Dementia and the Arts (Observer 19/7/2015) won the 2016 Orwell Prize for Exposing Britain’s Social Evils. So much of George Orwell’s most characteristic writing aimed to do just this and the prizes that are offered annually in his name are judged by their success in fulfilling his stated ambition, “to make political writing into an art”.

In her follow-up article (reprinted above) Nicci explains that her intention was “to find a language for what has become wordless”. Nicci has donated her Orwell Prize money to fund the production of this booklet, because, as she insists, “We are all human. We all have stories.”

Telling Your Story


Patient Opinion: An independent site about your experiences of UK health services, good or bad. Accepts comments from relatives as well as patients and passes them directly to the hospital concerned. Your identity is protected and changes may result quite quickly.


 patientopinion.org.uk


 twitter.com/patientopinion

 facebook.com/patientopinion

John's Campaign: We have a website and can be reached by email (addresses on the site) as well as via Facebook and Twitter. (There are however only two of us!)

 johnscampaign.org.uk

 twitter.com/johncampaign

 facebook.com/Johns-Campaign-1561603624080402

NHS systems: Opportunities to compliment, complain or simply feed back on your experience exist throughout the NHS in all areas of the UK and should be used. A Patient Experience manager in a hospital can be a key advocate for change. The inspection services in each of the 4 UK countries need to hear directly from patients and their families or carers.

Social media: Twitter and Facebook have been key platforms for John's Campaign, though old-fashioned letters + envelopes & stamps still have their place, especially when writing to government departments, MPs etc. Some people get their story heard by organising a petition, others write books or make videos. Local press and local radio like local stories.

Blogs and forums: Many of the key charities who advocate for vulnerable people and their carers host support blogs and forums. These are all places where you can share your experiences. At John's Campaign we have worked closely with Age UK, the Alzheimer's Society, Carers UK and the Carers Trust. Specialist charities such as Parkinson's UK offer targeted expertise and the Patients Association exists to promote the voice of all patients.

ageuk.org.uk alzheimers.org.uk carersuk.org carers.org
parkinsons.org.uk patients-association.org.uk

Cover photo: John Gerrard as a young man

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