

# What happens when it goes wrong?

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## **NHS Conference: What is Person Centred Health and Care and why do we need it?**

**Inverness: 50 delegates + VC from all over the country ...**

**24<sup>th</sup> August 2012**

## **Biography (1)**

### **Introduction ...**

I live in a tiny village called Portgower,

- near Helmsdale in East Sutherland, right up in the rural Highlands (2)...
- with my husband Andrew (3) ...
- and Lollipop (4) ...
- in an old croft (5)
- with a big garden (6)
- and beautiful flowers (7) ...
- with a wonderful view of the fields (8)...
- and the lambs (9) ...
- and the sea (10).

We retired there twelve years ago ready to do all the things we'd planned to do before we got too old to do them!

## **Credentials**

And then 6 years ago disaster struck. (11)

At age 58 my husband was diagnosed with Vascular Dementia and being his caregiver over the next years was probably the most difficult thing I ever had to do.

And that's because I'd never felt so alone ... not lonely, just so alone!

In those early years I walked around with tears behind my eyes ...

- ready to fall at the hint of a kind word ...
- not understanding that I was grieving ...
- grieving for everything that was changing so dramatically around me and
- for everything I was losing,
- including the man I'd married.

My understanding of person centred care comes directly from what I've learned as

- Andrew's caregiver on our journey as a dementia family

- and as a Care Attendant for Crossroads East Sutherland where I've worked with over 50 different families

The term person-centred has now become so widely used it is thankfully a buzzword across the health spectrum ...

- but I'm not sure everyone really understands what it means ...
- and certainly not from a carer's perspective.

Today I'll draw on these last six years of experience

- to analyse poor practice
- using challenging stories and
- case studies of poor care
- to show how devastating it can be for us
- the families.

## Person Centred Care

What exactly is person-centred care all about? (12)

It's about

- feeling safe and secure and
- about enjoying close relationships with people who matter.
- It's being able to freely express your views and emotions.
- It's also about doing things you enjoy doing
- but above all else it's about that feel-good factor
- that comes from having respect and dignity in your life
- and knowing you are in a position to make your own choices and decisions.

Every single one of us here has been, is, or will be a caregiver for someone we love,

- be it a child,
- a spouse or
- a parent and
- we all manage our own worlds as a matter of course.

Why suddenly when we become a family in crisis does it seem that professionals step in with no regard to our wishes? (13)

## 3 Case Studies

Take the case of **Mr and Mrs W**,

- a delightful couple in their early eighties,
- who lived isolated up the Strath

- with no children or family to support them ...

I met them at the beginning of that summer as their Crossroads Care Attendant after Mrs W was diagnosed with ME. By the time I got there – to give respite to Mr W who'd had prostate cancer and now kidney problems and a suspect heart - I was horrified to discover that:

- Mrs W was doubly incontinent and her bedroom/bathroom were a health and safety nightmare
- Mr W was trying to run the household and the kitchen/fridge and bins were also a health and safety disaster waiting to happen.
- By this time Home Care staff had refused to go into the house
- Even private domestic cleaners had taken one look and refused the job
- Mr W didn't know which way to turn...
- Their Social Worker was on extended sick leave and no-one had replaced her.
- he was a tiny man and she'd got very big ... so eventually he was simply unable to lift her ...
- And finally that Christmas, they hit crisis and Mrs W was admitted to a nursing home.
- She begged him not to send her away,
- but Mr W could no longer look after her without support ...
- And because it was an emergency admittance, she was given a bed up in Wick, two hours away by car and impossible for an 83 year old man to do a round trip using public transport
- But worse is that it took a year before they moved her closer to home ... into a care home just 12 miles away
- which meant Mr W ... at age 83 ... was driving his little blue car four hours every other day across the treacherous Berridale Braes through the snow on deadly roads - mostly in the dark - to visit her ...

I remember one day he said

- if I didn't find him at home ...
- I should go and look for his car over one of the cliffs.
- Because separating them like this
- after 60 years of marriage was cruel
- No-one had thought to consider this man.
- No-one had thought to ask him how he felt about it all ...
- or deal with the fact that he felt guilty about sending her away ...

And I was horrified that this man,

- who'd lived such a long and productive life and
- given so much to society,
- should end his life feeling like this.
- It's just wrong!

Then there's the **case study** of **Mrs B**,

- early fifties,

- hugely overweight and
- depressed five years after a car accident left her immobile and
- in her chair at home
- with nothing much in her life except the television.

Her caregiver husband was eventually forced to give up work to care for her.

Last August Mrs B was diagnosed with gastro enteritis and after three weeks of constant diarrhea and vomiting, her doctors decided it was a viral infection.

- But nothing was done:
- She was literally left on her sofa ...
- because by this time she couldn't walk to the chair lift to get upstairs to her bed ...
- with a commode at her head and
- her husband cleaning up.

This went on through September and October,

- despite visits from district nurses
- who went on dressing her legs,
- but this even stopped
- once she'd lost enough weight (three stone and counting) and
- her legs no longer needed special attention.

My Crossroads visit was on Saturday afternoons to give her husband a few hours to play bowls ...

- his only respite in the entire week.
- I watched her deteriorate and
- each week I'd ask her husband why they weren't getting help ... and
- he'd reply that the professionals had said there was nothing that could be done ...
- she needed to lose weight anyway!
- I red flagged the situation to my Crossroads' line manager and
- she too said there was nothing really that we could do.

This went on through November and December and finally in January this year Mrs B –

- during a routine annual care home respite –
- was diagnosed with crones.
- A few weeks later she was sent home
- via Raigmore Hospital ...
- but a month after that she was rushed back to Raigmore
- with internal bleeding
- apparently from a torn colon.
- A few days later her bowel was removed and
- she woke up from the operation traumatized –
- as was her husband –
- to find a bag on her tummy.

I visited her in Raigmore and will never forget

- that look of sheer horror and
- complete sense of panic
- on both their faces at the thought of their future.

Mrs B is still in hospital ...

- and likely to be there for many more months ...
- learning to cope with her illiostomy and
- after so many months of inactivity
- having to learn to walk again ...
- and eat properly ...

During all this time, her husband has watched helplessly,

- feeling totally inadequate, but worse,
- because she was in hospital,
- their benefits were cut and
- he, at age fifty something, was told to go out to work
  
- The bills didn't stop coming in
- So when she was in Raigmore,
- he simply didn't have the money for fuel to get there every day
- so you can only imagine his stress
- trying to find work and
- getting to see his wife in between.

He once said to me he felt he was on a tsunami rollercoaster which would eventually come crashing down, carrying him along with it and then what would his wife do? He is her sole caregiver.

My **third case study** is around **Mr M** and rural transport:

- it takes many stressful hours
- getting from our different villages in East Sutherland
- to hospital appointments down in Raigmore
- or up in Wick ...
- the Lawson which is central to us all seems to be doing less and less of what they used to do ...

Rural public transport is a nightmare if you're ill (for that matter ...even when you're not ill)

- First a local bus to the connecting point
- Then a 2-3 hour stage coach trip to say Inverness bus station for Raigmore hospital
- Then in Inverness a 3 block walk from the bus station to the local bus stop (too far for a frail person who is not well)
- Then the local bus to Raigmore bus stop (half an hour)
- And finally a walk up to the hospital

And that's if the schedules are working in your favour ...

So most patients use the Patient Transport Service –

- an excellent scheme
- whereby volunteers are paid mileage
- to use their own vehicles.
- Except that in our rural areas
- about two months before the tax year ends,
- most drivers reach their 10,000 mile tax limit
- and stop driving,
- ***leaving patients stranded until the new tax year begins in April.***

**Mr and Mrs M**, a Helmsdale couple,

- used the patient transport service
- to Raigmore's Kyle Court
- to stay overnight
- prior to an 8am cardiac appointment for Mr M.
- He also has moderate to severe dementia and
- his wife is his caregiver.
- But because he needed his wheelchair
- to get to the dining room,
- he was deemed unfit for health and safety reasons
- to stay at Kyle court and
- after a huge fracas,
- including being told they had to leave and return to Helmsdale,
- the consultant's secretary was called and
- eventually found him a bed in the hospital.
- By now it was early evening and
- Mrs M was told to go home on public transport
- because the volunteer Patient Transport Service was not allowed to take her
- if the patient was not with her!
- The last bus had already left for Helmsdale around 6pm,
- so Mrs M was eventually readmitted to Kyle Court and
- spent a sleepless night worrying about her husband.

A cacophony of errors! And on top of all this enormous distress - not good for either his heart or his dementia - Mr M found himself alone the night before the appointment ... something they'd both tried so hard to avoid in the first place.

True patient centred care would have ensured

- the consultant's office knew enough about Mr M's history
- to guarantee an organized and smooth admission.
- ***True patient centred care is not about putting out fires***
- ***...true patient care is about ensuring the fire barriers***
- ***are there in the first place***
- ***to prevent those fires from happening.***

## My Caregiver Experience

And finally my story! (14)

I remember in those first years after my husband's Vascular Dementia diagnosis,

- being very angry
- because although Andrew was the one who had been diagnosed with dementia,
- he was in total denial and
- I was the one who had to learn to:
  - live with this totally changed man
  - change to accommodate him
  - deal with an unsupporting family
  - keep the peace
  - diffuse difficult situations
  - simply get on and deal with it

Imagine the carer stress boxes being ticked off ...

## Holistic Approach

There's a long journey (15)

- between early diagnosis of dementia, and
- the need for final care home admittance
- but because ***someone is diagnosed with dementia***
- ***it doesn't mean they suddenly can't do anything anymore.***

People, including professionals, are so often surprised that Andrew can manage things e.g.

- go on a bus alone,
- use the microwave,
- the internet ...

he didn't suddenly lose all these skills overnight ... probably because they're things he has done which can be equated to riding a bike ... they're the last things you forget!

***But because he CAN manage to do these things, some people think his diagnosis is wrong.***

Another carer stress box to be ticked ...

So while I believe it's imperative we look at the man and not at the illness,

- it's not always easy and
- I've had to learn that while I'm desperately trying to see the man my husband was
- **before** the dementia diagnosis,
- Andrew is now a man living **after** a dementia diagnosis and
- is all the while changing and
- becoming a different man.

But above all else Andrew is still a man and not an illness

- which means although he knows where most of the dots are
- he just doesn't always know how to connect them ...

## Watering the garden ...

For example, his job is to water the garden. (16)

At the beginning of each summer I put out the sprinklers in their designated places. And at the end of any hot day when I'd check what had or hadn't been watered, the sprinklers were, more often than not, all over the place and sections of garden bone dry ...

Finally after many arguments, I understood that Andrew didn't know **when** the dots weren't connecting. And so although the illness was making him forget how to do things sometimes, the man was kicking in and instead of just giving up, he'd diligently sit down and work out every single day how to place the sprinklers to water the garden. That is really quite remarkable when you think about it.

And once I understood this, I realised it didn't matter if he got it wrong ... at least he'd tried ... at least he'd had the opportunity to try which is really what it's all about. The fact that bits of my garden were dead also didn't really matter in the whole scheme of things ... instead I started planting bulbs in pots and buried them in places where plants had died off ...

Then of course there would be the wonderful days when he'd know exactly where all the dots were. I guess the most profound incident which really brought this home to me was the day he dropped the marmalade jar on to the kitchen floor smashing it into bits! He went into a frustrated rage and while trying to clean it up and comfort him I asked 'why did you drop it? Did you get a fright?' ... **and in a moment of utter despair but complete clarity he said 'I forgot to hold it'.**

This stopped me in my tracks. Can you imagine having to remember to hold a marmalade jar? You and I make breakfast without thinking ... in fact most of us probably plan our day while buttering the toast and pouring the tea. Can you imagine having to remember every single step of making breakfast, including holding the jar so that it doesn't drop! I think that's mind boggling and to me brings home how everything can seem so normal on the outside when on the inside his brain has a fragility that we can't begin to understand.

Taking all of this into account,

- I still truly believe no-one has the right
- to take away our right to self manage our own lives.
- **While protection and care are important,**
- **I think quality of life is more important. (17)**

Andrew has categorically told me he would prefer

- to lead a shorter life doing what he wants to do,
- than a longer life molly coddled in front of a television.
- So, if we want to take risks,
- then surely that is our choice
- and our right?

## Taking Risks

Soon after Andrew's diagnosis,

- we sat down and
- he asked me never to stop him doing normal everyday things
- no matter how bad he got.
- So contrary to my pre-empting-problems-and-solving-them-before-they-happen nature,
- I had to learn to take risks ...

**Small risks** like:

- encouraging him ...
  - in his previous life he was a skilled engineer
  - who made beautiful things
- to build a pergola
- with climbing roses and clematis and honey suckle
- along a meandering stony pathway(18)
- but which just never happened ...

But a few years later

- we won 'best garden' (19)
- in our local flower show and
- Andrew was as excited as I was
- because he'd been part of it all!

Then there're the **bigger risks**, like:

- taking his camera on a bus
- to our local seal beach (20)
- because the sun is shining ...
- and fainting because he forgot
- to take off extra sweaters when it got too hot.
- But oh how happy he was with his pictures ...

And in some eyes, the **unacceptable risks**, (21)

- like taking Andrew along with me to India earlier this year.
- When I won the Churchill Award, Andrew's first reaction was 'I'm going with you, aren't I?'
- I gulped and said 'of course'.
- The professionals all said 'you're not taking him with you, are you?'
- Again I gulped and said 'yes, of course!'
  
- I wanted to show the world (22)
- a dementia family can still live a life (23) ...
- and I can still see me on that elephant (24)
- with Andrew loping behind with his camera...
  
- A most precious memory that'll be with me long after he's gone ...

## Life with Dignity

So one of the biggest learning curves for me was to learn to see the man and not the illness,

- i.e. to understand that we,
- both my husband, despite his dementia, and me as his caregiver (25)
- really do have the right:
- to be actively engaged in everything to do with his life
- and involved in all decisions about his life.
- Because it is both our lives that are being affected

And that a professional has no right to walk into our home, follow my husband in the lounge and close the door in my face,

- leaving me in shock and
- too scared to knock on that door and
- say 'hey, we're trying to do this together ...
- don't leave me out in the cold.'

And when he tells that professional

- he took the dog for a walk on the beach,
- she doesn't check with me whether in fact we even have a dog ...
- or when he says he was working in the garden all day
- she doesn't check with me if he in fact even left his bed that day...
- She goes away thinking 'he's fine ... he's coping...' and
- I'm left thinking 'she has no idea what's going on here ...' and
- until a crisis hits us,
- that's probably how it'll continue.

In her defence I'm sure that professional had

- no idea she'd upset me or
- that I'd been afraid to speak out ...
- I also understand she is respecting patient confidentiality and
- actually practising person centred care
- by giving my husband the feel good factor about himself.

But he suffers from dementia, so surely practitioners need

- to have accurate information and
- it's the caregiver who is generally in the position of being able to do so.
- At some point you have to balance things and
- this can be done
- whilst being fully mindful of ethics ...
- an issue that just has to be addressed.

Just how far do we go to give the patient the feel good factor without detriment to the rest of the family?

- How do we balance making him feel good about himself and
- at the same time keep the caregiver's needs in mind?
- I agree we have to look at the man and not the illness,

- but we also have to look at reality and
- understand what we are dealing with.

Two years ago the stress of doing all of this alone became so bad

- that my blood pressure shot up and
- I started having nose bleeds
- with the real worry that I might have a stroke and
- then what would happen to the pair of us?

And it was then that I stepped back and decided I had to change our world or it could kill us both!

- That I had to make people understand how difficult it is to be a caregiver, and
- that all we as caregivers want is to live a life with our families
- with some semblance of dignity where people recognise:
  - as a family we're in this together
  - and we need to work together with the professionals
    - having a potential problem red flagged
    - so that something can be done about it
    - before it becomes a crisis
  - so that the illness can be properly managed, allowing
    - the caregiver to cope
    - and the spouse or parent or even child to stay at home longer

***This is what person centred care is all about.***

**So how do we find: (26)**

- a cost-effective solution
- that can be easily implemented,
- using resources already in place
- so that person centred care can really work.

Is there a solution that allows

- caregivers to do their job at home effectively
- with as little stress as possible
- while supporting government priorities
- to reduce the costs of acute and residential care

***In other words what **cost-effective** preventative measures can we take to prevent this crisis management?***

## Churchill Fellowship

Earlier this year I used my Churchill Fellowship (27)

- to travel to India to research these issues,
- in particular Dr Amit Dias' grass roots cost effective lay programmes
- to red flag caregiver stress,
- but more importantly, to do something about it.

Goa has 25 primary health centres ...

- similar to our local surgeries ...
- they too deal with all aspects of family health
- except on average they each deal with 30K patients
- versus our one or two thousand ...
- and so they've had no alternative but to find a solution

- research there has shown in recent years that
- caregiver stress plays an enormous role in family affairs, and
- that by detecting this
- earlier rather than later,
- interventions for both the patient and the caregiver
- **can** be early enough
- to prevent later crisis intervention.

A classic preventative intervention, for example, is

- if a pattern of sleep disturbance emerges in an elderly person,
- which invariably means the caregiver too doesn't sleep
- the elderly person can be encouraged not to sleep during the day,
- to perhaps do more physical exercise and
- in some cases be helped with medication.
- Patient sleep is improved,
- caregiver stress reduced.

So I came away realising this is a frailty issue ...

- not just about dementia or dementia solutions.
- India has a population of 1.2 billion spread over a relatively small area.
- Scotland has 5 million people spread over a huge area.
- But our problem is the same: **too few professionals who end up dealing only with crises.**

**Family and friends will see signs of frailty long before professionals are aware of pending problems. So we need to close the gap between such recognition and crisis.**

Dr Dias has done just that.

- His work at the Goa Medical School in Panaji has
- won international health awards,
- including accolades and further funding from the World Health Organisation.
- In fact the whole Goa medical system
- revolves around simple checklists from lay people
- for early detection and
- prevention of all serious illnesses in the elderly, and
- indeed covers the entire frailty spectrum,
- the idea being that:
- if you prevent falls, there's less likelihood of, say,
- fractures,
- severe injury and
- disability; or
- if you prevent strokes, again
- cognition problems are prevented as in vascular dementia;

I spent six weeks in Goa researching this grass roots intervention

- ...actually working with Care Workers,
- training with them and
- going into patient's homes
- as well as working with the professionals assessing the data and
- learning how the whole system works.

## Grass Roots Intervention

So, if we also do not have enough professional people to provide the ideal scenario,

- then surely logic dictates we too go the next route, and
- that is to redirect existing resources
- to existing services and
- do what Goa has done so successfully. (28)

Let's ***stop fragmenting our rural support services***

- already working across the region and
- let's put Home Care, Crossroads, Red Cross and any other care workers,
- under ***one NHS Care banner*** and
- train them amongst other things
- to red flag ... not diagnose, simply red flag
- frailty and cognitive issues so that they can be referred on for action.

We may all be lay people, but most of us at some time have cared for our own families and would be able to identify key impairments like:

- **Nutrition** ... mother is eating too much or too little
- **Mobility** ... grandma is wobbly
- **Visual** ... father has stopped watching his football matches

- **Hearing** ... your husband doesn't answer when you call ... that of course could be selective hearing, but we won't go into that ...
- **Incontinence** ... why is there suddenly a strong smell of urine, or worse, on everything
- **Risk of falls** ... mother suddenly refuses to shower and you realise it's because she's afraid of slipping
- **Strength** ... your wife can't lift the things she used to e.g. she keeps dropping the tray or the Sunday lunch roast...
- **Cognitive** ... your mother keeps telling fibs and doesn't twig that you've caught on to this ...
- **Depression or behavioural issues** ... grandfather has lost his happy sunny nature and is behaving aggressively, something he never did in the past ...
- **Caregiver stress** ... the caregiver seems harassed, impatient or just plain worn out ...

The key is that you don't need highly trained specialists for these early kinds of interventions. You need to train lay people to

- Spot a potential problem
- and more importantly to understand when to call for help
- so that it can be passed on to the relevant professionals i.e. district nurses, OT, physios, CPNs etc before it becomes a crisis.

In other words

- Give an **83 year old caregiver** with heart and kidney problems support, before his wife is forced into permanent care in a home so far away he simply can't cope;
- when **diarrhea and vomiting** continue beyond what any lay person can recognise as the norm,
- allow that lay person to red flag it
- so that professionals can be brought in and something done about it before the patient's bowel has to be removed;
- Use common sense when making an **appointment for a rural** cardiac patient coming to the city
- to ensure he can get there and back with no stress.
- and finally detect **caregiver stress** in that dementia family before it's too late.

The British Red Cross recently commissioned an independent report to assess the value of person centred care in the form of preventative support <sup>1</sup> and the results are astonishing.

- They estimate the costs which could have been incurred
- by the state to treat and deliver crisis care
- for just five of their clients
- to be between £700 and £10K per person
- which reflects a minimum return on investment
- of over 3.5 times the cost of providing that person centred home care service.
- That is a staggering figure and
- confirms the value being delivered
- by a range of statutory services already bridging gaps
- between professionals and saving money.

But we need to go further. We need to shorten the gap between families seeing signs of potential problems and those professionals becoming involved, so that

- caregivers can do their job at home effectively
- with as little stress as possible
- while supporting government priorities
- to reduce costs of acute and residential care.

## Conclusion

So in conclusion, (29) I argue

- person centred care is not reaching our rural areas
- in line with government strategy and
- while I acknowledge that it'll take time to bring about change
- it's also very clear that the poor practice we have to contend with in the meantime
- is having a devastating impact on our lives,
- not only on our vulnerable and frail at home,
- but also and as importantly on us, the caregivers who look after them.

I understand the principle of planting an acorn and

- nurturing it until it's ready to be transplanted elsewhere,
- but we in the rural Highlands
- don't have the luxury of waiting for that acorn to grow into a grand oak ...

And I must also admit I have a vested interest in all of this:

- up until recently I used to tick those 50-65 boxes on official forms
- ... but as of tomorrow
- I'm on the *plus* part of the 65+ box and
- in just 10 years I could be one of those frail elderly ...

Thank you for listening ...

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<sup>1</sup><http://www.redcross.org.uk/~media/BritishRedCross/Documents/About%20us/Taking%20stock%20-%20assessing%20the%20value%20of%20preventative%20support.pdf>