

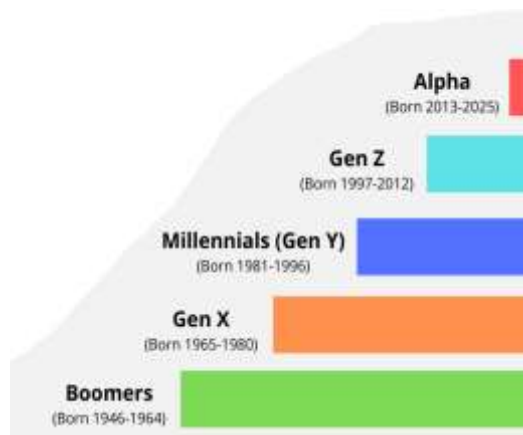
## It's a generational thing! That's what the doctor told me.

I am part of the sandwich generation. No, not the luscious thick artisan sourdough bloomer stuffed with filling, but more like the thin, damp, squashed, slightly grey, meat paste type of sandwich.

The sandwich generation are people who care for an elderly relative and children at the same time - this isn't new and feeling like a warm, damp, squashed meat paste sandwich is all part of growing older!

But I think the doctor was talking broader than sandwiches, he was referring to the different values and beliefs of generations.

I was born at the very end of Baby Boomers, to parents from the Post War period, and I have a son who is firmly part of Gen Z.



The changing values and beliefs of generations is a constant topic of discussion and never more so, than when discussing care.

Generations are a way to understand how different experiences interact with the aging process to shape people's views of the world.

## Dementia Diagnosis

Back to my discussion with the doctor - I look after my Mum, who was diagnosed with vascular dementia 18 years ago. Her caring needs, on a practical, emotional and physical level are demanding, and have had an impact on the choices I have made in my life, including my ability to work full-time and spend time with family and friends.

My Mum politely explains to the doctor that she doesn't need any help from health or care professionals, whilst giving me that look of 'don't embarrass me'. I have a daughter and "that is her job"! I find myself shrinking slightly as I told the doctor that she did need help and wasn't managing at home. Maybe it wasn't her needs that were changing, it was my willingness to deal with them!

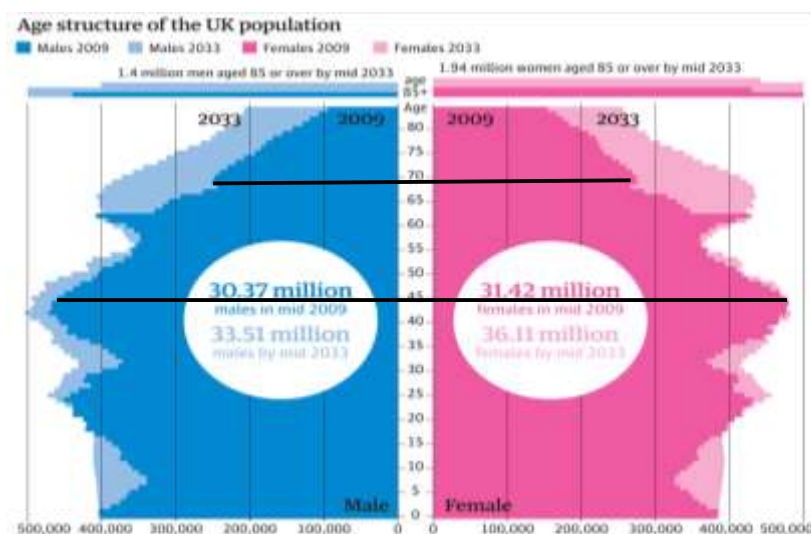
## Generational Thing

The doctor explained that this was a 'generational thing' as my Mum had expectations based on her values and beliefs that are unlikely to be felt by future generations. He explained that I was unfortunately caught in that cross-over generation from Post War to Gen X and expected to do it all.

## Keeping Up Appearances

Our Post War mothers had a tough time – they looked after the family, cooked, cleaned and cared for the sick or infirm but more than that, this generation learned about stiff upper lips, keeping up appearances and getting on with things, without complaining.

Baby Boomers were brought up with the same values on family, care and compassion, but had the opportunity to go out to work with increased confidence and purpose. Baby Boomers made a significant contribution to the economy, with a high proportion born between 1946 to 1964. We are very keen to step back and pass on the baton!



Gen X and Gen Y have started to teach us about the importance of looking after ourselves and making better use of services to help with the constant demands. But it has never quite resolved those inner voices and the sense of duty and obligation to 'just get on with it'.

Don't get me wrong, I love my Mum and will always be there to look after her – it is just about balance and understanding the wider implications of sustaining long term care.

## **Acknowledging the Impact**

To give an example, my son is 19, and has never known a time that my focus has not been on my Mum, every weekend and holiday and every conversation. He has learnt to be self-reliant and rarely asks for help. It is important that my son understands the importance of family, but at what cost to his own sense of worth and well-being.

I have faced a number of challenges whilst caring for my Mum, including what seems like targeted and deliberate attempts to hurt but I know my experiences are not unique, which is why I value [tide \(together in dementia everyday\)](#). It is a place to share stories with other family carers, without fear or judgement. Only a carer of someone with dementia can understand the complexities of the role and the impact it has on your life. I was slightly worn down by other carer groups who gave me sympathy (recommending a bath with candles) or made me feel like I wasn't doing enough.

But I am truly a Baby Boomer and don't like to dwell on a situation without making it better. [tide](#) has helped me put that into action.

Carers of people with dementia know about the feelings of love, guilt, frustration, resentment, sadness, grief, loss and joy and are constantly finding strategies to deal with new and demanding situations.

But let's face it – we are not carers! We are wives, husbands, daughters, sons and friends and we have skills and talents beyond our experiences as carers.

## **Shaping Dementia Policy**

So I wonder, what can Baby Boomers bring to the world of health and social care? Can policy makers develop an effective strategy for dementia care, without acknowledging the unique ability of carers to constantly adapt and meet changing demands?

Our carer experiences are vital in informing dementia policy and future strategies. Our generation has learnt the hard way, and want others to benefit from our experiences to ensure that nobody has to face dementia alone, including family carers.

## **Shared Experiences**

I spoke to 3 family carers about their experiences and the impact on their lives and was overwhelmed by the openness, empathy, compassion of carers, sharing similar experiences and themes.

Overall, the main feeling of family carers is a sense of isolation and feeling 'cornered', with a lack of choice or options. Caring for someone with dementia is not something you prepare for, and it can be a very gradual but overwhelming experience for the whole family.

## **Importance and Complexity of a Diagnosis**

Carers feel that getting a diagnosis is important, and is often a challenge. The person is often reluctant to face the reality of a condition with no known cure.

The health service can fail to commit to a diagnosis at an early enough stage and delays in a diagnosis are on the increase as a result of the pandemic and staff shortages.

The specialist who assessed my Mum asked me why it was important to have a diagnosis or for my Mum to acknowledge the diagnosis, as there was nothing medical that could be offered. As far as the specialist was concerned, it was just a matter of agreeing a care plan. I explained that the diagnosis allows a carer to access services and prepare for the future. I explained to the specialist that not everyone with dementia will accept a care plan, and this leaves families with a constant battle and daily negotiations, with no acknowledgement.

The other key point raised by carers was that dementia does not come alone. It is usually something that comes on top of other health problems, including depression, diabetes, heart problems, mobility issues and it can change the values and beliefs of that individual, resulting in increasing and unrealistic demands.

Some health practitioners view dementia as a social or 'behavioural' issue and treat specific health problems in isolation. A carer doesn't have that luxury and has to find a way to respond to the whole person, and how they are feeling at any given moment.

## **Unfair Work Practices**

Carers say that time off work to take loved ones for appointments starts as a 'no problem' but soon become a challenge, with comments and frustrations raised by line managers and other staff. Employers pay lip service to carers, with no real insight or personal experience of the challenges they face.

Carers who take time off work feel obliged to 'make up the time' as the work doesn't go away. Their days get longer, and their focus gets narrower, with limited time for friends and no opportunities for personal growth. Every conversation becomes about your loved one, as you go from one crisis to the next, constantly developing strategies to resolve irrational situations, resulting in increasing levels of stress and resentment.

Carers can feel like they are failing and many reduce working hours, take redundancy, or retire early. This is people who have worked for 20-30 years building up skills and experience in a range of industries, and are forced to become part of the 'great resignation'.

## **Impact on the Economy**

Their contribution to the economy reduces, their income reduces significantly (even having to sell family homes), and their lives become small and limited, with reduced confidence and feelings of self-worth.

Some carers have very poor experiences of employers, who provide no support, and take action to undermine trust in long standing relationships, gradually pushing carers out of work. This type of experience has a significant impact on feelings of well-being for the carer, and impacts others in that work situation, who become fearful to share their own challenges. Current HR Policies are not designed to support employees who have responsibilities as carers, and line managers are often left to make value based judgements that can have a significant impact on the carer and the organisation.

Carers mention the importance of building a support network to deal with their 'narrowing world'. This involves having open conversations with wider family, friends or others with similar experiences.

This requires the courage to face the stigma of dementia, and the potential to feel 'let down' by those who struggle to understand the complexities of the condition.

### **Self-Care**

One carer shared the importance of her dog in helping to keep a balance of emotions, to reduce stress and to keep focused in the moment with mindfulness. This highlights the importance of finding a strategy that works for you, and being kind to yourself.

But this is all about unpaid or family carers – what about the professionals? What role has social and health care in supporting carers? We know about the challenges facing the health service, and the impact on staff and waiting lists. However, we hear very little about the crisis in the care sector. The role of family carers is an unspoken crisis and a core dependency for our economy and economic recovery.

### **Future Plans**

Baby Boomers are growing old and Gen X and Y are starting to take on the role as family carers. Gen X and Y have different values in terms of caring responsibilities and are more reliant on technology to help manage responsibilities and commitments. I expect Gen X and Y will have an increased dependency on a double income (in current times of rising costs), and will have limited options for reducing income to take on roles as unpaid carers.

So what happens to the parents and loved ones of Gen X and Y when the number of people with dementia is expected to rise to 1.6 million in 2050, and Gen Y are just reaching that 'sweet spot' of early retirement?

### **Foreseeable Crisis**

Dementia is one of the most feared conditions, and is on the increase - are families having conversations about their future health and social care needs or is this yet another thing to avoid until it happens and then panic as we deal with yet another 'foreseeable' crisis?