First of all, I just want to say just how grateful I am to be here today.

Enormously grateful to Helen and all of the colleagues at Carers Uk for inviting me and Jane for such a nice introduction.

I wanted to start by saying, we're in the BMA. And I'll just say at the very beginning if they want to give us this for free that might be a nice contribution from the health sector to the social care sector.

Thank you very much for having me here today and I'm very conscious that you've got an extraordinary series of breakout sessions and lots of fantastic people throughout the rest of the day so I will continue this speech at a decent pace.

So, the very very great Mary Webster first established Carers UK as *the National Council for the Single Woman and her Dependents* in the 1960s.

Carers UK since then have done an absolutely brilliant job to help make life better for the almost 6 million carers throughout the UK.

And as Helen just said, from the tipping point report and throughout they've been great, since we started we've been enormously grateful for the support and the help and direction we've had from colleagues in Carers UK.

They have done a phenomenal job since then, and that's just the numbers of carers we know about. Not the numbers of carers we don't know about.

And as Helen said, probably every single person in this room if they haven’t already, they will at some point through their professional lives or through our personal lives - know the value of what it means to care for someone.

I think the capacity to care, to be kind, is one of the most incredible assets we have as humanity.

I looked up, despite my age, the word ‘care’ on AI - it brings up words like attention, diligence, caution, protection and nurture.

It’s how we transact and how we show love, actually, towards our family, our children, our partners, our friends, even strangers as well as neighbours.

It can be as simple as popping in for a cup of tea, sometimes cooking someone a meal

Imagine what happens when someone gets the diagnosis of cancer.

A lot of women they know will make the meals for the family, week in, week out during their treatment. That happens to thousands, millions of women, that get breast cancer. People step in and look after them.

It can just be checking how somebody’s feeling.

It can also mean carrying out the daily tasks which allow a loved one to be safe, to be independent, and to live with dignity:

Checking they’ve taken their medicine, taking them to the toilet, taking them to appointments, filling out the endless madness of the forms.

And sometimes, care can mean helping someone through the final days, hours or indeed minutes of their lives.

The experience of being a carer can be, I think, one of the most important and indeed uplifting things someone can do for the people they love and the people in their community.

But the reality of is that it is tiring, uncomfortable, repetitive, distressing and downright frustrating.

And, sometimes, it is not the person they are caring for that creates all of that frustration, but it is the system that can make the carer feel like they are living an agony.

I could stand here today and give you case study after case study after case study of people I have met in the last twelve months who I think are living with this agony.

And what strikes me every time I listen to carers, is they are not asking for the earth.

What they want is clarity.

They want to see the road ahead and know what’s going to happen.

To understand what support exists, how it works, how to access it, without having to fight every step of the way.

Carers talk about themselves as unpaid ‘project managers’, ‘care coordinators’ and, the latest, ‘navigators’.

They spend their days organising appointments, or coordinating the diaries of NHS staff, of local authority staff, of therapists, of the endless individuals that are trying their best to provide care but make it quite frustrating to get it organised.

Trying to figure out, for example, the difference between a local authority occupational therapist and what the difference is between that and an NHS occupational therapist. What the difference is and what they can offer, what the time frame is, what the bloody hell is going on most of the time.

When we actually just don’t really know what the difference is between the two of them, the system might know, this building might know one thing, the local authority might know another, but the human being trying to navigate it don’t really get it, we just want an OT.

Chasing equipment, filling out forms, battling delays, managing the crises that the failure of the system to coordinate creates, repeating the same information again and again to different parts of the system.

Whether that’s the GP surgery, the district nurse, the local authority or the local hospital.

Everywhere there’s different systems, different forms, different processes.

At every Carers UK or indeed Carers Trust visit I’ve been to, carers talk about navigating the social care system as if they are the first person that’s ever had to do it.

Every agency has its own rules and interpretations, these variations are put on the public’s plate and, frankly often it is is made their problem, not our problem to solve.

And I think that’s indicative of a system that isn’t putting the public first.

I’ve heard harrowing things from carers supporting people with some of the most brutal, rapid and terminal conditions.

Like the experience of a woman who had a diagnosis of motor neurone disease - a condition with a median life expectancy of 22 months.

And we use expressions like median life expectancy of 22 months so we don’t say plain English. You get that diagnosis, you might live on average for more than two years.

She was subjected because this is what the system thought it had to do, to repeated, painful and unnecessary hoisting. Not for her care, but so different parts of “the system” could tick their own boxes that the hoist was safe. Multiple agencies, multiple checking, not one agency that could check on behalf of everyone.

Carers spend more time sorting out problems out with the health and social care system I think sometimes, than spending time with their loved ones, and sometimes in in their loved ones last few months.

Becoming ill or having a disability, or indeed getting old, can be painful enough.

The system makes this far harder than it needs to be.

We’re not up front. We don’t say things like, “this is what’s going to happen and when”.

We end up in a position where elderly parents in their 70s are still carrying their 40-year-old disabled son upstairs to bed every night, worried that if they ask for help the consequences of asking for that help will make their lives worse and not better.

Or in a position where a man – who I met in one of your projects, whose wife has been diagnosed with dementia - wanted to know what will happen next and is handed over two leaflets, one on how to claim PIP, and one on how to get his council tax reduced.

He was fine for money, he didn’t need that. He’d just got a diagnosis for his wife of dementia and wanted to know what happens now.

I’ve known carers consumed by this anxiety, both in my personal life and in my professional life, unable to think about anything else, because the system offers them no reassurance, no continuity and no plan for the future.

I think the emotional toll of that will be enormous.

Frankly, we shouldn't have to keep making people tell stories of how flawed the system is, we know enough about it to bank that as truth and turn our attention to doing something about it.

And frankly, I think, we should be able to take the agony out of care.

Our adult social care "system" relies on someone filling the gaps.

And, of course, as Helen pointed out, that someone is a woman – she's a daughter, a wife, a mother.

59% of unpaid carers are women.

And indeed the bulk of paid carers are women and let's not shout out too much that being paid as a carer is fantastic because we all know it's very low pay.

A woman is expected to absorb risk, stress and responsibility so the system doesn't have to.

And all of this reflects the world Beveridge that I've talked about before of 1948 when Beveridge designed the welfare state, thank God that he did.

In 1951 only 35% of women were economically active.

Nowadays, that world no longer exists.

In 2026, 73% of women are economically active and in paid work.

And yet I feel and believe that we have a system that still behaves as if we are living in 1948, and not 2026.

And at the same time that that is happening, and it’s interesting that we’re in the BMA today, the NHS has changed and evolved too.

I think it has withdrawn from the community while putting more staff into hospitals and acute.

For example – just one example - between 2009 and 2024 the number of NHS district nurses – the powerhouse of going into people’s family lives – the number of district nurses in England fell by around 43%.

And the number of nurses working in hospitals increased by 43%. This is really interesting.

I’ve called the NHS a National Hospitals Service before and I’m doing it again today.

So broadly, we are left with a system that is fit for a world that no longer exists.

A system that doesn’t reflect the seismic changes we have been through.

A system that has withdrawn from communities.

The result, therefore, is predictable.

We now rely on unpaid carers and frankly poorly paid care workers to stretch and stretch and stretch to fill these gaps.

To hold things together in the community until they hit crisis point.

I for one, think this can’t go on any longer.

And yet, let me be absolutely clear about something.

Many families want – and they should want - to care for their loved ones.

To see it as an expression of love and indeed of duty that they welcome.

It’s meaningful. It’s deeply human.

The problem is not that people have to care for the people they love.

The issue is our lack of clarity and honesty with the public about what the “deal” is.

About what they can and should expect from the health and social care system.

And what the split is between the state and the family.

That is partly why we will commence shortly a National Conversation with the public.

We need, as a country, to be honest and explicit about what is fair to expect of families, and what the state will do to support them.

Where does responsibility sit?

Where does the state step in?

And what does contribution look like?

This conversation won't be held behind closed doors or in policy documents.

We will need the voices of carers themselves.

We will also need the voice of all of the public, many of whom already contribute financially each and every month for social care through their council tax and many others through a lifetime of paying taxes and national insurance.

A citizen who then hits the point of needing care themselves, and is told by the state they will have to foot the bill because they have savings of more than £23,500.

And on many a leaflet, I'm obsessed with this where I visit places I pick up leaflets, and we say this is a discharge from hospital, and they say make sure you have this, make sure you have this, and they say somebody will be in touch and they will discuss the charging policy with you.

And you think, yeah, what that really means is they are going to enter a financial vortex of a scale that's unknown.

And don’t get me started on Carers Allowance. One of my almost godsons, we call him little John he’s so tall, and he works for the CAB in Peckham, and he said working out Carer’s Allowance is the most difficult one to do out of all of the benefits that people walk in with, what’s deducted, what isn’t deducted, how do you do it.

We need those voices so that they can deliver an adult health and social care system built on a shared understanding of fairness, responsibility and contribution.

And a system which is not reliant, I think, on putting unpaid carers through an agony.

The carers I meet aren’t asking for miracles.

They are asking for clarity.

I think it shouldn’t be beyond us to devise ‘one pathway’ so people know what help and support is there and what they can rely on.

To give at least people some information on who to speak to, where to go, on what to expect and when.

Surely that is the minimum standard we should set ourselves in this society.

It shouldn’t be too much to ask in a country like ours. I think it’s the minimum we should be able to deliver.

Because I think if we get this right, the next generation of carers won’t have to feel like unpaid project managers, unpaid coordinators or indeed navigators.

They’ll be able to feel like what they are:

Somebody caring for their loved ones

With a system behind them, and not in their way.

Thank you very much.