

Written evidence submitted by Carers in Bedfordshire (ASC0020)

Adult Social Care Reform: The Cost of Inaction

Introduction

Carers in Bedfordshire is a charity whose aim is to help unpaid carers of all ages across Bedfordshire and to give voice to their concerns. The following evidence is submitted by our Carers' Panel, who form an advisory forum for the charity and are a formal part of our governance structure. It provides personal evidence on the impact of inaction from carers' perspective. More details about the Panel can be seen here:

[Carers Panel - Carers In Bedfordshire](#)

The evidence addresses **two** of the questions posed by the Committee:

- What is the cost of inaction to individuals and how might people's lives change with action on adult social care reform?
- Where in the system is the cost of inaction on adult social care reform being borne the most?

The submission is structured in five parts.

1. A summary of the issues raised by the Panel - bookmarked
2. The first presents an overview of the impact of inaction on carers and those for whom they care, from the perspective of one carer. We believe this powerfully symbolises the frustrations and anguish faced by the many carers who tell us about their experiences
3. This overview is illuminated by examples from other carers' personal experiences¹.
4. Last word – *what if we all just walked away for a week?*
5. Appendix: Brief details of the carers who have contributed to this submission

It is important to stress that the comments are not addressed at individuals, as carers recognise that there are some strong advocates for carers within Parliament. They are addressing the central question of inaction in reforming the social care system as a whole.

¹ One carer's comments is coloured blue for continuity

Summary of issues

<u>On personal impact, health and wellbeing</u>	<ul style="list-style-type: none">• Mental health: The stress and emotional toll on carers are profound, often leading to mental health issues such as depression and anxiety.• Physical health: carers' physical health often deteriorates due to the demands of caregiving. This also impacts on their wider families (e.g.: “sandwich” carers forced to divide their time between their children and dependent parents).• Lack of recognition and support: The need for better recognition of carers' roles and more support, both financial and emotional.
<u>On financial security, including employment</u>	<ul style="list-style-type: none">• Many carers are unable to work because of their caring responsibilities and lack of support: cost to carers and their families, but also to society in loss of vital skills to the economy and loss of tax revenue.• Personal financial impact: carers face significant financial burdens, including loss of earnings and direct costs associated with caregiving.• Carers unable to save for retirement, leading to vicious circle of poverty in older people.• When carers have children of their own, increase in child poverty due to financial impact.• Public financial impact: costs to the NHS and local authorities due to inadequate social care, leading to increased hospital stays and other expenses.• Funding and Resources: The financial strain on carers and the need for adequate funding for social care services.
<u>On fragmentation and lack of coordination</u>	<ul style="list-style-type: none">• Multiple agencies: carers often act as the glue between various agencies, which do not adequately synchronize their efforts.• No single point of ownership: there is often no integrated plan or single point of responsibility, leading to added stress and time consumption for carers.• Listening to carers: emphasis on the need for adult social services to listen to carers and involve them in care planning.• Understanding the criteria and getting reliable costs covered for what is clearly a health need have become far more difficult due to changes in Continuing Health Care.
<u>Inadequate Support and Services</u>	<ul style="list-style-type: none">• Limited services: services like Day Services and Reablement Services are often insufficient, especially for those with ongoing but non-critical mental health issues.• Poor quality of care: Issues with the quality of care in both home and residential settings, including inappropriate care plans and lack

	of personalized care.
On costs to NHS and public services	<ul style="list-style-type: none"> • Hospital discharges: delays in social care assessments and hospital processes lead to extended hospital stays, affecting both patients and carers. • Virtual wards rely on carers, but often no carer assessment made. • Economic Impact: The broader economic impact of inadequate social care, including loss of tax revenue and increased public spending.
The impact on future generations	<ul style="list-style-type: none"> • Inaction today just builds up more problems for the future. • Failure to invest now is a false economy. • Poor health for carers ensures that the cycle will continue and create burden for future generations who need to care for today's carer tomorrow.

An overview from the perspective of an unpaid carer

1) What is the cost of inaction to individuals and how might peoples' lives change with action on adult social care reform?

Mark, carer to two young adult children with profound special needs

"Carers may have been up all night with their charges, or at least locked into the unbreakable rhythms that care sets for them. They may be conducting exacting and deeply personal matters of hygiene or assisting with medication and mental care on their charge's behalf. Carers do not work 9-5. They work, unpaid, 24/7/365. Most consider a holiday to be exactly the same level of intense labour conducted somewhere else. For a carer, the simple notion of popping out for coffee with a friend might, in reality, be more akin to re-arranging the planets in alphabetical order.

Carers WILL NOT be found idly chatting around a water cooler or coffee maker, over business breakfast, working lunches or late networking suppers about trivial matters. Although most will wish that they were. They will not be attending or hosting dinner parties.

Many of these carers WILL NOT be going into any kind of paid work, because their charges' needs are so severe as to exclude them from any additional kind of socially productive activity, and their carers alongside them. They will also not be working because employers tend toward the inflexible, do not have even a basic understanding of the caring burden, and will almost always employ workers whom they know to be free of such burdens.

Most of these carers will never darken the doorstep of an MP's surgery, because their needs are so wide and so vast that they become difficult to synopsis. Perhaps their charges cannot queue or refuse to queue and break out of their restrictive routines. And carers are made hyperaware every single day about how other people are often very troubled and upset by seeing profoundly disabled people in their midst. Democracy is effectively being defrauded by government inaction on change.

These carers WILL NOT be near their family and friends because of the difficulties of their caring responsibilities, and the pressures that care exacts on those precious relationships. Many carers WILL NOT be with their partners anymore because the pressures of care cause so many relationships to implode under a burden with little hope that there will ever be relief. How do you itemise the cost to an individual of a failed relationship and broken family?

Many of these carers will be under virtual house arrest, condemned to favour times when town centres are quieter, and the restlessly intolerant world is busy elsewhere. Events will not see their patronage. Museums, galleries, cafes, restaurants, cinemas, concert halls, theatres, will not benefit from their custom. They will not be riding horses, cycling, bungy jumping, swimming, running, playing soccer, cricket, tennis, golf, throwing themselves out of aircraft or going to the gym. Essential maintenance: hairdressing appointments, dentist visits, optometrist, routine scans will either be missed or undertaken with their charges in the rooms.

Without a fully realised and costed care plan for the unavoidable care burden currently being rested on the shoulders of families, you therefore: remove a cohort that is measurably larger than the

combined armed forces of the UK from the workplace. Valuable people, talented people, stripped of self-respect, and personal determinism. People that the economy can ill-afford to mothball. And because these people are mothballed, they become economically inactive, socially isolated, stressed, ill and disenfranchised. If they ever able to organise, and coalesce into a political movement, they will represent nine million votes.

YOU WILL find carers clogging the waiting rooms of GPs and hospital services because care exacts a horrifying cost on physical and mental wellbeing. And carers will drain NHS staff hours and resources looking for expensive chemical solutions to our broken spirits and broken health that could be healed so much better by intervention and imagination.

If you ask many carers about their experience of the recent lockdowns, they will describe a time when their personal experience did not change at all. Meanwhile, the rest of society, for once, experienced the same degree of social isolation, fear and helplessness as full-time carers commonly do. The rest of society rapidly became demented with grief for their lost lives and then, when the lockdowns ended, they emerged from the shadow, recovered, and got on with their lives. Carers didn't, couldn't, and these days do the best they can with the little help that they are given. The process of caring is, at a basic level, a never-ending and debilitating process of grief and mourning for those we care for.

Carers firmly believe that the current model is that they exist to be exploited to destruction by government, and only when they are no longer fit to care is the burden removed from them. Many will not have the resources to recover – mentally and financially.

In short, the cost to carers from government prevarication is: EVERYTHING”.

2) Where in the system is the cost of inaction on adult social care reform being borne the most?

Mark, carer to two young adult children with profound special needs

“Always by single parent families, the already poor, the educationally or psychologically challenged, the frail and the mentally compromised – those without the inherent tools to become resilient. But the mental health burden knows no socio-economic barrier.

The general public loves to believe that carers are in some way superhuman, and pluckily optimistic, but media clichés aside, that is not our experience. We see people trampled by their experiences, crushed into the ground and then the dust kicked over them.”

Illustrative examples of the cost of inaction.

On personal impact, health and wellbeing

Julie *“Costs to individuals in my family include loss of personal dignity for those cared for and distress to vulnerable members of the household.”*

“The stress and distress of seeing the family home sold to pay for residential care despite government promises: no care agencies could cover Mum’s needs at home. Despite also being my sister’s home she was unable to cover the bills after giving up work to become Mum’s main carer; the stress of all this led to her having a breakdown. The amount of funding available from the council fell on average £400 a week short of the charges of all the care homes in Mum’s area - apart from one that was rated inadequate by the care quality commission and subsequently closed down; the other homes required top up fees which none of the other members of the family could afford to pay so the family home had to be sold to cover residential care.”

LG *“Major impact on both mine and my mother's mental health. When the assessment was done without my mother's involvement, she felt like she had lost all control, and it led to her taking an overdose. She was so angry when it failed, she became very depressed and was extremely angry with everyone and everything, particularly me as her carer. Nothing anyone did from then on could change how she felt. Her behaviour towards me with such, that I had a breakdown. Her view of the world became distorted, and she believed I didn't want to care for her or have her living with us, both untrue. My mum did eventually agree to see me again and I visited her regularly. She eventually took her own life in April this year.”*

Julie *“It has had a profound effect on my sister’s mental health leading to her not being able to return to anything like a normal life.”*

GM *“All the carers I know are very proud and dedicated people who are being taken advantage of by a very unfair system, that can be so destructive to everyone involved financially and emotionally.”*

On financial security, including employment

Julie *“Carers like my sister and me having to give up work because of our experience of inadequate provision of social care at home and poor-quality respite and residential care available for my stepfather and my mother who has dementia. I also have been unable to go back to work because managing the complexities of the various financial responsibilities and managing care responsibilities that still remain despite my mother and sister now being in a supported placement and residential care respectively.”*

Elaine *“Our daughter has received no help to develop an ability to return to voluntary or paid work. She does not claim benefits although would be eligible to do so which of course would be a cost to public finances.”*

LG *“I left my full-time employment to care for my mother. The repercussions had significant costs to adult services who had to arrange another face-to-face assessment, to another authority's adult social care department and to the NHS mental health services.”*

Julie *“I was the main person organising care for my stepfather, both at home and in residential care (from 2017 until he died in 2021) after he suffered severe disabilities after 2 major strokes. He self-funded all his care and was left with a sum of about £23,000 when he died. I was the main person organising care for my mother at home when she was diagnosed with dementia in 2016.*

“I was also the main carer for my sister after she suffered a mental health crisis as a result of being the main hands-on carer for my stepfather, my mother, and an elderly aunt. My sister is now in a supported placement. She is funded by Mental Health Services as she has no income. I have Power of Attorney for my sister and continue to manage all her affairs.

“After my sister was admitted to psychiatric hospital my mother was taken into emergency residential care. Powers of Attorney for Finance and Health and Welfare were transferred to me, and I now also manage all my mother's affairs including applying for financial support when my mother's funds ran out despite selling the family home and using all her savings. The total costs of my stepfather's care and my mother's care have so far amounted to approximately £750,000.”

GM *“Two important things that have stood out and concerned us in the process: the first question always asked by those assessing access to social care is money and finances. We know and appreciate the state of services and budgets, however from ours and the cared-for perspective, it currently feels like you are allocated support according to economics rather than need. Listening to other carers' experiences, additional self-funding gets you more appropriate care until the income is exhausted.”*

Julie *“My parents and my stepfather were solidly working class. They worked and saved hard all their lives which they were told by successive governments was the right thing to do. My mother owned her own home because she had the misfortune to become a widow at 40 years old and my father had been sensible in having life insurance which covered repaying the mortgage and providing a lump sum that she could invest to meet her needs and the two teenage children she still had living at home. When she met my stepfather a few years later he sold his house to enable them to convert hers to make it suitable for his teenage son to come and live there. My stepfather never claimed a*

penny in benefits and neither did my father. My mother did claim a widow's pension but only for a few years until she remarried. Society repaid this frugality by taking every penny they had when my stepfather and mother became ill later in life to pay for poorly funded and inadequate social care. I am so horrified by what has happened to them and how vulnerable this has made our family. We have no savings because of my husband's disability, financially supporting our daughter, and me having to give up work early to take on caring responsibilities.

"This has impacted on our pensions, mortgage, savings etc, so retirement is looking far less rosy than 20 years ago. I have been trying to get back to work for some time, not looking for a career but to replenish funds as we hurtle towards retirement, probably needing care in the future ourselves. It is soul-destroying, especially how limited your options are, experience counts for little, and our government want my age group to return to the workplace but have no clue of the complexities we face. Difficult to promise 100% commitment and flexibility when you still have same restraints, actually increased caring responsibilities at times. Our previous social worker wanted me to apply for unpaid carers allowance, but I was already concerned and aware of how easily you could fall foul of the income requirements and fall into debt with the DWP."

JR *"Carers allowances are geared fundamentally to the demonstrable physical difficulties of the cared-for. The carers of those adults with mental health issues (but with none or few of the physical characteristics) often fail to qualify for any allowance. Thus, they must allocate time to continue to do things for the cared-for person. This will entail actual financial cost on the carer in real terms or in the lost time that have to dedicate."*

On fragmentation and lack of coordination

Julie *"For me, extreme stress caused by:*

- the complications of making sense of the system of benefits for carers and those cared for particularly dealing with applications for financial support to councils towards the costs of social care*
- the continuing responsibility of managing all other aspects of a person's life including all their finances*
- finances for the people cared for (the complex system of dealing with applying for financial support when the money runs out and the day-to-day finances and lack of appropriate respite)*

JR *"Much time is taken by carers having to be the glue between various agencies supporting the cared-for. This is due to the reality or perception that they inadequately brief each other or synchronise their work and approaches on a given case. Each may reach a stage where, from their perspective, they have taken it as far as they can, but it can leave the carer and the cared-for unsure of which agencies are still monitoring the latter's situation.*

"There is often no single point of ownership or integrated plan in such multi-disciplinary cases, so it means that providing, or ensuring, this co-ordination seems to rest on the carer. This added stress is time-consuming and very draining for the carer. This is made worse by the turnover of practitioners

in each agency or by the practice of not allocating cases to named individuals which then entails updating different peoples as they come new to the case.”

On inadequate support and services

Julie *“Experience of care at home:*

- *incontinence pads only changed when carers visit leading to my stepfather having to sit in faeces soiled pads*
- *My stepfather sliding out of his chair between carer visits which meant my elderly mother (with dementia) and my sister had to try and get him back in his chair or call for help from neighbours or other members of the family (none of whom had safe manual handling training or appropriate aids to do this) or wait until the next carer visit with him on the floor*
- *For my daughters’ boyfriend carers not taking account of cultural or religious requirements when preparing food.*

“Experience of respite care – poorly paid, poorly trained or poorly managed carers leading to:

- *Mum having two falls during respite care despite never having had a fall at home*
- *Mum laying in a faeces soiled bed for half a day and would have laid there for longer if my daughter hadn’t visited.*

“Experience of residential care for my mother (at a cost of £1590 per week)– poorly paid, poorly trained or poorly managed carers leading to:

- *Mum being inappropriately dressed on numerous occasions (no bra – totally mismatched clothing)*
- *Dirt under her fingernails*
- *Failing to provide ‘bibs’ or clothing not cleaned up after meals*
- *Dentures and glasses being lost*
- *Other personal items going astray despite being named”*

LG *“Most of my experience of adult social care is regarding personal care for my mother and residential care for my father. The most significant issue for me, regarding my mother, was when a social worker refused to perform a care assessment for my mother directly with my mother. Instead, she asked me questions over the phone and as a result came up with a care plan that was completely inappropriate. This had a huge impact on my relationship with my mother and eventually led to her moving elsewhere. She believed that I had recommended this plan and no longer wanted to care for her. This was not the case and the only reason for contacting adult services was to discuss respite arrangements.”*

GM *“Without being dramatic, the transition from Children Services to Adult Social care has nearly broken me especially, both emotionally and physically, and is still not finalised from our end, but probably signed off, box ticked, onto the next case. It is clear how overwhelmed the services are, how overworked the staff and professionals are, it is the system that needs root and branch change. Living with someone whose mental health issues stopped being met and understood, cannot help but affect the carers wellbeing too. Sometimes just seeing them wake up the next morning in one piece is*

a relief and good start to the day. Sleep can be a luxury here, exacerbating my own auto immune and other medical conditions. Dealing with so many different departments, no single point of contact is frustrating and counterproductive.”

JR *“Social care provision is, or appears to be, fragmented. It is not sufficiently ‘patient-centric’ but is rather a statement of what each agency can (or is willing or able to) offer within the skillsets and budgets they individually have. Patient outcomes therefore are not the holistic concern of any one agency, it seems.”*

On costs to NHS and public services

Julie *“Costs to NHS (of multiple visits to GPs and hospital for various illnesses caused by the physical and mental stresses of being a carer (my sister and me) and the costs of medication to deal with these illnesses - particularly pain medication and anti-depressant and anti-anxiety medication) and personal costs to us as carers because of the stress of dealing with multiple agencies and care that doesn’t meet the needs of the people cared for whether at home or in residential care.”*

GM *“The cost to the NHS and public services other must be immeasurable, like many my own health has deteriorated, and I need medical intervention for conditions which I believe have been exacerbated by our caring responsibilities.”*

Julie *“Costs to NHS and loss of tax revenue for the Government because of individuals I organised care for not getting back to independent living (my stepfather after a stroke and my sister after a breakdown in her mental health).”*

GM *“I will repeat again, it is clear how overwhelmed the services are, how overworked the staff and professionals are, it is the system that needs root and branch change. Many of us are affected by longer NHS and other waiting lists, also reduced access to outpatient intervention for both ourselves and our loved ones. Sorting out arrangements when a procedure, or stay in hospital or residential care is needed, becomes a military operation on our part, but then falls apart on the first hurdle due to lack of beds, operating list overruns etc.*

Personal care seems to be the main focus of adult social care, but in my experience mental health issues, if not managed, supported, medicated, can bring down the pack of cards very quickly, despite military style planning, especially when travelling back and forth long distances, more often the case now families are spread out over the UK.

End to end service and communication would be fantastic, a joy to not keep repeating information to professionals parrot fashion.

Finally, carers not becoming piggy in the middle, when services are playing pass the parcel with prospective patient/service users, also would be an amazing, desired given! More money needed to support carers and ultimately their recipient of care, also directed to charities and organisations who currently provide support. Government and Local authorities sign post carers to these wonderful outside organisations for support at a time where they too are having to do much more with far less funding. It’s not sustainable and something has to give!”

The impact on future generations

Julie *"I am terrified that all the stress I have experienced in my encounter with the inadequacies of the care system has ruined my health and that I will be passing on all these caring responsibilities to my younger daughter and my son. As my elder disabled daughter is not able to manage if we had to sell our house to pay for care costs, I cannot afford for that to happen. What are my options but to be at the mercy of a broken care system which has caused me so much heartache. How can I face passing on this burden to my children."*

Last word

Mark, carer to two young adult children with complex additional needs

“Everything crossed here that people begin to sit up and listen at a time huge changes have been promised within the UK on limited funding and resources. There is a confident expectation that unpaid carers will continue to pick up the slack in a system that is neither efficient nor sustainable in its present form. We would never willingly endanger the wellbeing and safety of our friends and loved ones we support, but imagine the chaos, upset and devastation caused to the vulnerable and sick if we all just walked away for a week. Would anyone else even care?”

Appendix: List of carers who have contributed to this submission:

- Mark** carer for two young adult children with profound special needs
- Julie** carer for step-father in residential care, mother with dementia and sister with mental health problems
- Elaine** carer for daughter with severe and enduring eating disorder for 25 years
- GM** carer to adopted son, now with complex additional needs and disabilities, also elderly parents
- LG** carer for mother, father in residential care and uncle
- JR** carer for brother with mental health problems for 20 years

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