

Health & Social Care News

National Pensioners Convention

Health & Social Care Working Party

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Issue : September 2024

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We hope you continue to enjoy our newsletter and that you will share your stories with us.

Reminder of our new office address at the top of this newsletter.

We wish everyone attending the Annual Convention in Blackpool a successful event.

If you have a story to share, a comment to make, or a specific area of interest, please let us know.

Look out for further campaigns on the winter fuel allowance issue.

WILL YOU BE WARM THIS WINTER?

The devastating news from the new Chancellor of the Exchequer, Rachel Reeves, will hit older people again this coming winter with a much higher hike in energy costs without the support of the winter fuel allowance payment.

The decision that winter fuel allowance payments will be restricted to those on pension credit and other means-tested benefits, will have an adverse impact on all those who will now be excluded.

Since 2000/2001 the winter fuel allowance has not risen despite frequent inflationary increases to energy costs. On a static income, older people have to make choices when one or more of their bills increase.

Today, two million older people live in poverty in the UK, 6.5 million households in total are in fuel poverty. All will have to make critical decisions this winter with the increase in the energy cap in October with possibly more to come in January 2025.

For older people, the winter fuel allowance payment is a lifeline. Even so, we have to decide whether to switch the heating on or make a hot meal. Others have the dilemma of whether to cut the cost of some or all of their care package. Leaving your broadband provider isolates you from everyday life. Making cuts to travelling and other activities worsens your quality of life.

Cold, damp homes kill, cause ill health placing a further burden on the NHS and care services and many many not see the next Spring.

The NPC is supporting the Age UK petition and urge everyone to sign it and also get family and friends to sign too. Currently standing at over 442,00 we need many more signatures to get the message across to the Chancellor. You can download a paper petition for those not online:

<https://campaigns.ageuk.org.uk/page/154268/petition/1?locale=en-GB>

Write to your MP, write to your local newspaper, make sure they know this is not how retirement should be after a lifetime of work and contributing to our country.

FROM CARERS TO A NATIONAL CARE AND SUPPORT SERVICE

At last the unsung, unheard and largely unsupported army of unpaid carers have been thrust centre stage.

Sadly, this wasn't to receive recognition for the fantastic work they do or the £162bn they are estimated to save Government every year (1) but because they were being persecuted by the courts for over-payments of benefits inadvertently accrued owing to the ludicrous cliff edge nature of carers benefit, punitive restrictions on earned income (£151 per week) and failures in the DWP!

Let's hope that with a push there may be some overdue tweaking of the benefits system. However, that would only scratch the surface of issues for carers.

Dig just below that surface and it becomes clear that much of the stress, exhaustion, frustration, isolation and impoverishment experienced by many carers is not caused by caring for their loved ones but by having to battle every step of the way. Many toil through the labyrinth trying to establish what financial and practical support might be available to them and the person they are caring for. Then they have to jump through demeaning hoops of repeat and intrusive assessments, sometimes carried out by staff with very limited knowledge and skills.

As support is generally resource led not needs led, despite what it says in the Care Act, carers and disabled people have to highlight what they can't do in order to get help, knocking the stuffing out of their self-respect and pride.

Finally, carers have a massive uphill struggle to find and

retain providers who can provide safe, expert and reliable support.

Throughout all these battles the stress is magnified by carers finding that their knowledge and experience is not recognised and they don't have any seat at the table when key decisions are being made regarding the people they love and care for. Many carers are also desperately anxious about what will happen to their loved ones if they are sick or die. However, cash strapped Local Authorities winging their way on very short term financial allocations and almost totally dependent on outsourcing live for the moment and can't offer any answers. Increasingly carers are calling on legal advice and advocacy to challenge decisions, bringing a whole new raft of work and anxiety while only open to those with the means to pay.

It is clear that all actors in Social Care are woven together by many of the same strands: being undervalued, unheard, marginalised and often poor. Unpicking these strands and challenging the myths that sustain them is essential if we are to make serious progress towards setting up a National Care and Support Service that works for everyone. Piecemeal change will not suffice.

A powerful myth is that older people and disabled people are not as valuable as "workers" as they contribute less to the economy. This runs deep in a society where the neo-liberal doctrine that making profit for a small elite is the only hope of creating trickle down growth and wealth for the many is passed off as common sense, even though it patently doesn't work. Recent research by Oxfam (2) exposed the fact

that the world's five richest men have more than doubled their fortunes to £681bn since 2020, while the world's poorest 60% – almost 5 billion people – have lost money. In the UK, where 1% hold more wealth than 70% of Britons, the growing inequality gap provides fertile ground for frustration and resentment. This was shamefully and blatantly stoked by the last Government who consistently blamed migrants then turned their fire on disabled people and those with long term illness.

Unfortunately, in Labour's enthusiasm to maintain the status quo and sail with the wind pre- election, they focused repeatedly and uncritically on "working people". Whether inadvertently or not, this discounts the vast amount of "work" we all do every day supporting our children, grandchildren, partners, friends, relatives and neighbours and opens the gates to older people and disabled people being seen as a cost, even a burden. We are offered benefits not a guaranteed income, charity rather than rights.

We need to call out the way people and relationships have been commodified and stand up for a different way of living and relating to each other which recognises our shared humanity.

Another closely related myth is that social care is not a universal service like the NHS: it only affects a minority of people - them not us. The truth is that almost half of us will fall into the orbit of social care at some stage of our life, sometimes in several roles at the same time e.g. being disabled and a carer and sometimes shifting between roles throughout our life cycle.

The Department for Work and Pensions' Family Resources Survey (3) noted that 24% of the UK population, or 16 million people, had a disability in the 2021/22 financial year. Official estimates of the number of carers are over 5 million but Carers UK estimates that there are over 10 million (4). If you add in 1.6 million care workers, that is 28 million people – more than half the adult population – with family members, neighbours and friends also affected and numbers set to rise. Over 45% of adults over State Pension age and 58% of people over 80 reported having a disability.

Other countries have hooked onto the importance of recognising the universality of social care and its place alongside health as part of the bedrock of core services that underpin the health, wellbeing and security of the population. In a piece for the Nuffield Trust in February this year (5), Natasha Curry notes that Japan, Germany and France have been successful in building public support for taxes and levies by creating a positive story, framing social care as something worthy of investment, an essential part of national infrastructure. Germany created a narrative about solidarity and mutual support. France has recently established social care as the fifth pillar of the welfare state, bestowing on it a status and value equivalent to health and pensions.

The third key myth that needs dismantling is the age old “We can’t afford a National Care and Support Service”

A change of Government brings new hope. Taxing wealth, dividends and capital gains alone could release £40bn. which would go a long way to building a free and fair National Care and Support Service that would generate

income and boost the economy. However, such arguments will fall on deaf ears as long as Labour continue to trundle along the tramlines of fiscal prudence determined by a totally flawed, neo-liberal, household budget model of the national economy. You don't have to go the whole hog with modern monetary theory to appreciate what Keynes said in 1942: “anything we can actually do; we can afford”. Just look at how the NHS, education and social security systems were set up after the Second World War, when public debt was at 270% of GDP, and how the Conservative Government magically located £137bn to bail out the banks in 2008. The money can be found. What is needed is the political will.

So where do we go from here?

Tackling these myths, pushing for bold vision, insisting that change is needed across all sectors in social care and will benefit everyone is essential if we are to radically transform the current largely institutionalised and privatised, means tested, top down patchwork of provision in social care to one that offers choice, control, a guaranteed income, rights not charity.

But there are demands on Government that can be made here and now to alleviate suffering and to start chipping away in the right direction.

Backing improvements in pay and conditions for care and support workers is uncontroversial. Immediately improving benefits for carers and stopping prosecutions for debts will help. Dropping charges for care and support already has precedents - in Hammersmith and Fulham as well as in Scotland.

Broadening and localising contracts for in-home support to enable carers to do tasks

like taking people out rather than just basic physical care is happening in Haringey, Leeds and elsewhere. Cutting out the misery of reassessing people who have long term conditions that won't improve will actually save money. Setting up structures for genuine co-production of design and provision with disabled people, carers, care workers and local communities need not be hugely costly but will start laying the bedrock for change, as will encouraging innovative, local provision from user groups and co-operatives.

However, all this has to go hand in glove with challenging the myths that keep Social Care tied to Cinderella's hearth, mobilising the cross-parliamentary forces to help give the government a massive shove and building a broad based grassroots campaign for radical change. See

www.endsocialcaredisgrace.org.

References.

1. <https://centreforcure.ac.uk/updates/2023/05/valuing-carers/>
2. <https://www.oxfam.org.uk/media/press-releases/wealth-of-five-richest-men-doubles-since-2020-as-wealth-of-five-billion-people-falls/>
3. <https://commonslibrary.parliament.uk/research-briefings/cbp-9602/>
4. <https://www.carersuk.org/reports/state-of-caring-2022-report/>
5. <https://www.nuffieldtrust.org.uk/news-item/shifting-the-narrative-building-public-support-for-social-care-reform>

Gilda Peterson
Health & Social Care
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DEVELOPMENTS WITH GP PRACTICES

GPs used to have a reassuringly familiar and accessible way of working. We were used to phoning for appointments with our GPs and getting them without explaining why we needed them. We tended to see the same GP who got to know us, and developed ways of working with us as individuals. Then the waits for non-urgent appointments got longer. Then came Covid and access to GPs got very difficult, and did not improve following the pandemic. They started doing telephone or on-line video appointments which can be good under some circumstances, but which have their limitations. But that was just the start of the changes to how they operate. Why have they changed?

Demand for appointments has increased by 9% in England with similar increases in the other Three Nations of the UK since the pandemic, but there are shortages of GPs in all Four Nations. There has been a drop in GP numbers every year since 2015, so that each GP now has responsibility for an average of 366 more patients than in 2015, with needs tending to increase as people are living longer. To add to this pressure, about 4% to 5% of people do not turn up for their appointments.

Practices are independently owned and run mostly not-for-profit, but some are now owned by companies which take profits from them. NHS England has a national GP contract which is managed in each area by organisations called Integrated Care Systems. There have been attempts to develop new ways of working, and these are reflected in this contract. It includes the Additional Roles Reimbursement Scheme, under which practices receive a significant amount of money towards the cost of employing different types of healthcare professionals, e.g. Physician Associates who have less academic and on-the-job training than GPs and who take on some parts of their role, Physiotherapists, Pharmacists, Paramedics, Dieticians, Mental Health Practitioners, Health and Wellbeing Coaches and Social Prescribing Workers.

Practices are also bringing in Care Navigation systems, with receptionists and other staff trained to triage people who ask for appointments, i.e. ask them what is wrong, decide who they should see, and arrange an appointment. Under the new contract, practices can no longer tell you to call back, but they have to make appropriate arrangements the first time you phone, which is a very welcome change.

There are similar systems in the other Three Nations of the UK, with Wales and Scotland also

bringing in Care Navigation systems and additional healthcare roles in general practice. However, this does not seem to be the case in Northern Ireland where services are under extreme pressure but the way they operate does not appear to have changed.

There are no doubt benefits to having a range of different practitioners in practices. For example, it has long been argued that there should be better access to physiotherapy, and having Pharmacists there should help reduce problems with prescribing which have been widespread. As Mental Health services are under-resourced while the need for them has been increasing, having Mental Health Practitioners in practices may well be a step in the right direction albeit no substitute for fully funded services.

However, there are concerns about this such as the use of the lesser qualified and lower paid Physician Associates to take on some of the doctors' work, and while there is money for practices to employ lower paid healthcare staff in these different roles, there is insufficient money in many practices to employ all of the GPs they need. There are reports of GPs losing their jobs because of this, and of many more qualified doctors applying for GP training schemes than places available. This down-skilling looks like a system for reducing the costs of general practice, rather than developments for the benefit of patients.

With this new system of people with a particular condition for example back pain being booked in with a Physiotherapist rather than first being assessed by a GP, there is a risk that it might not be due to an issue with posture or joint problems but something which needs a different kind of treatment, and the cause of the back pain could be missed. A better system would be for an initial assessment by a GP followed by treatment by the relevant practitioner according to need.

Good practice by doctors particularly with more complex conditions involves understanding what the patient wants which may involve some discussion to help them work it out, which could be 'I want to be free from pain', or '...to be able to go out' or '...continue working' or '...to continue living independently' and so on, and then looking at how they can support those choices. I have heard examples of good practice where the focus is on patients' well-being. Some people have described sympathetic and supportive practice by doctors. This requires a doctor providing care over successive appointments and getting to know the patient. But we now tend to accept

appointments with different GPs rather than sticking with one who gets to know us, although everyone who is registered with a GP throughout the UK is entitled to have a named GP who is responsible for their care.

I go to the GP expecting to be able to discuss health issues, get information, and agree on any action that is to be taken. That is what used to happen but for me it no longer does, and I wonder how many other people have also experienced this change. There is a conflict between the NHS policy of Patient Choice and systems and requirements of GPs, so it seems that many now put pressure on patients to accept blanket treatments such as vaccinations and taking statins, e.g. with repeating texting to mobile phones and phone calls. I have read advice to practices to use SMS texts to patients' mobile phones to get compliance.

There are also Direct Enhanced Services for which practices receive additional funding which involve for example focussing on cardio-vascular health and avoidance of strokes and heart attacks. In my case GPs have refused to focus on my health problems which did not fall within that list. So is the funding system causing difficulties for patients in getting medical care for many conditions which do not attract additional funding?

It is understood that ageism which can result in older people getting poorer access to treatments exists within the NHS including in general practice. I and others have experienced ageist behaviour by GPs. I was told by a GP that my health problems were due to ageing, and nothing was done to identify the problem. My son worked out what it was – a life-threatening condition, and this was confirmed and treated by a different GP in another practice. Others have told me that they too have gone to their GPs with health problems for them to be dismissed as 'due to ageing'.

While it has been coming to light that a lot of women have experienced being told that their health problems were not real to have it confirmed much later that they were, this problem with being told that health problems are due to ageing is also being experienced by men. So work is needed by the NHS to develop an approach to working with patients by each type of practitioner and to implement this through training and guidance.

As well as the Care Navigation system, and bringing additional roles into practices, the NHS is also looking to the rapidly developing computer-based systems to help manage demand. In fact, GPs are now required to have a

range of on-line systems in place which include remote consultations via on-line video platforms, which suits some people but not others, on-line systems for booking appointments and for contact between patients and their practices, for people to look at their records.

There are systems for remote monitoring of people with long term conditions who are at home which are being used by some hospital services, and by some GP practices. Patients need to be able to or learn to use the equipment. Of course not everyone is happy to use computers or for various reasons able to use them, so the hope is that people's choices about this are being respected. We are still all entitled to go and read our records at the GP practice.

So what is likely to happen now, and are there more changes in the pipeline? The new Labour Government's manifesto commitments include: training thousands more GPs; face-to-face appointments for everyone who wants one; a better appointment booking system; bringing back continuity of care via the old 'family doctor' system; encouraging access to other treatments to take pressure off GPs (which may now sound familiar); and developing more self-referral routes, although I have seen nothing on any plans to tackle age discrimination. The changes are likely to continue, but we can at least hope for improvements.

Christine Sanders
Health & Social Care WP

ONE MILLION SCANS

Scientists are hoping that access to more than 1.6 million brain scans collected from patients across Scotland could help predict a person's risk of dementia.

A team of 20 researchers from the universities of Edinburgh and Dundee have been given permission by NHS Scotland to view a huge number of anonymous scans gathered from across the population of Scotland over the past 10 years.

AI (Artificial Intelligence) will be used to analyse the scans to see if there are patterns or signs of dementia.

Dementia is characterised by the build-up of different types of protein in the brain which damages tissues and leads to cognitive decline.

By studying such a large number of scans it is hoped that tools can be developed that will help radiologists with early detection. Early diagnosis of dementia is key to making changes and accessing treatments that work in the early stages

Dementia is the biggest social care crisis in the UK. 1.4 million are expected to be living with dementia by 2040; and 1 in 3 people born today will be diagnosed with dementia in their lifetime.

On 22 August, the Medicines and Healthcare Products Regulatory Agency (MHRA) approved 'lecanemab' for some people in the early stages of dementia. However, the National Institute for Health and Care Excellence (NICE) does not recommend its use for any NHS patients.

This will come as a huge blow to those who are living with dementia, their family, friends and healthcare professionals. Living with dementia touches every part of life and the lives of those around you. It is life-changing for everyone.

Whilst research continues, the crisis in care for those living with dementia goes on. The NPC policy of a National Care Service free at the point of use is more needed than ever now. It advocates parity of illness (i.e. treating physical and mental health equally); mandatory training for care workers and managers; lifting the pay of care workers to align with a grade on the NHS scale; ensuring family carers have rights and income to compensate them for leaving work and caring for a family member every day, all day.

With the new government kicking the care cap down the road, more older people will be forced to sell their homes to pay for care. Serious investment is needed in both the NHS and care sectors to give patients much needed and timely treatment.

Our NHS has been the envy of the world and can be again, but just as so-called tough measures like restricting the winter fuel allowance are deemed appropriate by the government, so must they take even tougher decisions to find funding to invest in the health of the nation.

INTEGRATED CARE BOARDS

NHS England (NHSE) who oversee Integrated Care Boards (ICBs) has been seeking to squeeze down the estimated £3bn deficit for 2024/25. The underlying problem is that this financial year real terms funding for England's NHS, after inflation, is increasing – but by just half of one percent (i.e. rising just £5,000 for every £1 million). This is well short of the 3-4 percent real terms annual increase needed to keep pace with the needs of an ageing population, rising drug costs, new technology and the need to maintain and renew crumbling buildings and equipment.

The public is still not being told what the impact of this will be. For ICBs the problem was compounded by NHS England's 3-month delay in sending out guidance on planning, now being made worse by refusing to accept many of the revised plans as 'unaffordable'

Worse still, NHSE, like Robin Hood in reverse, are offering cash incentives for the ICBs that are already best placed to deliver a balanced budget, coupled with penalties for those that are struggling to address hefty deficits. While there have been no public statements from NHSE on the scale of the deficits, the Health Service Journal has estimated the £3 billion figure having seen financial returns from two thirds of England's 42 ICBs, that are far worse than they were this time last year. Further plans for "savings" seem likely to lead to cuts in planned investment, raids on capital (that should be spent on repairs, replacing equipment and expanding facilities) and job losses.

So far there is insufficient information to judge what the impact could be on the availability and quality of patient care. Any system that fails to deliver on its financial plans will necessarily be subject to immediate nationally imposed spending restrictions. Several ICBs, and their local trusts have already had to drop or reverse plans to grow the NHS workforce in order to contain spending on agency and locum staff.

However, ICBs are taking key decisions in private session, behind closed doors. As the financial situation worsens we can expect the shroud of secrecy to be used extensively. Local communities and health staff can't fight back against threats that they are unaware of.

A new government must open up genuine accountability. Private sessions of ICB and trust boards should be limited to discussing genuinely confidential matters such as contracts, conduct and performance of individuals. All financial plans and their implications should be published and discussed in public.

Have you been able to be part of budget discussions?

Source: Health Campaigns Together