Lenny Shallcross â?? Executive Director, World Dementia Council

> This is a turning point. Treatments give people hope, and hope changes behaviorâ?¦ Now the question is: can policy, infrastructure, and public understanding keep pace?

30.06.2025

Tags:

Global, Dementia, Alzheimerâ??s, Association, Policy

Lenny Shallcross, Executive Director of the World Dementia Council, reflects on the evolving global response to Alzheimerâ??s disease and dementia; from the slow but significant rollout of disease-modifying treatments to the critical importance of knowledge-sharing between health systems. Shallcross discusses why this moment, though complex and incremental, represents a turning point in how patients, policymakers, and the public engage with dementia care, and why the greatest source of optimism lies in the growing demand for action from patients and families themselves.

How did the World Dementia Council come to be and what role does the organisation play in shaping a coordinated global response to dementia?

The World Dementia Council was set up by the UK government following a dementia summit held in London, led by then Prime Minister David Cameron. It was formally established as an independent body a couple of years later.

Its main aim is to connect global leaders in dementia under four priority areas that were set out at the original G8 summit: research into treatments, care, risk reduction, and awareness. At the same time, the council works to develop a global perspective on how to accelerate progress in each of these areas.

What are some of the Councilâ??s specific strategic goals, and how would you assess progress across key areas such as awareness, risk reduction, treatment, and care in recent years?

Like any think tank, the World Dementia Council responds to developments in the field. Right now, one of our key priorities is helping countries prepare for the impact that new treatments will have. These treatments, which include the introduction of biomarkers into clinical practice, are expected to roll out in many high-income countries over the next five to ten years. They will bring a whole range of new challenges that touch all the priority areas originally set out in the G8 communiquÃ©: treatment, care, awareness, and risk reduction.

To begin with, health systems will need to integrate both biomarkers and treatments. But beyond that, treatments will completely change how we think about awareness. In an era without treatments, awareness campaigns have generally focused on how the public should think about dementia by reducing stigma, promoting understanding, and so on. In an era where treatments are available, however, awareness becomes much more targeted. We want to encourage individuals who may be affected by the disease to take specific actions, such as presenting early for diagnosis. This is a very different kind of awareness focused on action. Some challenges, like stigma, will still remain, as we have seen in areas like HIV, but the conversation around treatment options and care has changed.

The same goes for prevention and risk reduction. Dementia is often cited as one of the most feared diseases among older people, but that fear has not always led to preventative behaviour. When there are no treatments, people often avoid the topic altogether. But the presence of treatments makes prevention more meaningful. It gives people a reason to engage, just as we have seen with campaigns around heart health or cancer prevention. When the first conversation between a person and their clinician includes treatment options, it transforms the care journey and shifts the entire dynamic.

All in all, across awareness, care, risk reduction, and research, we are going to see major changes over the next decade. A big focus of the Council is to help leaders around the world think through what those changes mean, and how to use this moment to drive real progress at a national level.

There remains a widespread perception among many healthcare professionals that Alzheimerâ??s is simply a natural part of aging. How much of a barrier does this mindset pose?

When we talk about awareness among healthcare professionals within the system, it is important to recognise that they typically undergo formal training and continuing professional development to keep up with medical knowledge. But if you look back to when I was a medical student in 1995, dementia was barely part of our training. The world was a completely different place then, and much of what we now know simply was not part of the curriculum.

That said, healthcare professionals who trained 10 or 20 years ago are constantly receiving new information and training updates. It takes time to shift ingrained knowledge and practice, but one of the most powerful drivers of change within a health system is patient demand. When patients start actively seeking diagnosis or access to treatments, that puts pressure on the system to respond. Clinicians begin seeing more people come through their doors asking questions they cannot yet fully answer, and that forces action whether it is someone in a GP practice needing to do a dementia training module, or a hospital rethinking its diagnostic and care pathways.

In that sense, I think we sometimes risk putting the cart before the horse. Without strong patient demand, expecting health systems to invest significant time and money in retraining staff when there are already so many competing priorities can be unrealistic. What will really drive systemic change is the emergence of viable treatment options. We are now entering a period where that is starting to happen. In the next five to ten years, we will see a broader range of treatments for Alzheimerâ??s, possibly for other forms of dementia as well, along with the widespread introduction of blood-based biomarkers that can support accurate diagnosis and even prognosis.

When treatments and tools exist, and patients are asking for them, that is the moment when the system begins to shift. As people working outside the system who want to see better outcomes for patients, our job is to think about how we support that transition. How do we help systems move from an era where there were no treatments, and little structural pressure to act, to one where effective intervention exists? We need professionals who are trained in dementia, who understand the patient experience, and who can support people through their care journey.

Rather than calling for a radical overhaul of professional education first, time, alongside the arrival of treatments, will address a lot of that change organically.

How do you view the relationship between public awareness and the demand for care pathways as it relates specifically to early detection and improved diagnostic practices.

The real shift that is going to happen in this field is tied to the fact that dementia and Alzheimerâ??s have a very long pre-symptomatic stage. When we talk about the â??early stages,â?• we are usually referring to the onset of symptoms. But there is an entire phase before that when something is already changing in the brain, but the person has not noticed it yet. You might be at home, and you or your partner sense that something feels different, but there was already a period before that when a simple blood test could have indicated that something was happening, even before any symptoms appeared.

We are now reaching a point where those blood-based biomarkers exist. While we do not yet have treatments that can fully stop or reverse progression, we are starting to see real advances in early detection. What will be fascinating in the coming years is how people respond to that. Will they want to find out their amyloid or tau status, even if they are not yet symptomatic, just as part of living a healthier life?

Ultimately, how individuals behave will be the biggest driver of change in this field. As we reduce the fear surrounding dementia by increasing the hope of meaningful pharmacological interventions, we will unlock a different kind of public engagement. People will feel more empowered to come forward earlier, and that shift in behaviour will fuel better diagnosis rates, earlier detection, and, in turn, greater demand for appropriate treatment and care pathways.

With the emergence of new therapies, do you believe there is a need for reform in how healthcare systems assess and provide access to these drugs, particularly with regard to cost, safety evaluation, and equitable rollout?

The important thing that sometimes gets overlooked is that we now know Alzheimerâ??s is treatable. There will always be debate around clinical endpoints and long-term outcomes, but the fact remains that we have shown removing amyloid slows cognitive decline. That is hugely significant, and it validates the path the field has been on for the past 30 years. If you look at other disease areas, this is the inflection point moving from an era of no treatments to one where patients have solutions, progress begins to accelerate. The long, slow accumulation of knowledge, and disappointments, when trials fell short has ended, and we are now in a new paradigm.

Still, some of the debates we have seen around these first treatments have been surprising. Having been a political advisor to Mark MacGregor in the UK, part of my job was managing health priorities to balance all the competing demands from across the healthcare space. There are leagues of advocacy and interest groups, each with compelling visions for how the system should respond to their disease area. That balancing act is the job of elected politicians. It is their responsibility to weigh priorities and decide what gets funded.

What has struck me in the Alzheimerâ??s space is how many stakeholders within the field have taken on that policymaking role. Taking it upon themselves to debate affordability, access, and whether or not health systems should pay for treatments. Those decisions should sit with politicians and payers. Our job as actors outside of the political system, whether we are researchers, advocates, or healthcare professionals, is to push the system to make these treatments available and accessible.

Of course, healthcare systems will push back. During my time in government, I remember vividly that we could not fund certain expensive cancer drugs. It was devastating, but that is the political reality. The job of the field is not to solve the economics, it is to make the case for patients.

Here is where I think we have also fallen into a bit of paternalism. In many of the debates around these new therapies, there has been a sense that policy makers and payers should decide what level of risk a patient is willing to take. We hear questions like: â??Would someone really want to go through this treatment at that stage of life?â?• or â??Do they understand the risks of ARIA?â?• These are valid questions, but they are not ours to answer. They are for the patient.

In oncology, you rarely hear this kind of debate within the field. Patients are trusted to weigh the risks and benefits for themselves. The dementia space is still catching up to that mindset, but it will come.

Ultimately, reform is needed. Systems will have to evolve in how they evaluate, pay for, and roll out these therapies equitably. But the key principle we must uphold is that someone pays, someone takes the risk. It is not the disease fieldâ??s job to make either of those decisions for patients. Our role is to ensure the science continues to move forward, and that patients have the opportunity to access the care they choose.

Are there particular health systems that stand out as leaders in building comprehensive Alzheimerâ??s and dementia care pathways that could serve as examples for international best practice?

When it comes to the rollout of new treatments, progress has undoubtedly been slow. We saw the controversy surrounding the approval of aducanumab, followed by an unsuccessful market launch. While the rollout of lecanemab and donanemab in the US and some other counties is underway, it has only been gradually building momentum rather than taking off quickly.

You can look at this in two ways. One is to say it has all been deeply disappointing that health systems are not moving fast enough. But I tend to lean more toward the second perspective that we are undertaking something enormously complex. This is not like oncology, where a new treatment might be introduced for a small, well-defined patient group already within an existing care pathway. In Alzheimerâ??s, we are talking about introducing treatments for a potentially much larger population, many of whom do not have a formal diagnosis, are not currently in the healthcare system, and for whom no clinical pathway yet exists. So of course, this is going to take time.

Right now, Japan and the US are furthest along, with patients receiving treatment and regulatory frameworks in place. However, we are still not talking about large numbers of people globally. Eventually that will change, but only if countries and systems continue to share what they are learning.

What really matters in this period is the exchange of experience. Health systems introducing these treatments need to be in continuous dialogue. At the World Dementia Council, for example, we have brought together several organizations, including the Alzheimerâ??s Association in the US, to share lessons from early implementation. This kind of cross-country collaboration is essential as more European and non-European countries begin to follow suit.

At the same time, we will see innovation not just in treatments themselves, but in how they are delivered. Future therapies may require less infrastructure or be easier to administer, which will accelerate adoption. But even now, there is valuable learning happening across systems.

So rather than pointing to one country and using it as a model to be copied, I would say that each health system rolling out treatment offers important insights. There is no single best practice yet, but rather there are lessons everywhere. The key is making sure we harness those lessons so that the next wave of implementation builds on real-world experience, and ultimately creates better systems for patients everywhere.

Looking ahead, what areas in the dementia space give you the most cause for optimism? Conversely, what are the aspects that you believe continue to present the greatest challenges or concerns?

The single biggest reason for optimism is seeing how patients and their families are beginning to change their behavior. In healthcare, we spend a lot of time talking about the benefits of timely diagnosis, and there are clear advantages for individuals and their families. It gives them time to plan, to make decisions, to take control. But despite these benefits, we know that many people still do not receive a diagnosis.

While some of that is due to system-level barriers, a significant part of the issue lies in how people relate to the disease itself. If you speak to people in the early stages of dementia and their caregivers, you often hear the same story: it started slowly, changes were noticed, but no one wanted to talk about it. For years, families live in denial because the truth is too hard to face. No one wants to hear that they have an untreatable disease that will eventually take their life.

What gives me hope is that having treatment options changes that dynamic. When you have even the first signs of effective treatment, it gives people hope to hold on to. We saw this with HIV/AIDS. Before effective treatments existed, it was common for people to only receive a diagnosis once they were gravely ill because no one wanted to face a future with no options. But once treatments became available, people engaged with the health system earlier. They got tested. They advocated. They took action. The presence of treatment shifted the incentive.

We are not yet at that stage in Alzheimerâ??s. The treatments we have today are not transformative in the way antiretrovirals were for HIV, but they are a beginning. They are starting to shift public awareness and patient behavior. Over time, as more treatment options become available, will become more proactive. Families will push health systems to respond. Individuals will seek testing, demand services, and expect care. That push from patients and the public will do more to drive systemic change than decades of advocacy and research alone. At a macro level, we are entering a new phase, even if it does not always feel like it to those in healthcare.

Of course, this transition will take time. We are moving from a world where there were no options to one where people will increasingly expect solutions. The challenge for everyone in the field is to figure out how to accelerate that transition. The science is advancing. Now the question is: can policy, infrastructure, and public understanding keep pace? That is the challenge, but it is also where the greatest opportunity lies.

See more interviews