



DementiaUK

Helping families face dementia



Impact report
2022-23

We are Dementia UK –

the specialist dementia nursing charity.

All too often, families affected by dementia struggle to know where to turn and are left feeling exhausted, overwhelmed and alone. But thanks to the generosity of supporters like you, our specialist dementia nurses – known as Admiral Nurses – offered a lifeline to more people than ever in 2022-23.

Admiral Nurses are experts in dementia, helping families through the fear and confusion of the condition. And because of you, we now have 437 nurses across the UK. Whether they are working on our Helpline, in virtual clinics or in the community, they help families have the best life possible, for as long as possible.

We need to keep increasing the number of Admiral Nurses so they can reach everyone who needs us – and we can only do this with your support. Thank you so much for helping us continue our life-changing work.

“We need to grow the number of Admiral Nurses to 1,000 by 2030 so they can offer a lifeline to everyone who needs it. Together, we can make this ambitious vision a reality. Thank you for helping ensure no one has to face dementia alone.”

Dr Hilda Hayo
Chief Admiral Nurse and
Chief Executive Officer



Dementia: a huge and growing crisis

Dementia is an umbrella term for a range of progressive conditions that affect the brain. Around 944,000 people in the UK are living with dementia.

There are more than 200 types of dementia. Common symptoms of dementia include:

- memory loss
- confusion
- problems with understanding
- speech and language difficulties
- problems with decision-making
- changes in behaviour

Dementia is the leading cause of death in the UK.



Someone in the UK develops dementia

every three minutes.



One in two

people in the UK will be affected by dementia during their lifetime.



More than half

of UK adults know someone who has been diagnosed with dementia.



70,800 people in the UK live with young onset dementia – where symptoms develop before the age of 65.





Our vision:

Specialist and compassionate dementia support for all families that need it.

We believe that every family affected by dementia should have access to the life-changing support of our Admiral Nurses. As experienced, compassionate dementia specialists, they offer the practical solutions and emotional support to help families who often have nowhere else to turn.

Together, we can ensure no one has to face dementia alone.

Our values

We listen, learn and collaborate

Listening to and working with families living with dementia; clinicians; our colleagues; and our supporters and fundraisers underpins everything we do.

We are empowering, supportive and respectful

We empower families to know what they are entitled to and advocate for them so that they receive it.

We act with integrity, transparency and accountability

Every penny we spend comes directly from our generous supporters – and we are committed to full transparency regarding how we spend this money.

We encourage creativity and innovation

We apply innovation and creativity to everything we do.

Maq's story

I was diagnosed with young onset frontotemporal dementia at the age of 54 when I went into hospital for heart surgery and had a brain scan. I'd had no symptoms, so it was difficult to accept the news.

I was working as an accountant at the time, and I thought, "If I've got this condition and there's no cure, there's no way I can carry on working" – so I stopped. It was a big adjustment and made me less financially independent. On reflection, I think I could have stayed at work for longer.

I didn't tell my family about my diagnosis for over a year. My wife had passed away, and my children were still at school. I wanted to protect them. In the end, I asked a professional to explain it to them. I couldn't bring myself to say it.

Dementia changes my mood and perception and affects me physically and psychologically; it isn't all about memory loss. Communication can be difficult and my mind wanders. It

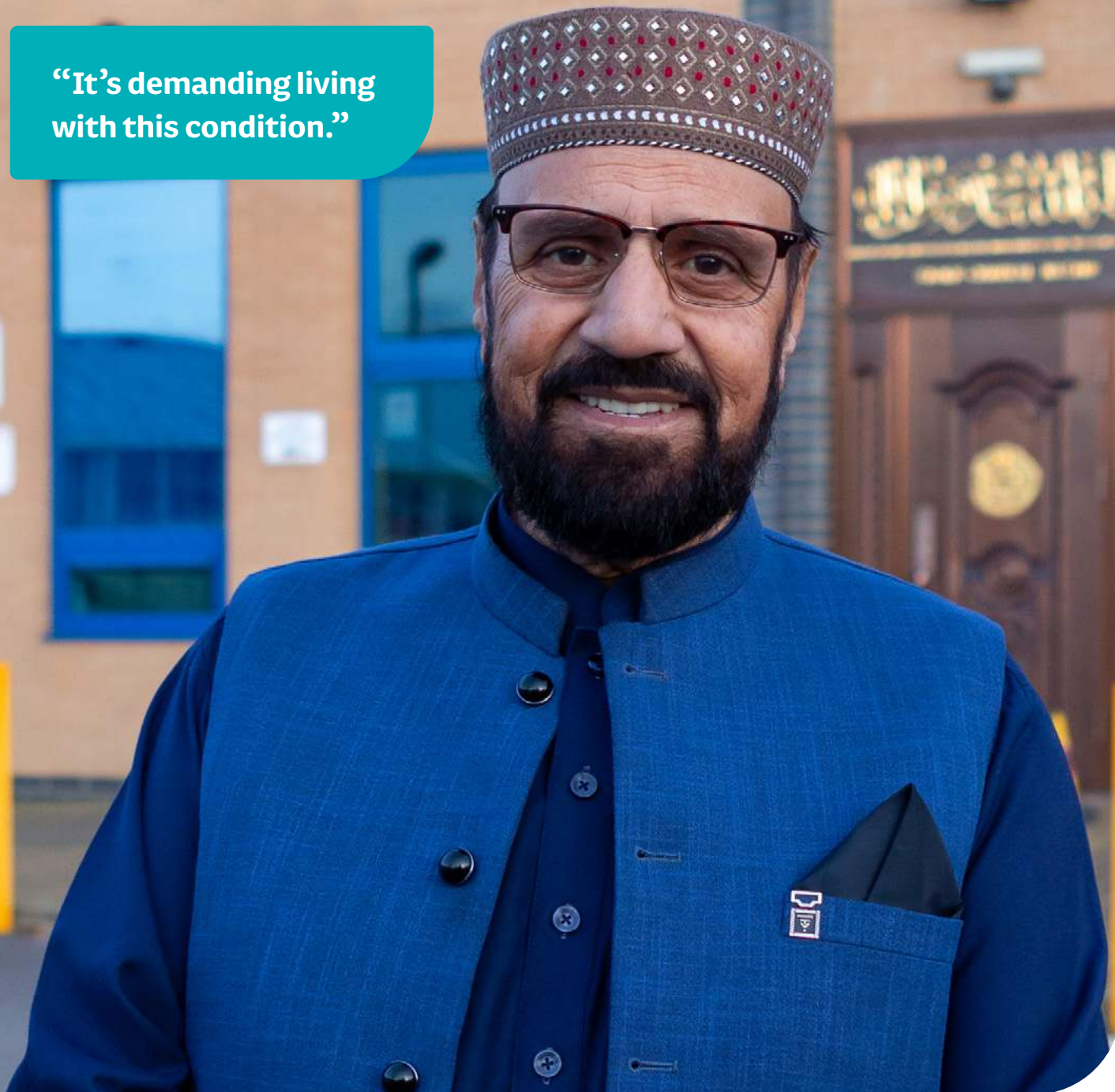
changes from day to day, hour to hour, minute to minute.

In the South Asian community, dementia is a taboo subject. People feel ashamed to seek help and don't know where to get support. I get asked to talk at many different events about my experience of dementia, and I am also a member of Dementia UK's Lived Experience Advisory Panel (LEAP), advising on many elements of the charity's work. Social connection is so important, and whenever somebody asks me for help, I'm there.

When someone says they have benefitted from what I have said it gives me a boost. I don't know how many years I have left, but I want to make a difference while I can.

Improving our services for all communities is a priority for Dementia UK, and with your help, we can ensure more people from minority ethnic backgrounds get the bespoke support they need.

**“It’s demanding living
with this condition.”**



How your support is changing lives

Dementia UK receives no Government funding, so we can only do what we do because of our supporters' generosity.

Here, four people affected by dementia share the amazing difference you have made to their lives.



Paul called the Helpline for advice on supporting his father, who lives with dementia.

“Speaking to Mark, the Admiral Nurse, felt like a weight had lifted off my shoulders. He reassured me that I was doing everything right and that I was doing a good job. I find it difficult to open up about my feelings which I think is common amongst men, but it’s okay to need help. Making that initial call to the Helpline was scary but I now know I have someone to fall back on and Dementia UK is there to catch me when I fall.”



Aqib attended a virtual clinic appointment with his sister Shahbanu when they needed support with caring for their mother.

“My sister and I disagreed hugely about what was happening to Mum. I would get annoyed that she was burying her head in the sand. We realised we needed some expert support and advice to help us get on the same page and to support Mum as best we could. So we took the plunge and contacted the virtual clinics service. The call was so valuable and informative. Where we have had competing viewpoints, having an expert to clarify and explain has been so helpful.”



Jude, who lives with young onset dementia, receives support from the Young Dementia Oxfordshire service, which is provided by Dementia UK.

“When I first got diagnosed with young onset Alzheimer’s disease, it was devastating. I didn’t know who I was anymore. I couldn’t tell the difference between the symptoms of dementia and grief. My wife Becky and I had to tell our two daughters, which was very difficult. It was really important for me to talk to a dementia specialist about the diagnosis as I found it difficult to talk to my friends and family about it. I felt more relaxed knowing that I had someone to talk to who understood what I was going through.”



Amy, whose mum was diagnosed with frontotemporal dementia aged just 47, turned to Dementia UK’s website for information and advice.

“Mum became like a child and our roles totally reversed. My sister and I washed and dressed her every day. It was really tough. I had just started a new job and I was always asking for time off to care for Mum. It was overwhelming at the time. Every day was a new challenge, but Dementia UK’s website and emails were a great source of support and gave us a lot of information on frontotemporal dementia and how to look after ourselves as carers.”

Our year in numbers

In 2022-23, your generosity meant that more people received the dementia support they desperately needed – in person, in virtual clinics, on our Helpline and through our information resources. Here's what you made possible.



There are
437
Admiral Nurses
changing lives
throughout the UK

Our Helpline
responded to

34,273

calls and emails



We published **13**
new information
leaflets, including:

- Keeping safe as a dementia carer
- Personal hygiene
- Medication and dementia
- Menopause and dementia
- Getting a diagnosis of young onset dementia



1,900

professionals developed their skills by watching our young onset dementia webinars



We launched

25

new Admiral Nurse services across the UK



We extended our virtual clinic's opening hours from four to

five
days a week

Around

3,200

families received expert support in virtual clinics



Our social media growth in 2022-23

Our social media channels help us raise awareness of dementia and our Admiral Nurses. You can help by following us and liking and sharing our posts.



LinkedIn
31%



Instagram
24%



Facebook
22%



Twitter
2%



Closer to home clinics: visiting local communities

In early 2023, we launched our Closer to Home dementia clinics in association with our partner, Leeds Building Society.

These clinics are visiting Leeds Building Society branches across the country, offering families free 45-minute appointments with an Admiral Nurse in their local community.

Admiral Nurse Joe Costello was part of the Closer to Home Team. He says:

“Closer to Home clinics are a fantastic way to deliver dementia support. Running the clinics in Leeds Building Society branches means they are easy for people to access in their local communities, and the relaxed setting can remove some of the stress for carers who are anxious in clinical settings like GP practices and hospitals.

“I have spoken to carers about everything from applying for benefits to supporting their loved one to stay at home for as long as possible. Families have told us how helpful it is to talk to a professional who understands what they are going through and has the time to listen to their needs and give them the appropriate advice and support.”

So far, we have offered appointments in many locations, from Aberdeen to Watford, and Cardiff to Belfast, and we will be visiting more branches so we can offer a lifeline to people in their local communities until March 2024. We are so grateful to all of the Leeds Building Society colleagues who have helped us bring dementia support closer to those who need it.

To find out more about Closer to Home dementia clinics, please visit dementiauk.org/closer-to-home



“I was worried about wasting someone’s time [but] the lady I spoke to was immediately welcoming and understanding and very warm. She really understood our worry. She offered practical advice and next steps but also offered further support for us if needed.”

– Family carer

How you helped families in 2022-23



Our generous supporters raised an amazing
£19.4m throughout the year –
£2.3m more than in 2021-22



62,143 supporters

took part in one of our virtual challenges, knitting, walking, jogging, cycling or dog walking for families facing dementia



Our London Marathon, Great North Run and London Landmarks Half Marathon runners collectively covered

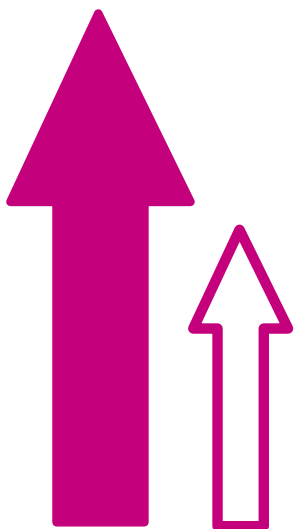
7,271 miles

– the equivalent of running to New York and back!

The number of supporters making a regular gift grew by

30%

– all helping us recruit more specialist dementia nurses



The number of people setting up tribute funds in memory of a loved one soared by

146%



1,025

brave supporters took on a challenge event for Dementia UK – including marathons, 100km treks and skydives

56%

more people pledged to leave a gift in their Will than in the previous year

400 festive supporters

joined us for our Christmas carol concert, raising over **£50,000**



“I walked 125 miles in under three days, from Molineux (home of Wolves FC) to Chelsea’s football ground. It was the craziest challenge I’ve ever done – but seeing the donations increase gave me more and more energy. I raised an incredible £27,500 – the emotion at the end is a feeling I will never ever forget.”

– Manny, Dementia UK Volunteer Ambassador and fundraiser

Penny's story

You helped thousands of people like Penny receive support from our Helpline in 2022-23. Thank you so much.

“My mum was always a happy, chatty and sociable person. She was a talented musician and a big part of the community – she helped organise the local music festival and was the musical director for many local productions.

I first noticed that something wasn't right when Mum started struggling to process information. She repeated things a lot and couldn't manage her diary. This went on for five years before she was diagnosed with mixed dementia in 2016.

Becoming Mum's carer was a big adjustment. As her dementia progressed, she started asking where everyone was, emptying cupboards looking for food, and getting upset and confused. She would call me constantly. It typically happened in the late afternoon or evening, and I was always going back and forth to her house.

I called the Admiral Nurse Dementia Helpline for advice, and the nurse explained that Mum was experiencing 'sundowning' – a state of intense confusion and anxiety that happens around dusk. I was given advice on anticipating Mum's sundowning and trying to occupy her with other things.

Over time, it became more difficult to keep Mum safe. When she was found on the street in her nightie, I knew it was time for her to go into a care home, but I really struggled with the decision. Again, I phoned the Helpline – the Admiral Nurse reassured me that it was the right thing to do and helped me to plan.

Life doesn't have to stop after a dementia diagnosis, and I can still spend time with Mum doing things we both enjoy. I visit her every week and do her hair and makeup. She still loves music and playing the piano.

Living with dementia is a rollercoaster, but the Helpline Admiral Nurses have been a great emotional support. They always take time to understand my circumstances and give solutions, help and advice. I couldn't have coped without them.”

“Being Mum’s carer as well as her daughter was a big adjustment.”



Supporting Chinese and South-East Asian communities

In August 2022, your support helped Dementia UK and the Chinese Welfare Trust launch a new clinic offering specialist dementia support to families from a Chinese or South-East Asian background across five London boroughs.

Clinic Admiral Nurse Emily Ka-Hei Lui says:

“Families of Chinese and South-East Asian heritage face many challenges in accessing dementia care and support. These include language barriers; cultural stigma surrounding dementia; conflicts within the family around care expectations; and a lack of dementia-specific, culturally appropriate services.

“Our new service aims to provide advice that fits families’ cultural needs; help them access local support; offer psychological and emotional support; and raise dementia awareness in the Chinese and South-East Asian community.

“Appointments are held in GP surgeries and Chinese community centres, alongside telephone and video calls. Although the service is based in London, we receive appointment requests from all over the country.

“The families I work with say it is helpful to speak to someone who understands their situation. Often, they do not want to let their friends and neighbours know about the dementia diagnosis because of the stigma, leaving them with no one to turn to. They also find it helpful to speak to me in their first language.

“Many carers cry in their appointments, stating that they are at a point of breakdown. This is rare in Chinese culture as people are in general very reluctant to seek help when they are struggling and do not like to disclose their personal feelings.”

In 2022-23, we also launched three other services for families from minority ethnic backgrounds within the city of Leicester and the Black Country. With your continued support, we plan to further expand these services so more people can access dementia support that meets their unique needs.



We can't do it without you!

By the time you finish reading this report, another 20 people in the UK will have developed dementia – and many of them will struggle to know where to turn.

But because of you, we're ensuring that more families every year receive the expert dementia support they need. Here are some of the amazing things you helped us achieve in 2022-23. Thank you so much!

We increased the number of nurses on our Helpline so more families in crisis have their call answered first time.

We created unique new clinics to support people with specific needs related to dementia, such as ex-professional footballers.

We created new Admiral Nurse services across the UK, providing essential dementia support in local communities.

We appointed new Admiral Nurses to support families with diverse needs – including those from minority ethnic communities, people with learning disabilities and those with young onset dementia.



We helped over 1,500 health and social care professionals develop their understanding of dementia through our online Summer School.

We grew the number of Volunteer Ambassadors to over 100, helping spread the word about Dementia UK in their communities.

We called on the Government to step up its dementia support for families, including by improving the complex application process for NHS continuing healthcare funding.

We launched our TikTok channel to raise awareness of our services amongst a new, younger audience.

‘I live with dementia’: our awareness campaign

In April 2022, we launched our national awareness campaign, ‘I live with dementia’, focusing on the key message, ‘If you love someone living with dementia, you’re living with it too’.

We wanted to show how dementia impacts family and friends – not just the person with the diagnosis – and increase awareness of our charity and the specialist support provided by Admiral Nurses.

The first phase of our campaign reached millions of people through Street Hub space generously provided by BT, bus shelter advertising, social media, and media and PR activity highlighting the challenges of dementia. It included a powerful film featuring

three family carers talking about their experiences, which won silver in the Smiley Charity Film Awards 2023.

We built on this success for phase two, centred on a new ‘Living with dementia’ guide featuring advice from Admiral Nurses, people living with dementia and their families.

We also produced a second series of films focusing on the experiences of carers, and made use of a bigger range of channels, such as connected TV (TV connected to the internet) and radio advertising.

The compelling stories we shared resulted in over 39,000 people signing up to receive the guide – more than doubling our expectations. This demonstrates that our message is spreading far and wide, and more people know how to access our support.

We are so grateful to all our supporters who watched and shared our videos and social media posts so that more people know about our Admiral Nurses and how they can help families when they need it most.

You can watch and share our 'I live with dementia' film at youtube.com/watch?v=OfU6zyDuViE

What's next?

We are now planning phase three of our awareness campaign, working with more families to reflect what it means to 'live with dementia too' and raise further awareness of our life-changing support.

“You’ve hit the nail on the head with this campaign because, yes, I’m living with dementia too. My whole family is as well.”

- Family carer



If you love someone living with dementia, you're living with it too.

Dementia affects everyone in the family. Our specialist nurses can help all of you live better with dementia.

dementiauk.org/together
#ILiveWithDementia



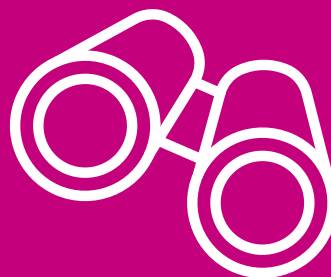
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Our plans for 2023-24

Over the coming year, we can work together to support more families through the fear and confusion of dementia than ever before. With your help, we will...



Respond to at least a combined 36,000 contacts on our Helpline and in virtual clinics, helping more families in urgent need of specialist support.



Create new Admiral Nurse clinics in areas without existing services so we can support more families in their local communities.



Increase the number of nurses on the Helpline so more callers get through on their first attempt.



Establish new Young Onset Dementia Admiral Nurse posts and ensure young onset dementia expertise is embedded within all our services to support more families with the unique challenges of the condition.



Campaign to ensure that dementia receives the attention it needs under the Government's new major conditions strategy and benefits families facing the daily challenges of dementia.



Redevelop and modernise our website so our must-read dementia information and advice is at people's fingertips whenever they need it.



Launch the third phase of our awareness campaign to spread the word about the lifeline our nurses offer.



Publish our first-ever research strategy in autumn 2023: we will focus on people with dementia who live alone; people with young onset and rarer dementias; and people living with multiple health conditions alongside dementia. This will grow the evidence base for Admiral Nursing and encourage more organisations – such as NHS hospitals – to launch a service.



Thank you!

We are so grateful to the thousands of supporters who helped us be there for families affected by dementia in 2022-23.

With one million people expected to be living with dementia by 2025, could you be part of our vision to ensure every family receives the support they need?

Donate

If you would like to make a single donation, set up a regular gift or donate in memory or celebration of a loved one, please visit:

dementiauk.org/donate

Pledge

A gift in your Will helps us support families facing dementia far into the future – and you can use one of our free Will-writing offers. For more information, please see:

dementiauk.org/leave-a-gift-in-your-will

Fundraise

We have a fundraising event to suit everyone – whether you're a kitchen crafter or a marathon runner – and every penny helps grow the number of Admiral Nurses so we can support more families. For inspiration, check out:

dementiauk.org/fundraise

Play our Weekly Lottery

Be in with a chance of winning cash prizes while supporting more families: sign up at:

lottery.dementiauk.org

Partner

Our corporate partners play a vital role in growing our services. Could your business support us? Find out how at:

dementiauk.org/corporate-partnerships

Volunteer


We always need enthusiastic supporters to become Volunteer Ambassadors or cheer on participants at our challenge events. If you could spare some time, head to:

dementiauk.org/volunteer

Campaign

Use your voice to help transform dementia care. Join our Campaigns Network at:

dementiauk.org/campaigns



“It's so much fun meeting the supporters and congratulating them. There is always such a buzz!”

- Lucy, cheer point volunteer



DementiaUK

Helping families face dementia

We want to ensure no one has to face dementia alone – and we can only do this because of our generous supporters. If you would like to help, please consider making a kind gift.

**To donate: call 0300 365 5500,
visit dementiauk.org/donate
or scan the QR code. Thank you.**



Dementia UK Helpline

Call **0800 888 6678**

Email **helpline@dementiauk.org**

Virtual clinics

Visit **dementiauk.org/book**

dementiauk.org • info@dementiauk.org

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