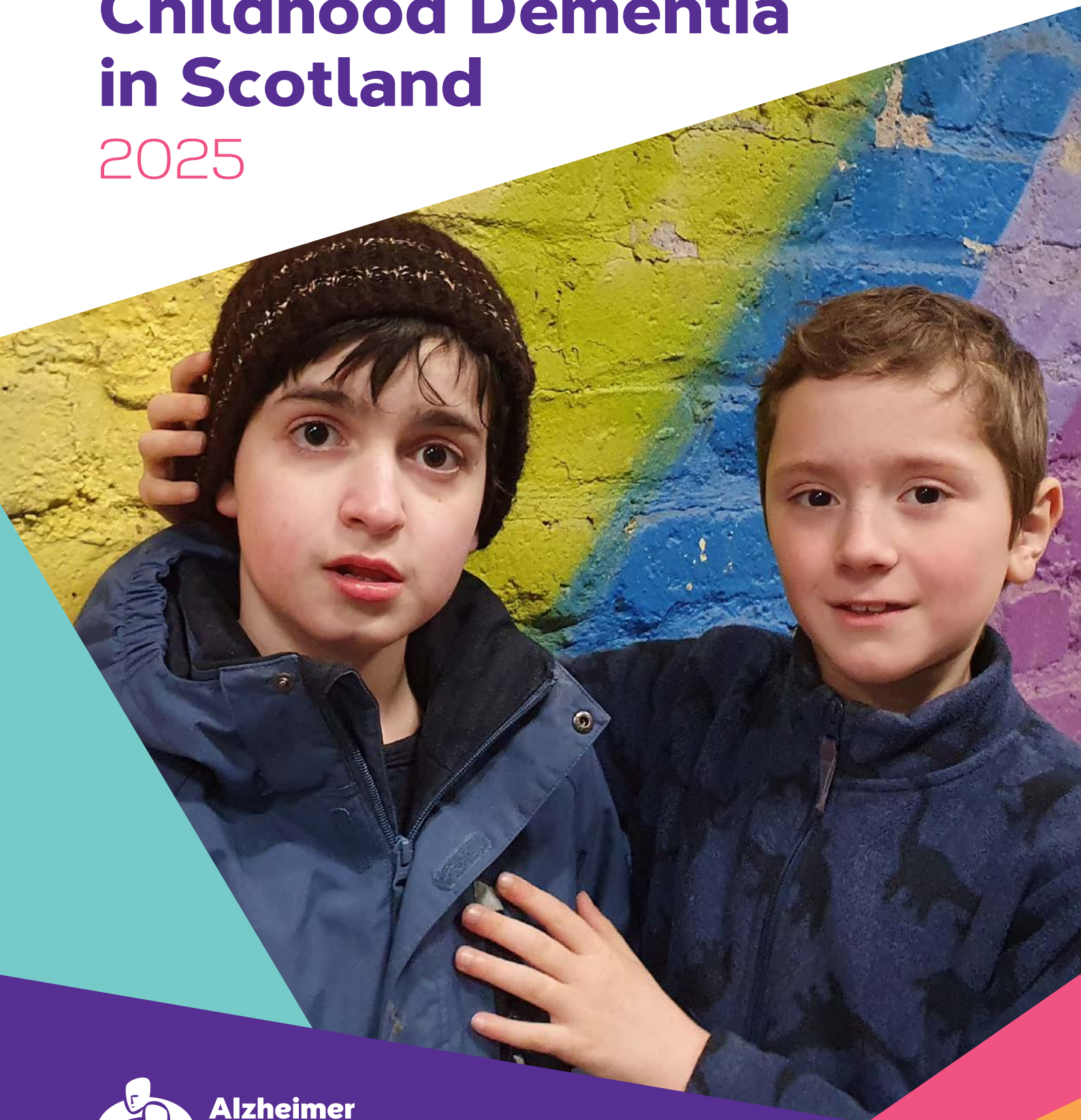
Childhood Dementia in Scotland

2025



Alzheimer Scotland
Action on Dementia

This report has been produced by Childhood Dementia Scotland: a collaborative network of family members, advocacy organisations, researchers, health, social care and education professionals from Scotland and across the UK, which is hosted by Alzheimer Scotland.

Childhood dementia

"There is a growing interest in understanding more about the rare genetic conditions, such as Sanfilippo Syndrome, that affect children and cause symptoms of dementia including memory loss, confusion, trouble concentrating and communicating. Personality and behavioural changes and emotional issues, such as fear and anxiety, also impact children who are affected. Through our engagement with the research community and affected families, we will consider with colleagues and partners how best to engage with and respond to emerging findings."

Dementia in Scotland: Everyone's Story. The Scottish Government, May 2023

"It should be recognised that children with degenerative disorders that lead to childhood dementia are a group of exceptional children, in exceptional circumstances, with exceptional needs, who require exceptional resources immediately, because later is too late; their condition may have worsened, or they may be dead by the time provision is made."

"Andrew; A Journey."

David and Sally Wray, from a paper based on a talk given at the Child Development and Disability Group of the Royal College of Paediatrics and Child Health, Annual Conference, Friday 15th March 2002

Andrew Wray, 11/07/1991 – 29/08/2000

Alzheimer Scotland Action on Dementia

childhood dementia INITIATIVE

BDFA Batten Disease Family Association Together we WILL make a difference

MPS Society transforming lives through support, research & awareness

np uk

DE MONTFORT UNIVERSITY LEICESTER

University of Glasgow

NHS Greater Glasgow and Clyde

THE UNIVERSITY of EDINBURGH

Acknowledgements

Childhood Dementia Scotland would like to thank the following key organisations and people for their invaluable contributions to this report:

Childhood Dementia Initiative

Childhood Dementia Scotland members:

Jim Pearson (Chair)	Deputy Chief Executive, Alzheimer Scotland
Jill Carson	Consultant - Public Policy, Alzheimer Scotland
Claire Fyvie	Family member
Darren Scott	Family member
Rachel Searle	Family member, PhD student researching Gene Therapy Vectors
Gail Hilton	Director of Programs, Childhood Dementia Initiative
Toni Mathieson	CEO, Niemann-Pick UK (NPUK)
Sarah Kenrick	Head of Support and Advocacy, Batten Disease Family Association CIO (BDFA)
Sophie Thomas	Senior Head of Patient Services & Clinical Liaisons, Society for Mucopolysaccharide Diseases (MPS Society)
Kate Sin	Conducting a Churchill Fellowship on Childhood Dementia & Education
Dr Chris Knifton	Associate Professor in Teaching & Learning (Neurocognitive and Neurodevelopment care) & Admiral Nurse at De Montfort University, Leicester
Professor Brian Bigger	Professor of Advanced Therapeutics (University of Edinburgh) Honorary Professor of Cell & Gene Therapy (University of Manchester)
Professor Simon Jones	Consultant Paediatrician for inherited metabolic diseases, Manchester University NHS Foundation Trust
Professor Sameer Zuberi	Consultant Paediatric Neurologist, Royal Hospital for Children, Glasgow
Dr Hassan Shakeel	Paediatric neurology registrar, Royal Hospital for Children, Glasgow
Professor Liam Dorris	Consultant Paediatric Neuropsychologist, Royal Hospital for Children, Glasgow
Caroline Russell	Communications and Campaigns Lead, Alzheimer Scotland
Suzie Beresford	Digital Learning & Development Coordinator, Alzheimer Scotland
Emma Gregg	Dementia Advisor, Alzheimer Scotland
Carleen Smith	Scottish Dementia Research Consortium Officer, Alzheimer Scotland
Hayley Lyons	Dementia Advisor, Alzheimer Scotland
Alana Ferguson	Dementia Advisor, Alzheimer Scotland
Teresa Doyle	Executive Assistant & Offices Manager, Alzheimer Scotland

Professor Tom Wishart	Professor of Molecular Anatomy, Nottingham Trent University & The Roslin Institute, University of Edinburgh
Paul Laird	Teacher, Braidburn Special School, Edinburgh
Hilary Munro	Chair, Allied Health Professions Federation Scotland

We would particularly like to thank the families of children with childhood dementia who have shared their insights and experiences.


Compost
Rich in nutrients for healthier plants
balanced peat blend for best planting conditions
enriched with 4-5 weeks feed
a compost for all plants, vegetables, trees and shrubs

Contents

Foreword

In 2023, the Scottish Government became the first national government to recognise childhood dementia in a national dementia strategy, marking a significant milestone in the global understanding and policy response to paediatric neurodegeneration.

Now, for the first time, **Childhood Dementia in Scotland** is the subject of a report to the Scottish Government. At the heart of this report are the families of children with dementia, who are uniquely placed through their lived experience to describe the challenges, inequity, burden and urgent need for change. This foreword is co-authored by these parents.

"We live in a different world from you. It's a world where the doctors can't fix our kids; where the teachers can't help them learn; and where we, as the parents of children with dementia, have to watch helplessly as young lives fade away.

We are told to "go home and make memories". That's hard to do when every day you're juggling appointments, briefing carers, fighting for support, coordinating services, managing complicated medication regimes, looking after other family members, and trying to work and provide the best life that you can.

Our clocks tick faster than yours. Anticipatory grief and loss follow us around like a black cloud, casting a shadow over everything we do. When we take our children to hospital, we feel the dread that they might not be coming back home with us. When they smile at us, or say: "I love you too", we wonder if this will be the last time they can do that.

We're exhausted, but we carry on because we have to. We fundraise, run marathons, become experts in rare conditions, travel long distances for clinical trials, write to politicians, and campaign for changes to a system where we simply don't fit. We do this because our children deserve a chance at life.

Our dream is that one day no parent will have to live in this brutal world of childhood dementia. But to realise this dream we need your help. You can turn our children's pain into purpose by reading this report and using your voice, your understanding and your support to change their world. Together we can make a difference and transform hope into reality."

Thank you.

Claire, Darren, Helen, Valerie, Lynne, Leila, and Donna, on behalf of our children.

Alexander (now 15)

Sophia (now 14)

Shona (now 25) & Kelsie (now 23)

Kayden (now 16)

Effie (now 8)

Evie (now 12)

Reece (forever 10)

Foreword: Henry Simmons

I would like to thank everyone who has contributed their time, expertise and lived experience to create this report on childhood dementia in Scotland.

In recent years, our understanding of childhood dementia has improved, thanks largely to the work of the Childhood Dementia Initiative in Australia. In response to this, Alzheimer Scotland established Childhood Dementia Scotland, a collaborative network of key stakeholders including families, researchers, health, social care and education professionals and disease specific family advocacy organisations.

Our aim in supporting Childhood Dementia Scotland has been to help raise awareness and understanding of childhood dementia, improve the response from health and social care, and encourage investment in research.

Childhood dementia is largely invisible, poorly understood by professionals, overlooked by policymakers, and unsupported by systems which do not meet their needs. This report shines a light on the lived experiences of children and families, revealing the impact made by delayed diagnoses, fragmented care, and overwhelming emotional and financial burdens. Behind every statistic in this report is a child, a family, and a community living with the daily reality of a devastating diagnosis.

The report makes recommendations to address the urgent challenges facing children living with dementia and their families in Scotland today. These recommendations are not simply policy proposals but lifelines for families who cannot afford to wait. By raising awareness, building consensus and expertise, and fostering collaboration across sectors, we can create a system where every child and family receives the timely, compassionate, and specialist support they deserve.

Childhood dementia should be considered as a distinct and urgent issue and given the recognition it deserves. By embedding childhood dementia in our national strategy, developing a robust framework for care, and investing in research, we can deliver meaningful change.

Henry Simmons
Chief Executive, Alzheimer Scotland

Executive Summary

Childhood dementia is caused by a devastating group of over 145 genetic, metabolic and neurodegenerative conditions that result in progressive brain damage in children, leading to the loss of cognitive and physical abilities, and ultimately premature death. In Scotland, a baby is born every three to four weeks with a disorder that causes childhood dementia. Half of these children will die before their 10th birthday. Despite its profound impact, and perhaps due to the breadth of symptoms, childhood dementia remains largely invisible to the public, professionals, and policymakers.

This report highlights the urgent need for a coordinated national response. Families affected by childhood dementia face significant challenges: delayed diagnosis, fragmented and inequitable care, inadequate health, social and educational support, and a lack of psychological and financial assistance. The current system fails to provide consistent pathways, standards, or specialist models of care, leaving families to navigate disconnected services. In addition to bearing a huge emotional and economic burden, families have to become advocates and care coordinators for their children.

Immediate action is needed to raise awareness, strengthen care and support services, and invest in research for life-saving treatments and cures. Scotland can lead the way in delivering meaningful improvements and setting a new standard of care and support for children and families living with childhood dementia.

The report recommends three key actions.

Key action 1: Include childhood dementia in the national dementia strategy second delivery plan

The national dementia strategy second delivery plan 2026-28 commits to the delivery of measurable objectives to improve the cross-service response to childhood dementia.

Key action 2: Develop a national framework

The Scottish Government works with Childhood Dementia Scotland to co-design a nationally standardised, evidence-based framework of practice for childhood dementia in Scotland.

Key action 3: Invest in research

The Scottish Government engages with the research community and with families to take action that furthers the understanding of childhood dementia and enhances the potential for children and families to benefit from emerging screening, novel therapeutic approaches and management of symptoms.

Introduction

This report has been produced by Childhood Dementia Scotland to shine a spotlight on the devastating impact of childhood dementia. Every three to four weeks, a child in Scotland is born with a disorder that will lead to childhood dementia. Every one of these children faces a heartbreaking and rapid progression of physical and neurological decline and unavoidable premature death. Half will die before their 10th birthday, and yet, childhood dementia remains largely invisible to the public, professionals, and policy makers.

The current system in Scotland fails children with dementia and their families catastrophically. Families need complex, child-centred care across health, social, education and palliative services, but there is no local, regional or national approach to address this. Individual rare disease charities provide a lifeline for families and carers. However, children affected by these conditions arguably carry the highest level of unmet need in the Scottish paediatric health and social care system.

Immediate action is needed to raise awareness and understanding, strengthen care and support services, and invest in research into life-saving treatments and cures. Through this report, Childhood Dementia Scotland seeks to drive genuine change in Scotland, by identifying a pathway that will achieve equitable, high-quality care, and lead to the development of treatments and cures for this neglected and underserved population. By investing in the actions highlighted in this report, the Scottish Government will not only lead the way for the people of Scotland but will also provide a model of good practice for the rest of the UK and beyond.

As a first step to positive change, Childhood Dementia Scotland on behalf of its stakeholders and everyone affected by childhood dementia calls on the Scottish Government to adopt a coordinated, national approach to childhood dementia, by committing to the key actions identified in this report.

"None of the doctors have seen anyone with his condition before, because it's so rare... so I've started just saying 'he's got childhood dementia', and then everyone knows what they're dealing with. Even the taxi driver the other day, when he asked what was wrong with him, I said 'he's got dementia', and he said: 'oh, I didn't know kids could get that'."

Mum of a child with dementia

Childhood dementia: what you need to know

Childhood dementia is an umbrella term for a group of more than 145 different genetic, metabolic, and neurodegenerative disorders that cause progressive brain damage with onset in childhood. These conditions share the symptoms of adult dementia, but they start in early life. For some conditions, this can be in very young children; for others, symptoms do not emerge until the teenage years. A minority of children with dementia survive into adulthood, but their condition remains childhood onset dementia with progressive loss of brain function.

Most variants of childhood dementia conditions are caused by inherited gene mutations. This means that many families (15-20%) are at risk of having more than one child with the condition.

Examples of the most common childhood dementia conditions include Batten disease, Sanfilippo syndrome, Niemann-Pick disease type C, and Metachromatic leukodystrophy.

Each child's experience of dementia is unique and symptoms can vary hugely in time of onset and rate of progression. However, all children with dementia face the same challenge: that childhood dementia is progressive. Parents see their children develop normally, and then have to watch as they progressively lose the ability to read, write, talk, walk, and play, becoming fully dependent on others.

One in every 2,900 babies
is born with a condition that causes childhood dementia

Estimated in the UK every year:
204 deaths in people with childhood dementia
260 deaths from childhood cancer (0–14 yrs)

50%
of children with dementia die by the age of 10

Approx.
70%
of children die before their 18th birthday

Childhood dementia results from **progressive brain damage** caused by
145+ genetic conditions

Children with dementia experience
- Memory loss
- Confusion
- Trouble concentrating, understanding, learning and communicating
- Personality changes
- Severely disturbed sleep
- Behaviour changes such as hyperactivity
- Emotional issues like anxiety and fear

[1] Graphics reproduced with permission from Childhood Dementia Initiative.

About Childhood Dementia Scotland

Childhood Dementia Scotland is a collaborative network hosted by Alzheimer Scotland. It brings together families of children with dementia, support organisations, researchers, academics, clinicians and other organisations. The network builds on a partnership established between Alzheimer Scotland and the Childhood Dementia Initiative in Australia. The key objectives of Childhood Dementia Scotland are:

To increase the awareness and understanding of the collective group of disorders that cause childhood dementia and to support and inform families, researchers, social work, health and education professionals, policy makers, and other relevant stakeholders in Scotland.

To support the voice of, and campaign alongside, those with lived experience of childhood dementia, shaping the discourse and ensuring their voices are heard in areas wherever change is needed.

To bring together those with lived experience, clinicians, researchers, social work, health and education professionals, policy makers, and other relevant stakeholders in childhood dementia to create a catalyst for positive change in policy, practice and lived experience in Scotland.

To use the learning from this partnership to support the Childhood Dementia Initiative to promote similar initiatives in other countries.

To support greater investment, collaboration in and focus on research into causes and treatments in the complex area of childhood dementia.

Childhood dementia: the impact

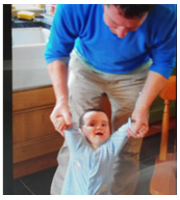
"The Neurologist was a man you could talk to, who made it quite clear he understood our worries and the shock we felt; I believe he found it difficult as well. He said: 'What you will be going through is like walking down a spiral staircase which descends in circles. How long the staircase is and what the next step is, will be hard to say; it is also a staircase with uneven steps, and it is easy to stumble. When you think one step is completed and you can move on to the next, you may find that you haven't moved at all – a very long step; there are shorter ones too, which will take you down quicker and further than you expected. A staircase like this makes you uncertain and constantly on your guard. You never really know where you are. Fortunately, the staircase does have a banister, which you will sometimes be able to find by touch and hold onto for a while. These are people you know or will get to know in your child's subsequent treatment. As parents you will have to descend that staircase alone, I'm afraid...'

We were all silent for a while..."[2]

[2] Growing Up To Dependence: children and young people with Batten-Spielmeyer-Vogt disease, comp. and ed. by: von der Junk M., de Jong C. G. A. 1992, ISBN 90-71534-21-9.

Alexander's journey

showing how childhood dementia typically progresses



Life is going as expected: developmental milestones are being met.

School notices Alexander's reading and writing are going backwards.

Aged seven, Alexander is diagnosed with a disease that causes childhood dementia. He travels to Birmingham every 2 weeks for a year, to receive an experimental drug.

His teachers and classmates say goodbye as Alexander is moved to a special school.

Alexander has multiple admissions to critical care. The palliative care team become involved.

Alexander starts school. Some minor developmental issues are a worry.

After a bewildering series of tests, a knowledgeable specialist makes a referral for genetic testing.

He starts to struggle with walking and begins to lose his speech.

The family have to move house as they need ground floor accommodation with hoists and other adaptations.

Childhood dementia in Scotland today

Prevalence and incidence

In Scotland today there are more children living with dementia than are living with cancer.

It is challenging to obtain accurate data on the number of children living in Scotland with dementia. This is due to several factors including the large number of individual conditions giving rise to childhood dementia; the lack of use of the term 'dementia' to describe the disease process; and the fact that official figures are not collected.

"We hope that better methods of tracking these conditions, a wider clinical use and acceptance of the term 'childhood dementia' and better historical and prospective data collection will give us more accurate figures for the rate of childhood dementia in Scotland."

Professor Sameer M Zuberi,
Consultant Paediatric Neurologist

The prevalence of childhood dementia is believed to be similar to that of motor neurone disease.

An estimated 382 people are living with childhood-onset dementia in Scotland today.

This number is based on the global average rate estimated by The Childhood Dementia Working Group study[3], which calculates that approximately 34.5 children per 100,000 will develop childhood dementia. This number can vary for several reasons, such as an increase in genetic illnesses in regions with reduced genetic diversity, poor clinician reporting and the lack of an internationally widely used definition of childhood dementia. Nonetheless, it should be noted that this will likely be an underestimate, as some conditions that can cause dementia (such as the Developmental Epileptic Encephalopathies) are often not included in the recorded data.

A Delphi study, coordinated by Childhood Dementia Initiative, is underway and is aiming to establish global consensus on a standardised definition of childhood dementia and on the inclusion criteria for conditions that cause childhood dementia.

[3] Elvidge K. L., Christodoulou J., Farrar M. A., Tilden D., Maack M., Valeri M., Ellis M., Smith N. J. C., the Childhood Dementia Working Group. The collective burden of childhood dementia: a scoping review. Brain J Neurol. 2023;146(11):4446-4455. doi:10.1093/brain/awad242.

A lack of awareness and expertise

Childhood dementia is largely invisible in Scotland. A systemic lack of knowledge and understanding, coupled with an absence of expert care and associated standards, is resulting in poor quality care for children with dementia and their families. This issue applies across the health, education and social care landscape, and extends from pre-diagnosis through to the end of life, and beyond.

Delayed diagnosis

The early symptoms of childhood dementia are often subtle and when flagged up by parents are dismissed or downplayed by health professionals, often explained as 'developmental delay' or early signs of conditions such as autism or attention deficit hyperactivity disorder (ADHD). The very limited and variable understanding of childhood dementia among health professionals often leads to delayed diagnosis, inappropriate care, missed opportunities for early intervention, and inadequate support for struggling families.

The long journey to a diagnosis is extremely challenging and highly dependent on the level of awareness and knowledge of the health professionals encountered by families. This is compounded by the relatively small number of conditions that the UK screens for in utero/newborn, compared to European counterparts; thus missing the opportunity to definitively diagnose prior to or shortly after birth. Even for conditions for which there is no current treatment, this would allow for earlier management and support.

After the onset of symptoms, delays of two years or more are common before a diagnosis is finally reached, resulting in children potentially missing critical windows for early intervention, and being exposed to inappropriate tests and unnecessary procedures. Once confirmed, the diagnosis is often delivered with little empathy, and without the required information or support.

"After lots of tests we were told that my son was autistic. But we kept going back to the doctors, saying that there must be something else going on. Nobody seemed to have a clue; in fact one of the consultants called my son 'an enigma'. And then eventually, after another two years, the community paediatrician bumped into a colleague in the corridor who thought he recognised one of the symptoms. It was pure chance though."

Parent of a child with dementia

"We were sitting down to tea, looking forward to our holiday the following day and I got a call from a local number. Assuming it was from the hospital and that it must be good news or they wouldn't phone me, I went out into the hall to take the call. He said: 'Hi, it's Dr here calling about Effie's test results. I'm sorry, Effie's got Batten disease.' I kept thinking: 'why would he tell me like that?' I heard white noise and had difficulty breathing. The children were in the next room. I don't know what else was said. I went out to the front step of the house and bent over. I vomited.

I had to tell my husband. We had to act normal for the children. I couldn't believe I would be told like that; you wouldn't be told you have cancer over the phone. No other information. We had to carry on, about to go on holiday and a bomb had been dropped on us."

Leila, Effie's mum, Perthshire

After diagnosis

Following the diagnosis, health professionals are not well supported by clinical teams, systems or services to attain and provide the expert support this group of children require. Opportunities to collaborate and learn from experienced colleagues are restricted by the limited and variable understanding of childhood dementia, and by the fragmented approach to care.

"Allied Health Professionals (AHPs) play a vital role in supporting function, communication, mobility, and family wellbeing for children with dementia. AHPs in Scotland recognise that the term childhood dementia is not well-used in clinical services; yet the benefits of recognising and responding to the features of childhood dementia, common across a range of genetic conditions, are clear. AHPs would welcome a co-ordinated approach across services to ensure that families are able to access the right support at the right time by well informed professionals."

Hilary Munro, Chair, Allied Health Professions Federation Scotland

In the absence of professional expertise, parents reluctantly become 'experts' in their own children's conditions as they search for answers from multiple health professionals in diverse healthcare settings over prolonged periods of time.

"I get most of my information from other parents. You hear about the problems they've had with their kids and you get ideas about things you can try. When you live with these sorts of problems every day, you become an expert."

Mum of a child with dementia

An ill-equipped education system

In the education system, awareness and expertise are similarly lacking, and finding appropriate school support for children with dementia can be particularly challenging. Most schools in Scotland, including schools for children with additional support needs, operate under the framework of Curriculum for Excellence, which emphasises skills development and personal achievement. Despite its focus on personalised support, the framework uses a strengths-based approach that may not be appropriate for children with progressive cognitive and physical decline. For some families, an emphasis on 'strengths' can feel unrealistic or even distressing when a child is steadily losing previously acquired abilities.

"We went to loads of meetings at his school where everyone sat round a table and had to start off by saying what my son's strengths were. It was painful. People were obviously struggling to find things to say, so they said things like: 'He's such a popular boy' and 'everybody loves him'. When it got to my turn I always felt like saying: 'he's lost all his strengths: he doesn't have strengths any more. Let's not pretend he does'."

Parent of a child with dementia

There is no training programme for teaching staff to learn how to maximise the residual skills and abilities of children with dementia, and schools are ill-equipped to make the necessary classroom adjustments, so children with dementia are reliant on the individual commitment of their teacher and school to research the skills they need to offer tailored and appropriate support. Scotland's long standing, national commitment "Getting it right for every child" (GIRFEC) demands that all children, young people and their families are provided with the right support at the right time, so that every child and young person can reach their full potential. To do this effectively, schools need a clear understanding of childhood dementia and its progression. With improved training and forward planning for regression, interventions can be implemented early enough to be effective.

"Alexander is supported in school through intensive, individualised care and sensory-based learning experiences. However, his condition means that he is gradually losing previously acquired skills. Greater awareness, staff training, and resources are needed to ensure that children like Alexander, who are effectively unlearning, receive the specialist support and understanding they deserve."

Paul Laird, Teacher,
Braidburn Special School, Edinburgh

Parents often feel isolated and uncertain about how to advocate for their child's needs within the current system. Strengthening collaboration between education, healthcare, and social services, while creating opportunities for parents to share their experiences and concerns, would help address this gap and ensure more coordinated and timely support.

Inadequate social care and support

The current social care system in Scotland is not designed to deal with children with dementia. Although support and benefits packages exist for people with degenerative conditions, they are universally challenging to access and manage.

"We used to have a really good social worker, but she retired and was never replaced. That's why last time, our payments for respite took six months to come through."

David, Alexander's dad

Social care services are unfamiliar with the conditions that cause dementia in a child, meaning that parents go through long and complex negotiations with Social Work, social security agencies and other support services, frequently experiencing inconsistent assessment and funding decisions which add to an already heavy administrative and emotional burden.

A general lack of understanding about the importance of continuity and consistency compounds the problem, particularly as children's conditions deteriorate and support needs intensify. Often, designated carers who come to the home, support staff at school, and even school bus escorts, are changed on a regular basis, with the result that close working relationships between children, families, and their carers, are broken again and again.

"My son had a fantastic support worker for more than a year. She really got to know him and could make him laugh like no one else could, you know, real belly laughs. Then all of a sudden we found out that she wasn't working with him anymore. When I asked why, they said it was important that my son got to know new people. You just don't do that to a child like him. I think it broke his heart."

Parent of a child with dementia

Assessments for children with dementia are often long and complex, with families experiencing a need for greater justification of necessary supports.

"In a conversation with the social worker, I was asked: 'What do you expect?' I answered: 'I don't know what I expect, I want what we are entitled to!' ..... Evie was given only five hours a week of direct payments. I top this up to 7.5 hours myself. I'm scared to ask for more hours as last time I asked, they reduced the hours feeling I could cope."

Lynne, Evie's mum, Scottish Borders

Each review requires families to retell their story and to educate the assessor on their child's condition, prognosis and increasing needs. However, suitably managed multidisciplinary regular reviews to meet the changing needs of the child and family can remove the burden from families to source, coordinate and resource their child's care and can reduce the long delays often experienced in the provision of specialised equipment and other essential supports. With the right resources and equipment at the right time, quality of life and well-being can be improved for the whole family as well as for the child.

"The wheelchair lift was broken for six months. We were having to manually lift him up and down the steps. It did my back in and for the first time I really struggled with my mental health."

Mum of a child with dementia

A lack of training across the workforce

Children with dementia require their needs to be met by well-informed and well-trained staff and appropriately modified environments. Failure to label neurodegenerative conditions in children as childhood dementia means that opportunities to develop and provide appropriate training right across the public sector workforce are lost.

"Further and Higher Education Institutes play a crucial role in training the workforce about childhood dementia. However there remains a lack of awareness, confusion over terminology, and minimal resources. Unlike dementia in adults, childhood dementia is rarely discussed or featured in dementia textbooks, lectures, course content and in other materials, leaving many schools, health and social care professionals, and the education providers responsible for training the workforce themselves, under prepared. Investing in workforce education about childhood dementia is not just important, it is vital for the development of a knowledgeable, skilled and compassionate workforce ready to support and advocate with families at a time when they may be feeling lost, alone, and need our support the most."

Dr Chris Knifton, Associate Professor in Teaching and Learning (Neurocognitive and Neurodevelopment care)

Key action 1: Include childhood dementia in the national dementia strategy second delivery plan

The national dementia strategy second delivery plan 2026-28 commits to the delivery of measurable objectives to improve the cross-service response to childhood dementia.

1.1 The Scottish Government establishes a lived experience network with appropriate resourcing to ensure that parents and their children can fully participate in decisions that affect them.

1.2 The Scottish Government establishes a National Advisory Body on Childhood Dementia, tasked with guiding and coordinating Scotland's national response to childhood dementia.

1.3 The Scottish Government ensures that workforce training needs are identified and met by bringing together the key national bodies including Health Improvement Scotland, NHS Education for Scotland, the General Teaching Council for Scotland, and the Scottish Social Services Council.

Care is inadequate and inequitable

Care for children with dementia in Scotland is currently inconsistent, fragmented and reactive. The absence of a unified approach leaves families to find their own way through disconnected services, resulting in substantial inequities of care and widespread inefficiencies throughout the health and social care system.

No framework

There is no single approach to the care of children with dementia in Scotland. As families and professionals navigate their way through multiple health, education and social care settings, there are no guides to help them; no national standards; no specialist models of care; and no standard pathways.

"There are no recognised, specific clinical pathways, guidelines or services for childhood dementia in Scotland."

Professor Simon Jones, Consultant Paediatrician for inherited metabolic diseases

This is in contrast to the progress that has been made in adult dementia policy and practice since 2009, which includes the introduction of a national guaranteed standard for post diagnostic support and clinical guidelines on the assessment, diagnosis and management of the condition.

Within the current Scottish healthcare system, the geographical location of a child with dementia determines their access to services such as genomic testing, imaging, and specialist assessments. There is no consistent referral pathway, no coordinated care planning, and no consistent clinical oversight. In this context, a family's ability to advocate often determines the quality of care and support they receive. Families facing socioeconomic challenges and families without high levels of health literacy are particularly vulnerable, including those from a culturally or linguistically diverse background.

"Doctors need to factor that parents are continuously processing the horrendous news of the disease. They must go at our pace and be prepared to answer difficult questions. To make informed choices you need to know the stark reality so you can make the best decisions for your child, especially when they get ill."

Donna, mum to Reece, age forever 10, Inverness-shire

Lack of coordination and consistency

In most cases, families find themselves in the centre of a complex web of services, including medical specialists, allied health professionals, schools, social security agencies and grant-making bodies, at home carers, and respite services. With multiple services to navigate and no effective care coordination, parents inevitably find themselves in a 'project management' role, sourcing clinicians, coordinating communication between speciality services, managing referrals and appointments, briefing and overseeing carers, and managing complex medication regimes.

"At the moment, we're seeing loads of people. We've got two consultant neurologists, a metabolic and a respiratory consultant, an orthopaedic surgeon, GI doctors, physios, OTs and dietitians. And that's just for health. The other day though, I needed to know whether I should take him off his antihistamine. It was a really simple question but I had no idea who to ask."

Mum of a child with dementia

Across the years of disease progression, and in the absence of care coordination, families must repeat their stories over and over again. Often one parent holds their child's entire medical history and current care details, including constantly changing drug regimens that are often prescribed by multiple health professionals.

"Every time we take him to hospital, we have to start from the beginning again and explain about his condition. They always want to know what drugs he's on, like I should be able to tell them off the top of my head. He's on 12 different drugs at the moment. Why can't they just look it up? I've got all his drugs on the computer at home, so now I just print out a copy and take it with me."

Mum of a child with dementia

Despite having a substantially increased need for support in the community for therapies, home adaptations, respite and carer support, healthcare for children with dementia is almost always experienced by parents as fragmented, disjointed, and opaque. The healthcare system is not designed to support the management of progressive and constantly changing conditions in children. Alongside the gradual loss of cognitive skills, the deterioration in physical ability, visual and auditory impairment, and other health conditions such as epilepsy, add significant complexity.

For some families, services and supports are available through child development centres; others may be available regionally or on a national basis; and some are delivered through nurseries and schools. Systemic inconsistencies also extend to palliative and hospice care, to which families are not always routinely referred. Adding to the complexity, children's palliative care services and hospices are usually funded through charity routes and as a result are not available equitably or adequately for all.

Limited support for transitions

Parents of children with dementia who survive into adulthood describe strong feelings of isolation as they try to manage the transition from paediatric to adult services, and from school to post-school support. Education can play a vital role in easing the transition from school to adult services by ensuring that information about the child's interests, abilities, and the accommodations they require is communicated effectively. As in schools, post-18 systems and services are not geared up to manage the specific support needs of children whose skills are regressing.

Even when qualifications have been achieved, there is little opportunity for independent living or supported employment. For those who need ongoing social care support after leaving school, there are no services designed to meet their needs, and as a result, young people with dementia have no opportunity to access age- and ability-appropriate activities outside of the family home.

"We were told 16 is when you're going to need to do guardianship. Then it's the battle of finding a solicitor covered by legal aid. It can take 18 months plus before the guardianship is official. I'm in the unknown. I thought I had no clue beforehand, but I definitely have no clue now."

Valerie, Kayden's mum, Edinburgh

Inadequate psychological support

The burden of unsupported care management is immense, with parents spending anything from 8 to 24 hours per day managing their child's needs[4] and others experiencing burn out as they struggle with the demands of round-the-clock care. For families of children with dementia, the psychological and emotional toll of caregiving is severe and relentless as they live in constant crisis mode.

"I often hear 'I don't know how you manage'. Well, neither do I .... I run on empty all the time but every ounce of strength is focused on making life better, holding on to hope that life can be better for my young people."

Helen, mum to Shona and Kelsie, Inverness

Mental health support for families is very limited, often delayed, and rarely tailored to the unique challenges of children and young people with childhood dementia. Parents experience anticipatory grief, chronic stress and exhaustion, as they witness their child's daily decline[5]. The unpredictability of disease progression and the constant threat of loss create a pervasive sense of anxiety and helplessness.

"They told me not to look it up, but I did of course. I looked it up on Google, so when they gave us his diagnosis, I knew it was the worst possible news. Then one of the doctors said: "Is there anything in particular you're worried about?" and I just remember my husband saying: "You mean, apart from the imminent death of my son?"

Claire, Alexander's mum, Edinburgh

Marital and family relationships are often strained or break down altogether due the absence of respite from constant caregiving duties[6].

Siblings often feel neglected or overshadowed by the intense care needs of the affected child, and can sometimes become secondary caregivers themselves. Research shows that siblings often feel overlooked, experience social limitations, and describe feelings of grief, worry, and guilt as they adjust to the shifting dynamics within their family[4].

"The hardest part is the pressure of it. You're constantly in a state of worry about it. It's ringing in the back of your head all the time. It's always there."

William, Alexander's brother

[4] Thomas S., Morrison A., Morton G., Roberts P., Clark V., Imrie J. The burden of disease in metachromatic leukodystrophy: results of a caregiver survey in the UK and Republic of Ireland. Orphanet J Rare Dis. 2024 Feb 25;19(1):87. doi: 10.1186/s13023-023-03001-z. PMID: 38403596; PMCID: PMC10895743.

[5] Nevin S. M., McGill B. C., Kelada L., Hilton G., Maack M., Elvidge K. L., Farrar M. A., Baynam G., Katz N. T., Donovan L., Grattan S., Signorelli C., Bhattacharya K., Nunn K., Wakefield C. E. The psychosocial impact of childhood dementia on children and their parents: a systematic review. Orphanet J Rare Dis 18, 277 (2023).

[6] Nevin S. M., Kelada L., Elvidge K. L., Maack M., Hilton G., Kershaw J., Da Ros E., Briggs N. E., Farrar M. A., Wakefield C. A. Navigating the complex landscape of childhood dementia: caregiver psychological well-being, grief, and health system challenges. Journal of Pediatric Psychology, 2025; jsaf095, https://doi.org/10.1093/jpepsy/jsaf095.

High economic costs

The economic cost of childhood dementia is staggering, with families experiencing major financial hardship and reduced income[6].

In parallel, the loss of economic productivity from parents leaving work or reducing hours, coupled with dependence on state benefits, reflects a substantial societal cost[7]. Many parents leave the workforce entirely, with a recent study reporting that 94% of caregivers had to modify their work status due to their child's condition, and almost one in three gave up their careers entirely to care full-time[6].

"We just couldn't carry on with both of us working full-time. There's too much pressure and something has to give. So we put our family first, even though that's meant losing an income just when we needed it most."

David, Alexander's father, Edinburgh

Just as household incomes are reducing, families often face significant expenses for medical care, equipment, and home modifications such as ramps, hoists and hospital beds. Specialist equipment like reclining wheelchairs, suction devices, and feeding systems are essential but costly, with long waiting times for statutory provision. Some families are forced to move house entirely, in order to find accommodation that meets the needs of their child[4].

Key action 2: Develop a national framework

The Scottish Government works with Childhood Dementia Scotland to co-design a nationally standardised, evidence-based Framework of practice for childhood dementia in Scotland.

2.1 The framework takes a family-centred care coordination approach that encompasses pre-diagnosis support, diagnosis, post diagnostic support and timely connection to community and social services.

2.2 The framework is embedded into services for children and young people throughout Scotland, ensuring standardised protocols throughout the entire care pathway from diagnosis to end of life planning and bereavement support.

[4] *Op. cit.*

[6] *Op. cit.*

[7] Ashby F., Park H., Svensson M., Heldermon C. D. Economic Burden of Sanfilippo Syndrome in the United States. Res Sq [Preprint]. 2023 Nov 1:rs.3.rs-3001450. doi: 10.21203/rs.3.rs-3001450/v4. Update in: Arch Public Health. 2025 Nov 10;83(1):269. doi: 10.1186/s13690-025-01733-x. PMID: 37398464; PMCID: PMC10312916.

There is no cure for childhood dementia

Childhood dementia represents a devastating reality in paediatric health. Every child diagnosed with a childhood dementia condition faces premature death. There has been no notable improvement in survivorship over recent decades: a situation in stark contrast to other paediatric conditions that have seen remarkable advances in treatment and survival rates.

"....part of my job [is] looking after children who've got no therapy and trying to fight, as everyone is, for appropriate care: understanding pathways, palliative care, school placements, cars, everything that is needed"

Professor Simon Jones, Consultant Paediatrician for inherited metabolic diseases

Where supportive resources and treatments do exist, this can be transformative for children, especially when delivered at the right time. The Scottish Government has led the way by introducing the ultra-orphan medicines pathway in 2018. Managed by the Scottish Medicines Consortium, this system has helped transform the lives of children with some forms of childhood dementia such as CLN2 and Metachromatic leukodystrophy by facilitating access to rare medicines. Scotland is the only UK nation with a formal pathway guaranteeing up to 3 years of funded access for ultra-rare medicines in advance of evidence-based decisions being made about treatment effectiveness. The success of this system demonstrates that with coordinated action Scotland can continue to lead the way in transforming the lives of children and young people with childhood onset dementia.

A fragmented approach

Nearly all known forms of childhood dementia are caused by specific, identifiable gene mutations.

"This professor had a look at my son's report and then explained what it meant. Basically, he's got a G where he should have a C in his genes, and he's also got an extra T. It sounds so simple."

Mum of a child with dementia

Historically, each individual condition that causes childhood dementia has been researched in isolation, limiting the potential to understand common pathways and develop broadly applicable treatments.

"Development of treatments for childhood dementias is complicated by a fragmented approach to funding, relying on small charities or foundations, often with little interest from national funders. All too often what is funded is the most novel approach, not the one most likely to give benefit to patients. Our hope is that development of therapies for childhood dementias will also improve our ability to treat all dementias."

Professor Brian Bigger, Professor of Advanced Therapeutics & Honorary Professor of Cell and Gene Therapy

Similarly, research into childhood dementia is seldom linked to work on adult dementia, despite the existence of shared biological pathways, shared therapeutic targets, and the potential for childhood dementia to offer researchers a window to study the early stages of neurodegeneration.

"It is important to note that almost all childhood forms of dementia are caused by known genetic changes. This means that they can be modelled to better understand what is happening and develop therapies if the appropriate resources are available. Mostly time and money. What many researchers seem unaware of is that these conditions often share pathological and mechanistic hallmarks of adult onset neurological conditions such as Alzheimer's, frontotemporal dementia and Parkinsons disease. With the difference being that whilst most adult onset forms don't have a known or common genetic cause and therefore cannot be modelled well, we can use what we learn in childhood dementia to inform on these adult onset conditions. It should be an obvious comparatively easy win."

Tom Wishart,
Professor of Molecular Anatomy

Data gaps

Children with dementia are currently unidentifiable in Scotland's current health system. Data captured in medical health records are not standardised or readily accessible, and there is no patient registry that captures childhood dementia as a collective group of conditions. Consequently, access to data about this group of children and their use of health and social care systems is severely hampered.

Without systematic data collection, researchers cannot identify suitable participants for clinical trials, health services cannot plan appropriate resources, and families cannot access information about treatment options or about what to expect from their child's condition.

Inadequate funding for research

Historic underfunding of childhood dementia research has significantly hindered progress. Due to its invisibility in the healthcare landscape, the lack of treatments and cures goes unseen by policymakers, commissioners and research funders. While significant advances have been made in some individual disorders, the research expenditure is dramatically lower than for groups of conditions of similar prevalence and importance to society, such as childhood cancers.

"If bodies like LifeArc or the Medical Research Council or the National Institute for Heath and Care Research, for example, UK-wide bodies, could put out calls specifically for research in childhood dementia that would completely change the game for many of us working in our relatively rare disease areas."

Professor Simon Jones,
Consultant Paediatrician for
inherited metabolic diseases

"What I wanted was to speak to other parents, but there weren't any, as it's so rare. We felt alone. We couldn't understand what the progression would look like. We were told 'nobody knows the timeframes'."

Lynne, Evie's mum, Scottish Borders

No research strategy

For many families affected by childhood dementia, research carries their hopes for the future.

However, the Scottish Government currently has no strategy for research into childhood dementia. Neither the Scottish Brain Health and Dementia Research Strategy (2021), nor the NHS Research Scotland Neuroprogressive and Dementia Network Strategy (2022-2027), mention the term 'childhood dementia'. Both focus predominantly on adult-onset neurodegenerative diseases. Similarly, the Rare Diseases Action Plan has no specific focus on or mention of childhood dementia.

In terms of Scotland's research infrastructure, some of the building blocks required to support childhood dementia research are already there, evidenced by the pioneering work currently progressing at the Roslin Institute in Midlothian, and at the Drug Discovery Unit in Dundee. However, infrastructure elements that are critical for the development of emerging treatments are not joined up or coordinated, and there is no dedicated data registry, there are no clinical trial networks, and there are no resources for horizon scanning. Consequently, Scotland attracts very little clinical trial activity and the opportunity for families to access emerging therapies elsewhere is severely limited.

"I remember speaking to the CEO of a big Pharma company and she said: "You know one day, the doctor with call you in and say: 'The bad news is that your son has this disease. The good news is that we'll book him in to the clinic next week and get that sorted for you'. That was years ago, but I still think about it."

Mum of a child with dementia

Key action 3: Invest in research

The Scottish Government engages with the research community and with families to take action that furthers the understanding of childhood dementia and enhances the potential for children and families to benefit from emerging screening, novel therapeutic approaches and management of symptoms.

3.1 Working with Childhood Dementia Scotland, develop a Research Strategy Steering Group, ensuring the inclusion of childhood dementia in relevant existing research strategies.

3.2 Data on childhood dementia is collected and analysed to provide a clear picture of prevalence and incidence in Scotland.

3.3 The Scottish Government works with funding bodies including UK-wide funding bodies on the development of specific research calls for childhood dementia, with ring-fenced funding.

3.4 The Scottish Government ensures that future funding allocated for dementia and neurodegenerative disease research is applied across the lifespan.

Conclusion

Childhood dementia is not only devastating for children and their families, but also a profound challenge for Scotland's health, social care, and education systems. This report has shown that, despite the courage and resilience of families living with childhood dementia, the current landscape is one of invisibility, inequity, and fragmentation. Too many children face delayed diagnoses, inadequate support, and a lack of coordinated care, while families shoulder the overwhelming emotional, financial, and practical challenges of caring for a child with complex and changing needs.

Yet, there is hope. The Scottish Government can lead the way by recognising childhood dementia as a distinct and urgent issue and through implementing the actions recommended in this report transforming outcomes for these children and their families. These actions - embedding childhood dementia in Scotland's national dementia strategy; developing a robust national framework; and investing in research - are not just proposals: they are lifelines for families who cannot afford to wait.

Immediate, coordinated action will ensure that childhood dementia is no longer in the shadows. By raising awareness, building expertise, and fostering collaboration across sectors, we can create a system where every child and family receives the timely, compassionate, and specialist support they deserve. Moreover, by investing in research and data infrastructure, Scotland can contribute to breakthroughs that may one day offer hope of effective treatments and cures, not only for childhood dementia, but for neurodegenerative diseases across the lifespan.

The voices of the families who have contributed to this report are clear: the time to act is now. We must turn understanding into action, and compassion into meaningful change. Together, we can ensure that no child or family faces childhood dementia alone, and that Scotland becomes a beacon of hope and leadership in this vital area.

Further information

www.childhooddementia.org

www.alzscot.org

www.bdfa-uk.org.uk

www.mpssociety.org.uk

www.npuk.org

Alzheimer Scotland
Action on Dementia

Prevent.
Care.
Cure.

Alzheimer Scotland
160 Dundee Street
Edinburgh EH11 1DQ
T 0131 243 1453
E campaigns@alzscot.org

Twitter @alzscot
Facebook @alzheimerscotland
Instagram @alzscot

www.alzscot.org