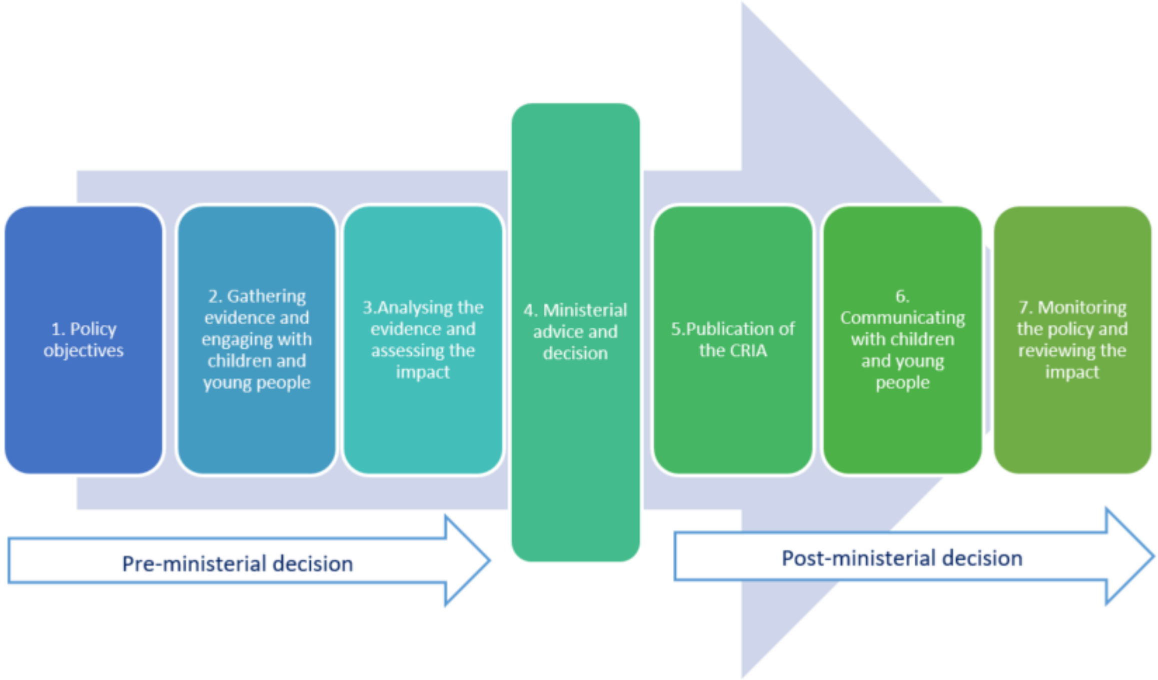
Dementia Strategy 2026-2036: Children's Right's Impact Assessment

All completed Children's Rights Impact Assessments must be sent to the CRIA@gov.wales mailbox.

The Rights of Children and Young Persons (Wales) Measure 2011 places a duty on the Welsh Ministers to pay due regard to the United Nations Convention on the Rights of the Child (UNCRC) and its Optional Protocols when exercising any of their functions.

The CRIA process is the agreed mechanism officials should use to support Ministers to meet this duty and ensure they give balanced consideration to children's rights in their decision making. A CRIA should be used to inform ministerial advice and must be completed prior to a ministerial decision being made. Once a decision has been reached, your CRIA must also be published.



For further advice and guidance on the CRIA process, please consult the Children's Rights Manual for Staff or contact the Children's Branch CRIA@gov.wales

Policy objectives

What decision are you impact assessing?

Welsh Government is publishing a successor to the dementia action plan for public consultation. *This impact assessment considers the information provided in the evidence gathering consultation to inform the next dementia strategy. Impact assessments will be updated to reflect the full and final strategy when this is published.*

This Impact Assessment has considered the impact of the new strategy on Children's Rights. This proposal is relevant to children and young people in terms of the life course approach to dementia, encouraging healthy options from a young age on a range of modifiable factors will prove beneficial throughout a child or young persons lifetime. It is also relevant where children and young people may find themselves as young carers, or as a member of a family living with dementia in either a parent or grandparent.

The proposed vision is:

'Wales will be a nation where people living with dementia are respected, supported, and empowered to live independently and with dignity in their communities. We envision a society where stigma is not accepted and an increased awareness of dementia, supports people living with dementia and their families to live and socialise in inclusive and compassionate communities, that will empower people to live independently and with dignity in their communities through diagnosis, care, and treatment. Achieving this vision requires a united, cross-government and multi-agency effort, grounded in the voices and experiences of those living with dementia. Together, we will build a future where rights are upheld, support is person-centred, and no one faces dementia alone'.

Principles

We want to ensure that our next dementia strategy focuses on the things that matter most to people. These principles are those we will consult upon:

Person-centred: Offering care and support which is coordinated and individualised, whilst ensuring that people are empowered, included in decision making and treated with dignity, compassion and respect.

Rights-based approach: Supporting people to recognise and develop their own strengths and ability to make informed decisions about their own health and care. Ensuring that care and support is provided in a way that respects, protects and fulfils the rights of individuals, and fully considers the specific rights some groups have, for instance disability rights.

Co-production: A way of working whereby people with lived experience and practitioners work together as equal partners to plan and deliver care and support.

Equity of access, experience and outcomes without stigma and discrimination: Across all settings, stages of dementia, and regions, we will focus on:

- Equity of access to information, including that to support brain health and dementia care
- Reducing stigma and misconceptions about dementia.
- Equity of access to other essential services for people living with dementia.
- Promoting equality, diversity, and inclusion in all aspects of care.

Recognising intersectionality: understanding how different aspects of a person's identity—like race, gender, sexuality, disability, and more—combine and interact to shape their experiences. This will look at how multiple factors overlap to affect someone's life, taking a person-centred approach rather than focusing on just one aspect at a time

Ensuring timely and accurate diagnosis: enabling early access to support and planning.

Taking a preventative approach by focusing on brain health, improving resilience and reducing risk, but recognising people will still develop dementia and we need to ensure people are supported to live healthier for longer.

Services will be integrated and coordinated, and will foster collaboration across health, social care, housing, and community services and will develop evidence-based care and support.

Support for unpaid carers and families will provide emotional support, education and access to respite. We will recognise the rights that unpaid carers and families have, ensuring they are key partners in care and be supported to be involved in care planning.

We will ensure we develop our workforce, enabling staff across health, social and voluntary sectors can recognise dementia symptoms, understand the impact of dementia and use this knowledge to deliver compassionate and quality care.

We will support research and innovation, including by supporting people living with dementia to be involved in research on causes, care, and potential cures and support innovation in service delivery and care models.

The Alzheimer's Society have estimated that 982,000 people are currently suffering from dementia in the United Kingdom. This number is projected to rise to approximately 1.4 million people by 2040[1]. The main reason for the increase in people with dementia symptoms would be the increasing age of the population of the UK due to people living longer. A report commissioned by Alzheimer's Society also highlighted the economic impact of dementia and summarised 'The cost of dementia is forecast to be £42 billion for 2024, increasing to £90 billion for 2040, due to a forecasted increase in dementia prevalence and cost of services'.

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[1] https://www.alzheimers.org.uk/blog/how-many-people-have-dementia-uk

Gathering evidence and engaging with children and young People

What existing research and data on children and young people is available to inform your specific policy? Your policy objective may impact on other policy areas – discussions with other policy teams will be an important part of the impact assessment process ensuring you have gathered a range of information and evidence.

We have reviewed what the evidence tells us about dementia and children and young people in Wales. Key findings include:

Childhood dementia

While dementia is usually associated with older people, children also experience dementia-causing disorders. A major review has estimated the incidence of untreatable childhood dementia conditions at approximately 34.5 per 100,000 births (around 1 in 2,900), with a prevalence of about 5.3 per 100,000 persons in the general population[2]. Childhood dementia results from progressive brain damage and can be caused by over 70 rare disorders. These conditions are genetic and children are born with them.

Given the genetic nature of childhood dementia, many families have more than one child living with the condition. This can impact many areas of their life, including their capacity to work and socialise. Children living with dementia can face additional challenges in accessing dementia care and support services due to limited pathways and specialised services. Like people with younger onset dementia, the care and support needs of children living with dementia are different to older people and research is underway to articulate those needs more clearly.

Childhood dementia is an umbrella term of rare mostly genetic neurodegenerative disorders that show symptoms before the age of 18. Their main characteristics are chronic and widespread cognitive decline, loss of previously acquired developmental skills after a period of development and the behaviours and psychological symptoms of dementia. Examples include Sanfillippo Syndrome, Niemann Pick and Batten disease.

We will be conducting a literature review to examine issues around:

- Young onset and rarer dementias
- Diagnosis
- Service Models
- Lived experience

At the conclusion of this we will review and amend the Children's Rights Impact Assessment if necessary.

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[2] Collective burden of childhood dementia: a scoping review | Brain | Oxford Academic

Priority Areas

Importance of good brain health

Although children and young people are not the group at greatest risk of dementia, it is important to consider them from a life course perspective. Modifiable risk factors for children and young people include healthy eating, alcohol and drug use, exercise, hearing loss, smoking, pollution/environmental factors, and social isolation. Addressing these factors could reduce dementia diagnoses globally by up to 45%[3]

Individual level interventions such as stopping smoking, increasing exercise, maintaining a healthy diet and keeping your brain active over the course of an individual's life are to be recommended. However, it is also important to consider population level approaches to aid in the reduction of dementia prevalence across society more broadly.

Examples of this could include regular monitoring of blood pressure, introduction of legislation to reduce salt and sugar in foods, introduction of minimum unit pricing for alcohol, such as in Wales and the creation of low emissions zones.

Good brain health is influenced by factors from pre-conception through to adulthood, including nutrition, prenatal care, safe environments, and healthy lifestyle choices. Research suggests that interventions such as compulsory education and reducing smoking rates can reduce dementia incidence.

The relationship between brain health and the development of dementia has been reframed in recent years. Whilst children and young people are not the group at greatest risk of dementia, it is vital that they are considered as part of taking a life course perspective. Alzheimer's UK highlighted that this 'is needed to integrate advice on the prevention of ill health and encourage, facilitate and maintain healthier living'.

The World Neurology Foundation highlighted this life course perspective and restated that Brain health must be supported across the full human lifespan:

- **Pre-Conception**: A parent's health and habits shape a child's brain even before birth. Good nutrition, regular check-ups and lifestyle choices form a strong foundation for brain health.
- **Pregnancy & Postnatal**: A mother's physical and emotional well-being is critical for healthy brain development in the womb. Prenatal and postnatal care, proper nutrition and stress management protect both mother and child.
- **Early Childhood & Adolescence**: Early life experiences influence learning, emotional growth and social development. Safe environments, immunizations, and positive parenting support long-term brain health.
- **Adulthood**: A balanced lifestyle habits—healthy eating, sleep, exercise, and stress control—reduce the risk of neurological disorders.

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[3] Next generation brain health: transforming global research and public health to promote prevention of dementia and reduce its risk in young adult populations - The Lancet Healthy Longevity

- **Aging Adults**: Staying socially engaged helps preserve independence and quality of life in later years, in addition to regular check-ups for early detection of conditions ranging from mild cognitive impairment to dementia

The Lancet Public Health have also highlighted this issue - Naaheed Mukadam and colleagues leveraged data from 27 cohort studies on dementia risk factors and interpreted their results as ‘Our findings suggest that lifestyle interventions such as compulsory education and reducing rates of smoking through country-level policy changes could be associated with an observed reduction, and therefore future reduction, in the incidence of dementia’.

Whilst it is of vital importance to encourage the life course perspective it should also be noted that it is never too late to do something about an individual’s brain health.

In July 2025, the Public Health Network Cymru hosted a webinar on Brain Health and Dementia Risk Reduction, asking the question: How can we affect change? The event was attended by 190 people, with representation from health boards, local authorities, third sector and Public Health Wales.

Presentations included a discussion on the Prevention-Based Health & Care Framework, developed by Public Health Wales and published in May this year. The Framework provides a systematic approach to understand the actions required to achieve specific prevention goals and this will inform our future work programme and how this can be incorporated into messages for young people.

Awareness and early intervention.

Young carers

Children and young people can be involved in caring for family members with dementia, potentially grandparents or parents with early onset dementia. This can significantly affect young people’s health, social life and self-confidence. Finding support as a young carer can be vital as it can be overwhelming and stressful. Support groups for young carers exist all over the UK. dewis.wales can provide information regarding wellbeing services available throughout Wales. Bangor University have added online resources concerning training and support for adult and young dementia carers to help people to manage different aspects of dementia caregiving. There are specific pages relating to support for young people (11-17 years) which include caring for yourself, providing everyday care to a friend or family member and dealing with behaviour changes. iSupport for Young People | iSupport Dementia Courses.

Bangor University are also working on a young carers peer support project which is currently under development. It is intended that this will offer young people the opportunity to meet others in similar circumstances so they can learn how to understand dementia together and feel less alone.

Building awareness of dementia for children and young people

Schemes have been created to try to lessen stigma around dementia for children and young people within their schools and communities.

Dementia Friends

The dementia friends programme was designed by the Alzheimer's Society to help people understand what dementia is and how it affects individuals and their families. It aims to encourage members of the community to learn more about dementia and how taking small actions can make a big difference in the lives of those living with the condition. Building dementia awareness across the population is a critical starting point, and schemes such as 'dementia friends' [4] have a key role to play in raising awareness, as part of considering this in the context of children and young people we also need to look at opportunities for intergenerational working.

Reading Well

Reading Well for dementia recommends helpful reading and digital resources for people living with dementia. There are also books for family, friends and carers. The booklist provides reliable information, advice and support as well as personal stories and age-appropriate books for children.

The booklist is targeted at people living with dementia, carers and family members including younger children to help them understand more about dementia.

Dementia UK have compiled a list of books that could help children across a range of ages better understand dementia amongst family members - Books about dementia for children - Dementia UK

Regional Partnership Boards across Wales were established as part of the Social Services and Wellbeing Wales Act 2014. They hold responsibility for improving the health and wellbeing for people who live in their geographical areas. This includes service provision around dementia.

Planned engagement with children and young people.

The impact on children and young people is predominantly indirect and as such we are not planning engagement with the general population of children and young people but will ensure that we link with groups that represent them and will seek out specific engagement with young carers through this process.

Analysing the evidence and assessing the impact • Using the evidence you have gathered, what impact is your policy likely to have on children and young people? What steps will you take to mitigate and/or reduce any negative effects

Encourage healthy behaviours

As illustrated in the modifiable factors section, encouraging healthy behaviours in people across the whole life cycle would be beneficial in terms of reducing dementia rates. Children and young people must be supported to live healthier lives by looking at the following factors:

Diet – for example minimise sugars, ultra processed foods and refined carbs.

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[4] https://www.alzheimers.org.uk/get-involved/dementia-friends

Physical activity – opportunities for active play should be encouraged for children and young people via sport, outdoor games and other family activities. NHS guidelines suggest that children and young people should do 2 types of activity per week based around aerobic exercise and exercises to strengthen muscles and bones. Ensuring that screen time is limited is also another factor in children's development.

Importance of good quality sleep – Sleep is important for everyone but even more so for children and young people as it directly impacts on their mental and physical development. (Children's Society) Good quality sleep supports:

- Cognitive functioning
- Emotional wellbeing
- Physical health
- Immune functions

Social interaction – Peer support

Support for young people dealing with family members with dementia is vital. Demands on young people can lead to feelings of stress and isolation. Access to peer support can help to reduce feelings of isolation, by understanding other young people have similar issues to deal with and that they are not alone. Numerous organisations offer assistance, such as Dewis Wales, Carers Trust, Mind and The Children's Society as some examples. Talking therapies can prove valuable

Smoking

Smoking has been associated with an increased risk of dementia for some time now. A 2020 Lancet report on dementia prevention highlights smoking as one of the modifiable factors and gives the following recommendation. 'Avoid smoking uptake and support smoking cessation to stop smoking, as this reduces the risk of dementia even in later life'. The Alzheimer's Society have stated that 'Smoking increases the risk of vascular problems (problems with the heart and blood vessels). These vascular problems are also linked to the two most common forms of dementia: Alzheimer's disease and vascular dementia'.

• How does your proposal enhance or challenge children's rights, as stipulated by the UNCRC articles and its Optional Protocols? Please refer to the articles to see which ones apply to your own policy.

We consider that the new Dementia Strategy will support children's rights in Wales. We have outlined our consideration against the impact in relation to the following Articles of the UNCRC in Table 1 below.

UNCRC Articles or Optional Protocol	Enhances (x)	Challenges (x)	Explanation
Article 2 (no discrimination): All children under 18 should enjoy all the rights set out in	x		The strategy has been developed for all (including young people) regardless of religion / belief / ability / protected characteristics. One of the principles underpinning the strategy is "equity of access, experience and

the UNCRC without discrimination, including those with mental health conditions.			outcomes” recognising the need to ensure services and support are accessible and appropriate for all. The strategy draws on the Welsh Government’s Strategic Equality and Human Rights Plan and the social model of disability, recognising that barriers (like language, digital exclusion, or stigma) must be actively removed. The strategy commits to providing accessible information and services for all, including those in rural or low-income households, and will monitor for any unintended inequalities.
Article 6 (Life, survival and development): Every child and young person should enjoy the same opportunities to grow and develop in conditions that do not impact negatively on their mental wellbeing.	x		The strategy takes a life-course approach, meaning it supports brain health and wellbeing from childhood onwards. The strategy recognises the need to be trauma informed and to consider specifically the needs of care givers (including young people). It also talks about the importance of brain health and tackling inequalities. The strategy highlights ways to reduce risk factors for children and young people and commits to early diagnosis and tailored support for those at risk. It also works alongside other policies, such as the Mental Health Strategy to tackle inequalities and support vulnerable groups.
Article 12: Children have the right to say what they think should happen, when adults are making decisions that affect them, and to have their opinions taken into account.	x		The strategy supports the vision outlined in A Healthier Wales with its focus on integrated, person-centred care, which is delivered in a way that has been informed by service users and carers. This runs throughout the strategy and complements other strategies with the same ethos e.g. Unpaid carers strategy. The voices of children are heard through public surveys, targeted engagement, and ongoing consultation.

Article 17: calls for access to information for children and young people, particularly with regards to issues that involve their health and wellbeing.	x		The strategy outlines the need for effective communication and clear and accessible information – including those supporting preventative health activity. The strategy ensures that children, young people, and families have access to clear, accessible, and culturally appropriate information. It addresses barriers such as language, disability, and digital exclusion by providing materials in various formats such as Easy Read, British Sign Language, and in Welsh.
Article 30: Children have a right to learn and use the language and customs of their families, whether these are shared by the majority of people in the country or not.	x		The strategy outlines the importance of ensuring information and resources is available in languages of choice and that are accessible. The strategy supports every child's right to use their own language and maintain their cultural identity. It includes the "Active Offer" for Welsh speakers, the development of Welsh-medium dementia care pathways, and the provision of information in languages of choice. The strategy also emphasises culturally sensitive diagnostic tools, workforce training in language and cultural competence, and engagement with minority and migrant communities to ensure everyone can access support and achieve good outcomes.

Consider whether any EU Citizens Rights (as referenced in the Equality Impact Assessment) relate to young people up to the age of 18.
The proposed Strategy / policy proposal will not negatively impact EU, EEA or Swiss citizens whose rights are protected by the Citizens Rights Agreements.

Ministerial advice and decision

- **How will your analysis of these impacts inform your ministerial advice?**

All Ministerial Advice regarding the Dementia Strategy will confirm that we have considered the UNCRC when developing this policy. The draft Children's Rights Impact Assessment will be submitted to Ministers for their consideration alongside the draft Strategy.

We will also consider the consultation responses once received to see if further amendments need to be made to this assessment, and the Strategy itself. A draft Integrated Impact Assessment, a Children's Rights Impact Assessment, an Equality

Impact Assessment and a Welsh Language Impact Assessment will be published for consultation alongside the draft Strategy.

These documents will be revised to take on board feedback from the consultation. A final version of the CRIA (and other supporting impact assessments) and the Dementia Strategy for Wales will be submitted to Ministers following the consultation.

Publication of the CRIA

As part of the consultation on the draft Dementia Strategy we will consult on this draft Children's Rights Impact Assessment. We will use the consultation period to gather further evidence of impacts on children and young people.

Communicating with Children and Young People

If you have sought children and young people's views on your proposal, how will you inform them of the outcome?

It is intended that Children and Young Peoples groups in Wales will be consulted with as opposed to children and young people directly. We will consider what focused work that is needed in the space of young carers.

Monitoring and Review

- **Please outline what monitoring and review mechanism you will put in place to review this CRIA.**

All impact assessments (including the CRIA) will be reviewed following the planned consultation on the draft Dementia Strategy, and ahead of publishing the final version of the strategy and its supporting Delivery Plan.

There will be opportunities to review progress in relation to the implementation of the strategy and its supporting Impact Assessments (including the CRIA) on an ongoing basis, through the role of the Ministerial Assurance Board.

- **Following this review, are there any revisions required to the policy or its implementation?**

Ongoing reviews of the CRIA will inform future actions for strategy/delivery plans.